

Navigating the Finances of Blood Cancer

A practical guide

Introduction

You or your loved one has been diagnosed with blood cancer. Now what?

If you or a family member has been diagnosed with blood cancer, it's natural to feel a wide range of emotions, from the initial shock and disbelief, fear and anxiety to sadness. These emotions can fluctuate and vary in intensity throughout the journey. It's important to acknowledge these feelings and seek support from healthcare professionals, counsellors, or support groups to help manage them.

Alongside the emotional toll, there are often significant financial challenges. Medical treatment can be costly and needing to take time off work or even leave your job can make it hard to see a clear path forward.

Some of the most pressing questions you might have include:

- Will my treatment be intensive so the financial impact will be for a defined period?
- Is my blood cancer either a chronic but incurable cancer or requires post-acute treatment monitoring and/or maintenance, which may require reconsidering my financial/working situation for life?
- How much will the treatment cost?
- What impact will this have on my income?
- Will I have to stop working or reduce my working hours or seek more flexible working options?
- How will this affect my family and dependents?

About this guide

This guide is the result of collaboration between [Financial Training Australia](#) and the [Leukaemia Foundation](#).

It aims to help you manage the financial challenges that come with a blood cancer diagnosis. While every situation is unique, staying on top of your finances doesn't have to be complicated.

We'll walk you through the process of budgeting and point you to resources that can help alleviate your financial worries.

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How can budgeting help?

If you or a loved one are going through either short-term or long-term medical care or treatment, you already have a lot on your mind (and on your plate). Creating and tracking a budget on top of all that may seem overwhelming, but budgeting can help you figure out how to pay for medical costs by using your money more effectively.

This booklet recognises that there may be different financial challenges for those diagnosed with an acute blood cancer typically requiring short-term intensive treatment(s) as well as those diagnosed with a chronic blood cancer such as chronic myeloid leukaemia, chronic lymphocytic leukaemia, or a myeloproliferative neoplasm, who typically require ongoing medical care or treatment for life and may need to adjust their lifestyle due to symptom burden. However, the underlying steps to good financial management can be adapted to your situation and needs.

Just take it one step at a time, keep it simple and remember, you can always ask for help.

The budgeting process – step by step

Step 1: Record your monthly income and expenses. (Monthly keeps things simple.)

Income

- Write down your total income each month, including all sources such as your job, tips, side gigs, contract work, etc.
- Will you continue to receive some or part of this income if you are temporarily or permanently unable to work and/or need to reduce your hours of work? A diagnosis may mean you have to take time off, permanently reduce your hours, or leave work, leading to a loss of income. Based on these factors, estimate your monthly income while undergoing treatment and write this down.

Tips to retain as much income as possible or plan for upcoming changes:

- Ask your doctor how much time you'll need to take off work or if you should reduce your working hours now that you have been diagnosed.
- Ask your employer if you can work part-time or from home during treatment or come to any other arrangement that allows you to manage your health and wellbeing, including attending appointments and managing symptoms .
- Ask your employer about leave entitlements, e.g. sick/personal leave, leave without pay.
- Ask your partner's or carer's employer about carers or unpaid leave - this may allow them to take time off to care for you as required.
- Use disability or income protection insurance (if you have it) to supplement your income while you take time off. Your employer or superannuation fund may provide this insurance.

Expenses

Before recording your expenses, you'll want to decide on some categories. Categorising expenses helps you understand where your money is going, making it easier to budget, save, and avoid overspending. It also simplifies things like tax reporting and financial planning by keeping your spending organised.

One way to categorise your expenses is to split it into **fixed** and **variable**.

Fixed expenses are bills that cost the same amount each month, such as:

- Rent
- Mortgage repayments
- Monthly subscriptions (e.g. Netflix)
- Car loan repayments
- Insurance payments
- School or daycare costs
- Education costs (university or other further education)
- HECS debt repayments

Variable expenses change from month to month. These include things like:

- Petrol or transport costs
- Car and home maintenance
- Utilities
- Medical expenses, including pharmaceuticals
- Pet expenses
- Groceries
- Clothing
- Technology
- Personal care
- Recreation and entertainment
- Gifts

Another way to categorise your expenses is to split it between **discretionary** vs. **non-discretionary** expenses.

Discretionary expenses are things you could do without if you had to, but that make life more enjoyable and contribute to wellbeing, such as:

- Subscriptions
- Streaming services
- Gym membership
- Travelling
- Dining out
- Entertainment

Non-discretionary expenses are ones you can't do without, such as:

- Rent
- Education (ie university or further education)
- School or daycare costs
- Loan repayments, including HECS-HELP and FEE-HELP debt
- Groceries
- Utilities
- Gas

In practice, it makes sense to use both types of categories. This is because a fixed expense can either be discretionary or non-discretionary. Rent and mortgage repayments would be considered as fixed and non-discretionary. Whereas monthly subscriptions to Netflix would be considered as fixed and discretionary.

Likewise, a variable expense can either be discretionary or non-discretionary. Utilities would be considered as variable and non-discretionary while clothing would be variable and discretionary.

Tip: When setting up your budget, enter the fixed non-discretionary expenses first – because you know the amount in advance and it's something you feel you must spend on.

If you want to have greater insight into where your money is going, you could also divide your expenses into further categories like:

- Home and utilities
- Motor vehicle and transport
- Food and drink
- Personal care, interests and entertainment
- Children and financial dependents
- Education
- Professional services
- Investment and wealth creation

The main thing is to keep it simple! Too many categories can overcomplicate things and lead to decision paralysis. Once you've decided on your categories, start putting in the numbers.

Do you have a shortfall or surplus?

- Add **estimated medical costs** to your monthly expenses
- If applicable, take account of fewer hours worked in your monthly income
- Subtract your total monthly expenses from your total monthly income.

Positive number = surplus

This means you have enough money to cover all your expenses with some left over.

Negative number = shortfall

This means you'll need to reallocate your money to cover medical costs, e.g. doctor's appointments, medications, treatments, and procedures.

Step 2: Reallocate money (if you have a shortfall)

Reallocating is moving your money around, finding more sources of income, and cutting down on expenses to make your budget work for you. If you realise as you're putting together your budget, or after tracking it for a few months, that you're simply not going to be able to afford the medical costs on your current or estimated reduction in income, it's best to take action early so you can feel secure you have things in place and less to worry about.

Step 3: Review

- Review your budget at least once a month.
- Compare your targets to your actuals – how much money you expected to make and spend in each category, versus how much you actually made and spent.
- Review if your health is getting better or worse and if you need to make changes that affect your income.

If you require more money to cover medical costs, you may need to go back and repeat [Step 2: Reallocate](#). Set a goal (or two or three) to spend less in a certain category. Start small and work up to bigger goals as your confidence grows.

The most important rule of budgeting is to keep at it.

If you're undergoing treatment, feeling unwell, or caring for a loved one, you may not have time to sit down and work on your budget every day. But it doesn't have to be a huge time commitment. Just keep your bills and receipts in a safe, easily accessible place until you can put them into your budget. This can be stored electronically if you're more tech savvy. Otherwise you can put the printed receipts in a box (e.g. a showbox) and go through them at the end of the month.

Estimating the cost of treatment

Knowing roughly how much you can expect to spend on medical costs will help you prepare an effective budget, so let's take a moment to look at that.

While it's impossible to know exactly how much you may have to spend in the future. If you require treatment for an acute blood cancer, on average, blood cancer treatment for acute blood cancers cost anywhere from \$5,000 - \$11,000 out-of-pocket¹. That cost includes gap payments (see below) and costs not fully covered by insurance, which may include:

- Treatment from a general practitioner (GP) or specialist
- Scans and blood tests outside of the public health system
- Prescriptions and over-the-counter medications
- Medical devices and clothing
- Surgery and hospital stays
- Travel and accommodation costs when seeking out-of-town care
- Childcare

Although some of these costs are more relevant for treatment for a blood cancer that needs acute treatment, many of the expenses and the terminology are still relevant for a chronic blood cancer although costs are different and ongoing for life.

Covering these costs can be especially hard if you have to take time off work for recovery – which many people do. In fact, a [recent study](#) found that 42% of blood cancer patients are forced to take more than three months off work, while 30% have to permanently leave and 50% are unable to return. (Parker, et al., 2022)

All this can make a troubling diagnosis even more stressful and difficult, but you have options. We'll outline many of them in the following pages, but remember that you can talk to your doctor, caregiver or social worker for help, and you can reach out to the Leukaemia Foundation for [support](#).

As you review your medical bills and calculate expenses, you may run into some confusing terms, like “out-of-pocket” and “gap payment.” Let's go over what those mean so you can have all the facts when you prepare your budget.

What's an out-of-pocket cost?

An out-of-pocket cost refers to anything you pay out of your own “pocket” or, to be more accurate, out of your own bank or credit account – as opposed to costs covered by Medicare or your insurance provider. This may include gap payments, which we'll discuss below, as well as any care you receive out of network (that is, if it's from a healthcare provider not covered by your insurance).

¹ Based on Leukaemia Foundation data

What's a gap payment?

When you receive treatment, Medicare and your health insurance may only cover a certain amount. The amount you still have to pay is called a gap payment.

Example

A doctor charges \$200 for a procedure, Medicare plus your private health insurance covers \$150.

The gap is \$50 – which you pay yourself.

Some insurers offer gap coverage, which covers or reduces, the amount you have to pay. Before starting treatment, ask your healthcare provider if they participate in gap coverage and if your insurance offers it. If possible, make sure that any healthcare providers or specialists you see are in your insurance's network.

The [Medicare Safety Net](#) provides additional financial support for people who incur high medical costs for out-of-hospital services. Once your out-of-pocket costs for certain services exceed a set threshold in a calendar year, Medicare increases the rebate it pays for those services – reducing your personal financial burden.

How do I avoid running into unexpected costs?

Before you begin treatment, your doctors and healthcare providers are required to give you a cost estimate (this is called **informed financial consent**). While there's no way of knowing exactly how much you'll end up paying, your healthcare providers should be able to give you a pretty accurate estimate based on other cases they've seen.

This is a good time to ask your providers how you can lower the cost of treatment and how you can apply for financial aid.

Ways to access more funds

If you are in paid employment, the first approach you'll want to try is supplementing your income. While it may not be possible to earn more through your job or side hustle – especially while you're undergoing cancer treatment – there are other ways to add to your income.

Apply for benefits

If you've been diagnosed with blood cancer, you may be eligible for several Centrelink benefits to help manage your financial situation. These benefits are provided through [Services Australia](#) and depends on your health, income, assets, and care needs. The most relevant options are:

- **Disability Support Pension** – for people with a permanent physical or mental condition that prevents them from working. Blood cancer may qualify if it significantly affects your ability to work.
- **Carer Payment and Carer Allowance** – if someone is providing daily care for you, they may be eligible. Carer Payment is income-tested while Carer Allowance is not.

Seek an appointment with a Centrelink Financial Information Service Officer

These extremely knowledgeable staff can explain how:

- Financial products work
- A change to your personal circumstances may affect your financial situation, in the short and long term
- To find resources to help you with your financial matters.

This [information](#) can help you take control of your finances and make informed financial decisions.

Apply for a no interest loan

If you have a low income and don't qualify for other affordable credit, you may benefit from a **No Interest Loan Scheme (NILS)**. This allows you to borrow as much as \$1500 for household appliances, furniture, medical devices, or other items needed for your health or wellbeing. In most cases, you'll need to repay this loan in 12-18 months.

To find an NILS provider near you, go to goodshep.org.au/services/nils or call 13 64 57.

Apply for early access to your super

Technically, you can't tap into your super until you are at least 60 and retiring – but there are certain conditions where you can access it. These include:

- **Permanent incapacity** – if you're permanently incapacitated and unable to return to work

- **Severe financial hardship** – if you’re facing severe financial hardship and have been on government income benefits for 26 weeks
- **Terminal medical condition** – if you have a terminal injury or illness with a life expectancy of up to two years
- **Compassionate grounds** – if you need funds to pay for medical treatment or related expenses, such as travel to and from medical treatment. Or you may need to make home loan repayments so the bank doesn’t foreclose on your home, or modifications to your home or vehicle due to disability. This covers if you need to pay for palliative care, funeral expenses, burial or cremation.

To qualify, you may need to meet [certain eligibility requirements](#) and provide proof of your medical condition or hardship. Contact your super provider for guidance or go to ato.gov.au.

There are different rules for how you’ll receive the money from your super and how it will be taxed:

- The money you need will be paid to you in a lump sum
- If you’re unable to work due to a medical condition, you’ll receive it in regular income payments
- Your payments may be taxed as a super income stream or a normal lump sum
- If you have a terminal medical condition at the time of the payment or within 90 days of receiving it, the money will be tax-free.

It is important to get financial advice as accessing your super prior to retirement has long-term financial implications.

Make an insurance claim

Your super may also include insurance. This might include:

- **Life insurance** (also known as death cover), which is a lump sum, income stream or combination of the two
- **Total and permanent disability insurance (TPD)**, which is a lump sum, income stream or combination
- **Income protection or salary continuance insurance**, which is an income stream over a specified period of time

If you have insurance outside super, check all your policies, including: health insurance, income protection, trauma or critical illness, total and permanent disability, and life insurance.

How to lodge an insurance claim (in 3 simple steps)

Lodging an insurance claim may seem overwhelming, but it doesn’t have to be. Here’s how to do it.

Step 1: Contact your insurer

First, contact your insurer. This is simply the person or company you bought the insurance policy from, which could be:

- An insurance company
- A broker or financial advisor
- Your super fund manager
- Your employer, if you have insurance through your work

When you call, have your policy number ready, as the insurer may ask to look up your account.

Ask:

- How you can file a claim
- Which forms you need to fill out
- What information you need to provide and;
- How to submit it.

Step 2: Gather details

To have your claim approved, you'll need to provide certain information, which may include:

- Your medical reports and test results
- Your doctor's contact information
- A description of your current job
- Payslips and tax returns proving how much you earn

Your insurer should tell you what's needed when you talk to them, then you can ask your healthcare providers and employer for the right documents.

Step 3: File a claim

Fill out the required forms and send them in to the address (or email address) provided by your insurer. Once everything has been submitted, the insurer will probably get back to you within two months of receiving your claim, or within two months after the waiting period is over.

If you're struggling to make ends meet while you wait for your claim to be approved, ask your insurer or super fund manager for help – and provide documents (such as bank statements) showing your need for urgent help. Your insurer may be able to speed up the claims process or give you an advance payment.

What if my claim isn't approved?

If your claim is denied, or if you feel that the insurer made the wrong decision about how much to give you, lodge a complaint with your insurer as soon as possible. If this doesn't help, contact the Australian Financial Complaints Authority (AFCA) at afca.org.au or 1800 931 678. They can help you lodge a complaint and get free dispute resolution.

Ideas to reduce expenses

You may have already looked into this but here are some ideas:

- Make your own coffee instead of buying it
- Shop for used clothing
- Buy unbranded supermarket products
- Do meal planning to avoid eating out
- Limit your alcohol consumption
- Switch to a cheaper phone and/or internet package
- Take advantage of deals and coupons
- Find free entertainment
- Consider reducing your subscriptions, memberships and streaming services

Let's say you're already doing all that. Fair enough. Here are some ways to go deeper.

Cut insurance costs

Most insurance coverage levels automatically increase each year and you may not need that extra coverage. At the start of each year or at renewal time, review your insurance coverage and make sure you're not paying for more than you need.

But don't underpay either. Having the right insurance for your house, car, health, and family can help provide you with peace of mind, not to mention be a lifesaver if an emergency or if an unexpected event occurs.

It's a good idea to review your insurance coverage after:

- Your job or financial position changes
- Your family situation changes
- Your health changes

When it's time to renew coverage, don't be afraid to negotiate with your insurance provider. It does pay to shop around.

Cut living expenses

If your energy, electricity and gas bills seem too high, take a look at your household's lifestyle and try to figure out what could be affecting those costs.

Here are a few tricks you can try to reduce your bills:

Unplug Your TV, computer, kitchen gadgets.	Turn off the lights Every time you leave the room	Buy efficient light bulbs LEDs are efficient
Check insulation Under-insulated homes let the hot or cool air escape, meaning higher energy bills	Buy smart appliances New energy-efficient appliances can save money	Upgrade energy systems Replace your electric hot water with solar hot water or a heat pump.
Compare providers Negotiate a better price with electricity / gas providers Bundle services to get a discount.		

Consolidate or refinance your loans

If your loan repayments are a major monthly expense, consider consolidating or refinancing. Some lenders offer discounts for automatic payments, and it's also a great way to avoid late fees by ensuring you never miss a due date. You may also be able to consolidate multiple debts in one, which means you'll only have to make one monthly payment instead of several. This may be a good idea if you can get an interest rate on your consolidated loan that's lower than the total rates of your existing loans.

If your credit score has improved since you first took out a loan, you may be able to refinance and get a lower rate.

Apply for hardship programs

If you have to stop working or deal with high medical bills, paying your other expenses – like mortgage repayments, rent and utilities – may become a struggle. In this case, you may be able to apply for hardship assistance from your bank, your landlord, or the government.

Access financial hardship assistance through your bank

Did you know your bank has a team dedicated to helping people work through financial hardship? Contact your bank and ask to speak to the financial hardship assistance team. They should be able to walk you through a number of options to help you resolve financial hardship.

Ask for help with rent

If you think you may not be able to pay rent, reach out to your landlord immediately; don't wait until the due date passes. Ask if you can negotiate a lower rent, put a temporary freeze on your payments or put off paying for a certain period of time.

If you can't work, see if you're eligible for any Centrelink benefits. If you're already receiving benefits like the Age Pension, Disability Support Pension or Carer Payment, you may qualify for [Rent Assistance](#).

Your state may also offer financial assistance: check with its housing office or tenants advice service.

Ask for help with utilities

If you're struggling to pay your bills, your utility provider is legally required to provide you with a flexible payment plan – but how that plays out will depend on your provider. Some may allow you to defer your payments (meaning you can wait until later to pay) or pay by instalments (meaning you can pay in small amounts over a period of time). Check your provider's website for details.

You may be able to get a discount on your gas, water or electricity bill if you:

- Have a low income
- Receive Centrelink payments
- Have a concession card
- Can't regulate your body temperature
- Need special medical equipment, like an oxygen contractor, at home.

Talk to your provider to find out if you qualify and how you can apply.

Some states offer grants and payment vouchers to help people in financial hardship pay for utilities. Community welfare organisations, like the Salvation Army, may also offer them. Talk to a community organisation or your state department for more information. You can find contact details at moneysmart.gov.au if you search for 'utility bills'.

Get a free energy assessment

Many states and territories provide free assessments to help you reduce the amount you're paying for water and energy. They may also help you make repairs or modifications to save energy and water costs. For more information, go to energy.gov.au.

Apply for state-based assistance

Your state may offer financial assistance with things like utility bills, phone plans, and educational costs. Here are some links to more information about what your state offers:

- [Australian Capital Territory](#)
- [New South Wales](#)
- [Northern Territory](#)
- [Queensland](#)
- [South Australia](#)
- [Tasmania](#)
- [Victoria](#)
- [Western Australia](#)

Getting financial advice

If this is the first time you've struggled with finances, you may feel embarrassed to ask for help. Don't be. Financial stress is common for people who are diagnosed with cancer, and you don't need to feel ashamed or guilty for needing help.

If you need advice from a qualified financial adviser, then complete the [Leukaemia Foundation Support Service Application Form](#).

This is a pro bono service to support the Leukaemia Foundation – meaning there will be no fees or charges to you for the financial advice.

The services can include assistance with:

- Preparing a budget
- Application for early access to super – financial hardship or compassionate ground
- Lodging insurance claims
- Accessing financial hardship programs
- Support with Centrelink applications
- Creating a financial plan

The services will be provided by the financial planning arm of Financial Training Australia – Evolucion Pty Ltd, trading as [Transfigr](#) (Corporate Authorised Representative No. 1307597). Transfigr is authorised under Financial Mandate Pty Ltd ABN 75 686 236 180, holder of Australian Financial Services Licence no. 700151.

Transfigr is on a mission to transform the lives of individuals through practical financial planning that is accessible, insightful and affordable. Utilising the experience and expertise of **Financial Training Australia** to create a platform for empowerment and education.

Resources and more help

A blood cancer diagnosis can be challenging, but you're not alone. Here are some organisations that may be able to help.

The Leukaemia Foundation:

- [Transport Services](#): get help with transportation for medical treatment
- [Accommodation Services](#): get accommodation when travelling for treatment
- [Healthcare Professionals](#): chat with our coordinators to get the support you need
- [Information and Support Service Referral](#): request support, advice or a referral to get help
- [Online support groups](#) for your particular blood cancer can be very helpful for day-to-day advice and support.

More information about cancer and finances:

- [Cancer and Your Finances](#): booklet by the Cancer Council

Financial counselling:

- [National Debt Helpline](#): call 1800 007 007 or use the live chat
- [Mob Strong Debt Helpline](#): for Aboriginal and Torres Strait Islander peoples, call 1800 808 488

Emergency relief and assistance:

- [Centrelink](#): call 132 850, or call the Centrelink Indigenous call centre at 1800 136 380
- [St Vincent de Paul Society](#): offers financial and other support to those in need
- [Salvation Army](#): offers help with bills and buying food
- [Department of Social Service Grant Services Directory](#): provides a list of emergency relief services in your state or territory

Prescription costs:

- [Pharmaceutical Benefits Scheme \(PBS\)](#): offers help paying for prescriptions, call 1800 020 613
- Rare Cancers Australia

Treatment costs:

- [Redkite](#): offers financial aid for children with cancer
- [Cancer Council](#): offers financial aid and guidance for those with cancer

Insurance questions and complaints:

- [Insurance Law Service \(ILS\)](#): provides answers to your insurance questions, Call 1300 663 464

Dispute resolution:

- [Australian Financial Complaints Authority \(AFCA\)](#): offers financial dispute resolution, call 1800 931 678
- [Telecommunications Industry Ombudsman \(TIO\)](#): offers dispute resolution for phone and internet services, call 1800 062 058

Legal advice:

- [Community Legal Centres Australia](#): offers free legal advice and services