Living with Chronic Lymphocytic Leukemia (CLL)

Designed to support patients and their families through the various phases of their lymphoma journey.

www.lymphoma.org.au

Lymphoma Australia

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Lymphoma Australia
Raising awareness. Giving support. Searching for a cure.

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Lymphoma Australia is as an incorporated charity and is providing education, support and awareness across Australia.

Lymphoma Australia relies on grants, fund raising initiatives, donations and sponsorships to continue our work, support research, and to develop our free resources for patients, hospitals and cancer clinics. We are a member of the Lymphoma Coalition which provides global support to the millions of people around the world living with cancer of the lymphatic system. Lymphoma Australia is endorsed with deductible gift recipient (DGR) status from the ATO and receives no government funding.

The feather in our logo symbolises a guardian angel because our founding patient group wanted to make sure no one felt alone in their lymphoma journey. It is also a symbol of hope to those with lymphoma, and reflects the fact that people are searching for cures for this group of cancers everyday.

Lymphoma
Australia

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> "Cancer is just part of my life now, and I always try to have hope." *– Jennifer, living with CLL*

Overview of CLL

Chronic Lymphocytic Leukaemia (CLL) is a cancer that affects a type of white blood cell called a “lymphocyte.” It is a slow growing lymphoma that affects the developing B cell lymphocytes which are a specialised type of white blood cell. Under normal conditions these B cells produce immunoglobulins (also called antibodies) that help protect our bodies against infection and disease. In people with CLL, these B cell lymphocytes undergo a malignant (cancerous) change and become lymphoma cells.

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are often grouped together as they affect the same lymphocytes. CLL and SLL are essentially the same disease, the only difference being where the cancer primarily occurs. When most of the cancer cells are located in the bloodstream and the bone marrow, the disease is referred to as CLL, although the lymph nodes and spleen are often involved. When the cancer cells are located mostly in the lymph nodes, the disease is called SLL. Otherwise they behave in very similar ways and treatments are the same. Quite often the diagnosis is written as CLL/SLL when there is no clear predominance of one or the other.

CLL/SLL are subtypes of lymphoma which is the most common blood cancer as classified by the World Health Organisation as a lymphoma. There are over 80 different subtypes of lymphoma. Lymphoma occurs when cells of the immune system called lymphocytes, a type of white blood cell, grow and multiply uncontrollably. Cancerous lymphocytes can travel to many parts of the body, including the lymph nodes, spleen, bone marrow, blood, or other organs, and form a mass called a tumour.

Many patients with CLL do not have any obvious symptoms of the disease. Their doctors might detect the disease during routine blood tests and/or a physical examination. For others, the disease is detected when symptoms occur and the patient goes to the doctor because he or she is worried, uncomfortable, or does not feel well. CLL may cause different symptoms depending on the location of the disease in the body. The symptoms may include a tender, swollen abdomen, feeling full even after eating only a small amount, fatigue, shortness of breath, low blood counts, bruising easily, night sweats, weight loss, and frequent infections. However, many patients with CLL will live for years without symptoms.

Both CLL and SLL are slow-growing lymphomas, although CLL, which is much more common, tends to grow more slowly. Treatment is the same for CLL and SLL. They are usually not curable with standard treatments, but depending on the stage and growth rate of the disease, most patients live longer than 10 years. Sometimes, these slow-growing lymphomas turn into a more aggressive subtype which needs to be treated in a different way.

CLL is a common type of lymphoma in Australia with over 1000 new cases diagnosed each year. Around 80% of new

> **"Like many people who face a life threatening illness, I have appreciated the value of friends, family and a supportive working environment."**
> ***– Beverly, living with CLL***

cases are diagnosed in people over the age of 60 years and it is quite rare in people under 40 years of age.

A cancer diagnosis is always overwhelming, no matter what. It's important to know that CLL can be a slow-developing, chronic condition that may not need medical treatment right away. In fact, some people with CLL may never require medical treatment. Although there is currently no cure for CLL, it is possible to live a healthy life with the disease and continue to do what you love.

Living with CLL

For many people living with CLL it can be confusing and overwhelming. Due to the chronic nature of this cancer living with CLL can include a variety of different types of approaches to treatment including watch and wait, active treatment or maintenance therapy. A common term many people use to describe life after a CLL diagnosis is “Survivorship”.

Because CLL can include a number of remissions and relapses it is sometimes hard to manage the range of emotions that can occur before, during and after treatment. You may also experience a number of physical changes and effects to your body so it is important to give yourself the time you need to work through these and be patient. It will take some time to come to terms with everything you have been through and manage any side effects of treatment you may be experiencing.

Often during the treatment phase you don’t have the capacity to properly process everything that has been going on because your focus and energies were spent on trying to make it through treatment. When it stops it is like you get an influx of emotions and feelings, some may call this “post-traumatic stress” where you have been through a traumatic experience and now it’s time to deal with everything that has happened. But remember that it does not always stay like this, many people find that they come through the treatment and diagnosis as a stronger person and there are many positive outcomes that can come through such an experience.
It is also important to remember that there is plenty of help

available to support you. Open communication with your medical team, doctors and family and friends is helpful. You may also wish to speak with a counsellor during this time as sometimes it can be difficult to talk with family and friends about certain topics.

At the end of the day we want you to use this resource to help you take control and drive your health care. Don't be afraid to ask questions and even suggest what you think might need to be done to your doctors. Use this to load yourself up with plenty of knowledge and start carving your own path towards renewed health!

What is "normal" about living with CLL?

When you are living with a cancer that does not go away you may feel like you are stuck – you do not know what to expect or what is going to happen next.

Living with CLL is not so much about "getting back to normal" as it is learning what is normal for you now. People often say that life has new meaning or that they look at things differently now. Every day takes on new meaning.

Your new "normal" may include making changes in the way you eat, the things you do, and your sources of support. It may mean fitting cancer treatments into your work and holiday schedule. It might mean making treatment part of your everyday life, treatments that you are getting for the rest of your life.

> **Being able to learn more about my disease has given me the confidence and hope to move forward with my life." – *Jonathon, living with CLL***

Most people who are diagnosed with CLL will receive treatment for the lymphoma at some stage, but it might not be straight away after you are diagnosed. Treatments will depend on factors such as the stage of your CLL, whether you have any symptoms and if your disease is progressing enough to warrant any treatment. Depending on these factors the treatment will vary for people with CLL. Many people find that after treatment that the CLL might progress again after a period of time and more treatment may be needed. These treatments may be repeated many times over many years. Sometimes there might be shorter time periods between these relapses of CLL. Repeated relapses, can become discouraging and exhausting. The question of whether to keep treating cancer that doesn't go away or comes back again and again is a valid one. Your choices about continuing treatment are personal and based on your needs, wishes, and abilities. There is no right or wrong decision on how to handle this phase of the CLL.

It is important to know that even those who are not cured of CLL can go on living for many, many years, even though there may be changes in their lives. Most families adjust to this kind of treatment schedule. Having a cancer that cannot be cured doesn't put you beyond hope or help; you may be living with a lymphoma that can be treated and controlled for a long time.

Living with uncertainty

We always have to live with some uncertainty. We can not be certain about the economy, or about our jobs, or even about the weather on any given day. A diagnosis of cancer brings with it a heightened sense of uncertainty, and it may take you a long time to be able to plan for the future with confidence. You can not alter the fact that you have been diagnosed with CLL, but you can learn to adapt to it and to manage the necessary life changes required to live as fully as possible after your diagnosis.

Not being able to know enough about the future to be able to plan for it the way you would like is extremely challenging, but not all change is bad. A cancer diagnosis and treatment can bring about permanent change, the goal after a cancer diagnosis is to get back to normal, but most often a "new normal "must evolve so you and your loved ones can move forward. What is hard is getting used to the change. Concentrate on putting your efforts in to what you can control and let go of the things you can not control. Some people say that putting their lives in order makes them feel less fearful.

Being involved in your health care, trying to find your "new normal," and making changes in your lifestyle are among the things you can control. Even setting a daily schedule can give you more power. While no one can control every thought, some say they have resolved to not dwell on the fearful ones.

Here are some ideas that have helped others feel more hopeful and deal with the uncertainty and fear of cancer that does not go away:

- Be informed. Learn what you can do for your health now and about the services available to you and your loved ones. This can give you a greater sense of control.

- Be aware that you do not have control over some aspects of your cancer. It helps to accept this rather than fight it.

- Be aware of your fears, but practice letting them go. It is normal for these thoughts to enter your mind, but you do not have to keep them there. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle. However you do it, letting them go can free you from wasting time and energy needlessly worrying.

- Express feelings of fear or uncertainty with a trusted friend or counsellor. Being open and dealing with emotions helps many people feel less worried and better able enjoy each day. People have found that when they express strong

> Having cancer and being told by my doctor that we are going to 'watch and wait' was overwhelming to begin with but once I gained the knowledge to understand why we were waiting I was able to get on with my life and live better with this disease.”
> *– Max, living with CLL*

feelings, like anger and fear, they're better able to let go of these feelings. Thinking and talking about your feelings can be hard. If you find cancer is taking over your life, it may be helpful to find a way to express your feelings.

- Enjoy the present moment rather than thinking of an uncertain future or a difficult past. If you can find a way to be peaceful inside yourself, even for a few minutes a day, you can start to recall that peace when other things are happening – when life is busy, scary, and confusing.
- Make time for what you really want. You may find yourself thinking about all the things you have always wanted to do but never made time for. It is OK to pursue these things, and do not forget to enjoy everyday pleasures and have fun too.
- Work toward having a positive attitude. This can help you feel better about life even if a cure is out of reach. Nearly everyone can find things to feel grateful for or hopeful about. But do not try to be upbeat or positive all the time – no one is! You need to pay attention to your feelings, even the "negative" ones. You are allowed to have bad days, feel sad or angry, or grieve whenever you need to.
- Use your energy to focus on what you can do now to stay as healthy as possible. Try to make healthy changes in what you eat. If you are a smoker, this is a good time to quit and encourage others to quit with you.

- Find ways to relax. Enjoy some time alone and with others doing things you enjoy.

- Exercise and be as active as you can. Talk with your cancer care team about what is realistic for you.

Watch and wait

For many people diagnosed with CLL the approach for them is “watch and wait” and this refers to a period of time when you have no treatment but you are monitored by your doctors and any treatment is delayed until you may need it. For many people, this approach may cause worry and uncertainty. It is important to remember that “watch and wait” is an effective approach for various reasons:

- Medical studies have not shown that immediate treatment prolongs survival in people with CLL. In fact, because some treatments come with unwanted side effects, it can be preferable to wait until treatment is necessary.

- CLL treatments are often intended to control the disease and manage its symptoms. So, until symptoms occur, treatment may be unnecessary.

If your doctor has recommended a “watch and wait” approach, there are things you can do to ensure you are as healthy as possible:

- Eat a healthy diet
- Exercise regularly
- Avoid close contact with people who are sick
- Wash hands frequently and thoroughly
- Talk to your doctor about getting the flu shot and pneumococcal vaccine
- Talk to your doctor about age appropriate cancer screenings
- Maintain a regular sleep schedule
- Manage your stress
- If you are a smoker, begin a smoking cessation program
- Find relaxing activities to engage in while waiting for test results
- Familiarise yourself with the treatment options available, should you need to begin treatment in the future
- Closely monitor your health for any changes and know when to call your doctor

- Connect with local support groups
- Speak to your doctor about other ways to maintain your health during “watch and wait”
- For further information you can download our free fact sheet, 'Understanding Watch and Wait' on our website www.lymphoma.org.au

Coping practically with CLL

As well as coping with the fear and anxiety that a diagnosis of CLL brings, you may also have to work out how to manage practically. There may be money matters to sort out. You may need information about financial support, such as benefits, sick pay and grants. Who do you tell that you have cancer? And how do you find the words? You may also have children to think about.

Just try to remember that you do not have to sort everything out at once. It may take some time to deal with each issue. Do ask for help if you need it though. It is likely that your doctor or specialist nurse will know who you can contact to get some help. They can put you in touch with people specially trained in supporting those with cancer. These people are there to help and want you to feel that you have support so use them if you feel you need to.

Understanding your CLL

You can find out about CLL and the treatments available, understanding this will help you and your family. If there are specialist cancer nurses where you are being treated, you can talk to them about what you can do to help yourself, and any problems that you might have. They can also give you information about CLL. Or you can contact our free Lymphoma Nurse Support Line by calling 1800 953 081. It is important to:

- Do something to help yourself
- Know more about what to expect
- Talk to someone who really knows about cancer, like your cancer doctor or specialist nurse
- Making lists of questions for your cancer doctor, specialist nurse or GP before you go
- Take someone with you to your appointments to remind you what you wanted to ask and help you remember the answers

Practical and positive things you can do

When you are having treatment, or recovering, you may not be able to do all the things you used to. As you begin to feel better it can help to;

- Have a go at simple tasks
- Try to do a little more each day
- Success will give you confidence but remember, take one step at a time
- Planning a healthy, well balanced diet
- Learning relaxation techniques
- Doing some regular exercise
- Join a support group if you want to meet people with similar cancers
- Trying not to dwell on the cancer
- Making the most of what you have – do the things you've put off in the past
- Not making too many life changes at one time

Only do these things if you want to, and only if they make you feel better. Well-meaning friends or relatives may make all sorts of suggestions about what you can do but you don't have to make any sudden or drastic changes to your lifestyle. If you have recently been diagnosed and treated you may feel you have had enough change for a while. If you do decide to exercise;

- Build up slowly
- Set realistic targets
- Base the type of exercise, how strenuous it is and how often you do it, on what you are used to and how well you feel
- Seek advice from your cancer care team who can refer you to an exercise physiologist to assist further'

Follow-up care

As CLL can be a slow-growing cancer you will be monitored and supported by your doctors regularly during your lifetime. It is very important to go to all of your follow-up appointments to see your doctors. During these visits, your doctors will ask questions about any problems you may have and may do physical examinations, blood tests and scans to look for any signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. A benefit of follow-up care is that it gives you a chance to discuss questions and concerns that can arise. Talk to your cancer care team about any changes or problems you notice and any questions or concerns you have. It is important that you report any new symptoms to the doctor right away so that the cause can be found and treated, if needed.

Treatment of CLL is not expected to cure the disease. This means that even if there are no signs of CLL after treatment (known as a complete remission), the cancer may come back again at some point (known as a relapse). Further treatment will depend on what treatments you have had before, how long it has been since your last treatment and your overall health.

Most people with CLL do not have a normal functioning immune system which may raise their risk for certain infections. Some treatments for CLL, such as chemotherapy, may also raise this risk. Your doctor may recommend vaccines or other medicines to help prevent or control certain infections.

Seeing a new doctor

During the course of your CLL disease and treatments which can be lengthy, you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you are able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have the following information handy:

- A copy of your pathology report(s) from any biopsies
- If you had surgery, a copy of your operation report(s)
- If you were in the hospital, a copy of the discharge summary that doctors prepare when patients are sent home

- If you were treated with drugs (such as chemotherapy, monoclonal antibodies, or targeted therapy), a list of the drugs, drug doses, and when you took them

The doctor may want copies of this information for their records, but always keep copies for yourself. It is also important to remember that you can also ask for a second opinion regarding your CLL management at any time.

Subsidised visits to allied health professionals

Managing some of the effects of treatment can be helped by visiting certain allied health professionals. If you do need to visit an allied health professional, you may be eligible for a Medicare rebate under the “Chronic Disease Management Plan” (formally known as the “Enhanced Primary Care Plan”). The rules surrounding this can change so it’s best to discuss this with your GP first or download the patient information sheet at www.health.gov.au.

Generally you may be eligible for 5 subsidised visits per calendar year for all allied health services combined (i.e. - 3 visits to a podiatrist and 2 visits to a dietitian). Some allied health services are excluded such as dental.

Also under the Better Access to Mental Health Care initiative you may be eligible for rebates for up to 10 psychological visits

> "I am amazed at how much exercise and a healthy diet has made to my mind and how I cope living with this disease for the better."
> *– Jill, living with CLL*

per calendar year if seeing a psychologist. Speak with your GP to find out more information on what you are eligible for. When you call your GP to make your appointment make sure you mention that you wish to discuss the "Chronic Disease Management Plan" and/or "Better Access to Mental Health Care" initiative as this may require a longer consultation time to fill in the necessary paperwork.

When accessing any allied health services you may be required to pay a gap payment fee which is at the discretion of each health professional. Allied health services could include:

- Audiologists
- Chiropractors
- Podiatrists
- Dietitians
- Diabetes educators
- Aboriginal health workers
- Exercise physiologists
- Physiotherapists
- Occupational therapists

- Osteopaths
- Mental health workers
- Psychologists
- Speech pathologists

Symptoms to watch out for

You may experience many new symptoms that can occur over various time periods due to late effects of treatment. If you experience any new, persistent or unexplained symptoms then make sure you report these to your doctor. The symptoms listed here are ones that you should be particularly aware of to discuss with your doctor should they occur. These could indicate that the cancer has returned and may require treatment.

It can be difficult having to be on alert for signs of the CLL coming back and sometimes any type of symptom or feeling unwell can cause distress. It is important to remain logical with your thoughts and understand that not everything you feel means your CLL is coming back. It's necessary to simply be aware of what to watch out for so you can mention any concerns to your doctor.

- Unintentional weight loss (where there has been no change in diet or exercise routine)

- Persistent loss of energy
- Loss of appetite
- Night sweats
- Generalised itching
- Swollen lymph nodes
- Persistent cough
- Headaches, seizures and problems with vision
- Any other symptoms you may have experienced just before diagnosis

Below is a table of physical effects, emotions and feelings which can be experienced by people after a diagnosis and treatment for CLL. The list may seem overwhelming however many of these may not apply to you and it is best to discuss your individual concerns with your doctor. It is useful to know what you should watch out for or maybe identify certain feelings or symptoms you are experiencing to follow up further. It is important to remember that there is help and support available for everything in the list to ensure a good quality of life and we encourage you to seek help if you need it.

	Side effect	Cause
My body	Fatigue & lack of energy	• Common after cancer treatments such as chemotherapy & radiation • Feelings of depression & anxiety • Physical factors such as thyroid function, anaemia, nutritional deficiencies & deconditioning (after long period of low physical activity)
	Heart problems	• Some chemotherapy drugs including high dose chemotherapy used in stem cell transplants • Radiation to the chest area • People of older age, with a history of heart disease or high blood pressure are at higher risk
	Lung problems	• Radiation to the chest area • Certain chemotherapy drugs • Increased risk for transplant recipients & after Total Body Irradiation • Increased risk for smokers or people with a history of lung disease
	Kidney problems	• Certain chemotherapy drugs Increased risk for transplant recipients & after Total Body Irradiation • Immunosuppressive therapies • Increased risk for people with diabetes
	Liver problems	• Increased risk after Total Body Irradiation
	Eye problems	• Chemotherapy • Steroid medication • Radiation involving the eye (including Total Body Irradiation)

How to help
• Exercise • Eat well • Planning ahead • Talk to your doctor if you're concerned about your energy levels or if symptoms are worsening • Fatigue can last for months to years after treatment ends & generally improves with time
• Various screening tests (ECG, Echo) • Blood pressure & cholesterol checks • Regular exercise • Eating well & maintaining a healthy weight (avoid a high fat diet) • Avoid smoking, drug use & a sedentary lifestyle (not moving or sitting too much)
• Monitor lung health & report shortness of breath, cough, wheezing or coughing up of blood to your doctor • Avoid smoking (including second hand smoke) • Recommended not to scuba dive without medical clearance • Screening & lung function tests • Flu & pneumococcal vaccines (speak with your doctor)
• Kidney function tests through blood test & urinalysis (urine samples) • Blood pressure checks • If necessary, strict control of blood pressure using medications & blood sugar levels for diabetics
• Avoid heavy alcohol consumption • Report abdominal pain, swelling of the abdomen, weight gain & yellowing of the skin • Liver function tests (blood test)
• Regular annual eye tests • Report blurry vision, light sensitivity, poor night vision, double vision in one eye, seeing halos around objects, fading or yellowing colours

	Side effect	Cause
My body	Bone density problems (increased risk of bone fractures)	• High dose steroids & certain chemotherapy drugs • Radiation • Increased risk for transplant recipients & after Total Body Irradiation • Premature menopause due to some chemotherapies & treatments
	Mouth & dental problems	• Total body irradiation • Increased risk for transplant recipients
	Skin problems	• Radiation • Chemotherapy
	Nerve damage (peripheral neuropathy)	• Certain chemotherapy drugs

How to help
• Minimise the drinking of alcohol • Avoid smoking • Complete regular weight-bearing & impact exercise (see an Exercise Physiologist) • Increase calcium & vitamin D intake through diet & by taking supplements (speak with your doctor before taking supplements) • Report any bone pain • Bone density scans • Bisphosphonate infusions if necessary
• Practice good oral hygiene, frequent tooth brushing, daily flossing & regular use of mouth wash • Saliva products if experiencing chronic dry mouth • Regular dental checks • Do not see a dentist until you have clearance first as your immune system may still be at risk immunocompromised
• Practice good hygiene & skin care • Wash with mild soap & use hydrating lotions for dry or scaly skin (specific lotions for conditions are usually available at a pharmacy) • Protect open skin wounds • Always use sunscreen outside and protect your skin • Report loss of flexibility and movement • Vitamin E cream can help tight or sore skin • Annual skin checks are recommended
• Report changes to feelings in your toes & fingers, “pins & needles”, tingling, burning, numbness, sudden sharp or stabbing pains, changes in perception of temperature, constipation • Report difficulties with fine motor skills (i.e. - buttoning up a shirt) • Side effects usually improve in time • Use of pain patches, physiotherapy, acupuncture, occupational therapy, compression socks, high fibre diet (to manage constipation) may assist • Speak with your doctor about pain medication & topical creams

	Side effect	Cause
My body	Lymphedema (persistent swelling of the limbs)	• When certain lymph nodes are removed or treated with radiation (usually underarm or groin lymph nodes)
	Raised cholesterol, blood pressure & diabetes	• Transplant recipients at higher risk • Chemotherapy • Those with GVHD and/or taking long-term immunosuppressive medication are at higher risk
	Risk of developing secondary cancers	• Chemotherapy • Radiation
	Thyroid problems	• Radiation in the neck area • Transplant recipients at higher risk
	Increased risk of infections	• Chemotherapy can affect spleen function • Transplant recipients at increased risk
	Fertility problems for women	• Some chemotherapy drugs • Radiation to the pelvic area • Infertility in transplant recipients
	Premature menopause	• Some chemotherapy drugs • Transplant recipients at increased risk

How to help
• Report swelling, pain or difficulty with everyday tasks • Speak to your doctor about a referral to a Lymphedema specialist • Exercise (see an Exercise Physiologist
• Regular cholesterol blood tests, glucose intolerance tests & blood pressure checks • Maintain a healthy lifestyle & weight, eat a balanced diet with fruit and vegetables & exercise regularly Avoid high fat foods, smoking & sedentary lifestyle. Be active and move regularly
• Maintain a healthy lifestyle by eating a balanced diet, exercising regularly, not smoking & limit alcohol consumption • Attend your check-up appointments • Attend screening appointments • Report any symptoms or concerns to your doctor
• Report fatigue, weight gain, constipation, dry skin, brittle hair or intolerance to cold temperature • Thyroid function test via a blood test • Hormone levels can be managed with medications & treatments
• Attend your regular check-up & immunisation appointments • Do not visit other healthcare providers when your immune system is still low without clearance from your medical team first (especially dental & gynaecology exams) • Take preventative medicines if recommended by your doctor
• Hormone level blood tests • See a fertility specialist to discuss options you may have (you may have had eggs or ovarian tissue samples stored)
• Report symptoms such as vaginal dryness, hot flushes, mood swings, irritability, fatigue • See a specialist to manage symptoms and discuss medication • Exercise, yoga & acupuncture may relieve symptoms

	Side effect	Cause
My body	Fertility problems for men	• Some chemotherapy drugs • Radiation treatment near testicles • Transplant recipients at increased risk
	Sexual problems for women	• Some chemotherapy drugs • Radiation to the pelvic area • Increased risk for transplant recipients • Lower levels of Oestradiol & other female sex hormones • Sudden onset of menopause • Some other medications you may be on affect sexuality • Body image concerns • Stress and anxiety • Changes in your relationship • Various psychosocial issues may be impacting on sexuality
	Sexual problems for men	• Some chemotherapy drugs • Radiation treatment near testicles • Increased risk for transplant recipients • Lower levels of testosterone • Some other medications you may be on affect sexuality • Body image concerns • Stress and anxiety • Changes in your relationship • Various psychosocial issues may be impacting on sexuality
My mind	Cognitive issues (thinking issues also known as "chemo brain")	• Chemotherapy • It's not well understood but other factors such as stress, anxiety & depression may play a part • Fatigue can worsen cognitive function • Hypothyroidism (thyroid dysfunction) can make you feel "out of it"

How to help
• Hormone level blood tests • See a fertility specialist to discuss options you may have (you may have had sperm samples stored) • Seek out information, resources & support on the topic
• Report vaginal dryness, painful intercourse, reduced sexual desire & reduced ability to achieve orgasm • Report thinning & inflammation of vaginal wall, loss of tissue elasticity & decreased vaginal lubrication • Exercise, yoga & acupuncture may help with symptoms • Consider seeing a sex therapist to learn techniques & strategies to assist in your sex life (some are specialised in dealing with the cancer experience) • See specialist for medications, lubricants, specialised moisturisers & more • Communicate openly with your healthcare team & partner • Seek out information, resources & support on the topic
• Report decreased libido & sexual desire & erectile dysfunction • Medications, devices, injections & other forms of treatment can help, ask for a referral to a Urologist • A sex therapist can assist you to learn techniques & strategies to assist in your sex life (some are specialised in dealing with the cancer experience) • Open communication with your healthcare team & partner • Seek out information, resources & support on the topic
• Report issues with memory loss, concentration, confusion or delays thinking things through • Treatment for hypothyroidism (if appropriate) • Brain training exercises, puzzles & memory games can assist (use of mobile phone apps) • Get enough sleep, exercise & eat well • Often improves with time

	Side effect	Cause
My mind	Anxiety, stress (particularly fear of cancer recurrence	• Overall treatment and cancer experience • Important to remember you are only human & the emotions & feelings you have are a normal response after a traumatic experience
	Low mood or depression	• As above (cancer experience & normal human response) • Some medications • Hormone dysfunction (premature menopause)
	Anger & frustration	• Anger at the after effects of treatment, why me? • Frustrated due to others not understanding, frustrated with your body not performing the way you want it to or not being able to do the things you used to • Other causes unique to each person
	Guilt	• Survivors guilt • Guilt of pressures placed on loved ones
	Sad & sense of loss	• Sad about everything you & your loved ones had to endure • Sense of loss (time taken from your life to receive treatment - a ”pause” on life) • Loss of health, infertility

How to help
• Understand that your medical team have developed necessary plans & follow up care for you • Do things that are in your control to reduce risk of cancer recurrence (healthy lifestyle, maintain healthy weight, balanced diet, exercise, avoid smoking including passive smoking, reduce alcohol intake) • Try activities such as meditation, yoga, relaxation massage, mindfulness & more (see next sections for details) • Do the things you enjoy & make you feel relaxed • It may be useful to speak with an experienced counsellor or psychologist for techniques on managing stress
• Be open and discuss your mood and concerns with your doctors • Understand that having a low mood is normal but be aware of continuing signs of depression such as sleep disturbances, difficulty completing daily tasks, feeling hopeless & suicide thinking. Seek professional help if needed such as from a counsellor or psychologist. Ask your GP about the use of the Mental Health Care Plan • Exercise, eat well and maintain a healthy sleep routine
• Undertake activities to help you relax such as meditation, yoga, mindfulness • Some forms of exercise may help release feelings of anger & frustration • Communicate openly with loved ones to help them understand your experiences • Discuss with your doctor and seek support services as needed
• Usually gets better with time • Speak with counsellor or psychologist • Connect with others who have had similar experiences as you
• Seek support services such as counsellors, psychologists & other resources (• Do what is in your control to try & regain health (exercise physiologists & rehabilitation, balanced diet, smoking cessation)

	Side effect	Cause
My mind	Isolation	• Social isolation may be caused by others not understanding what you're going through • Unable to relate to others • Particularly strong feelings of isolation when surrounded by friends undertaking activities which you may be struggling with (full time work, sex, having babies, relationships & more)
	Feeling vulnerable	• Less frequent visits with your medical team results in less reassurance about your health
	Finding meaning or purpose through illness	• Cancer experience changes perspective in life & questioning purpose
	Self-esteem, identity and body image. Loss of confidence	• Treatment causing changes in the physical appearance of the body • Changes in sense of identity due to overall cancer experience (feeling like everyone identifies you as the person who had cancer) • Confidence may be lost in the performance of your body because you feel it failed you in the past (not knowing what you are/are not capable of)
	Feeling "lost" or confused	• The time when active treatment stops & recovery starts can feel a bit like "limbo" - you are better but still not quite well enough • Cancer experience can change your perspective on life which sparks a reassessment of your values, goals & so on

How to help
• Connect with others who have had similar experiences as you • Formal support groups or casually chatting with others you met during your experience • Online forums & support • Open communication with loved ones for better understanding • Use other support services
• Understand that your medical team have developed necessary plans & follow up care for you • Turning to spirituality may help • have developed necessary plans & follow up care for you
• Spirituality may help some people find meaning & purpose
• Set goals for yourself, think about how much you want to be associated with your cancer experience or not • Consider speaking with a counsellor or psychologist • Exercise (use an Exercise Physiologist to comfortably build trust in your body again) • Overcoming challenges is unique to each person (i.e.- some people feel better after being pampered or buying new clothes they're comfortable in.) Participate in the cancer "Look Good Feel Good" program if appropriate
• Be kind to yourself & focus on recovery & taking control of things that can make you feel better (exercise, eat a balanced diet, doing things you enjoy) • Do not put pressure on yourself to have to go out and "do things". Be patient & give yourself the time you need to work things out • Set goals & work towards them • Gain assistance from others to help support and achieve your goals

Future of CLL

For people diagnosed with CLL it is important to understand that there are new treatments being developed all the time. There are currently many studies for CLL being done in research labs and in clinical trials around the world. These trials look into new treatments for CLL and investigate current treatments to try and improve ways they can work better.

There are some new areas of advancements such as:

Genetics of CLL

Scientists are making great progress in understanding how changes in a person's DNA can cause normal bone marrow cells to develop into lymphoma cells. Learning about changes in the genes (regions of the DNA) that often occur in CLL is providing insight into why these cells grow too quickly, live too long, and fail to develop into normal blood cells. Doctors are also learning how to use these changes to help them determine a person's outlook and whether they will need treatment.

New drug treatments for CLL

Dozens of new drugs are being tested for use against CLL. Many of these drugs are targeted at specific parts of the CLL cells and work with the body's immune system.

Ibrutinib (Imbruvica™) is a treatment that aims to target the CLL cells and leave normal healthy cells relatively unharmed. It works by blocking a protein in the body. This protein is called 'Bruton's tyrosine kinase' (BTK) so this drug is called a BTK inhibitor and is given in the form of a tablet.

Obinutuzumab (Gazya™) is a treatment that aims to target the CLL cells and make your immune system recognise these and destroy them. It works by attaching itself to the CLL cells in your ody and helps your own immune system recognise them and destroy them as well as directly targeting and destroying the CLL cells on its own. This is a monocloncal antibody drug which targets CD20 on the surface of CLL cells and it is given as a treatment into the vein.

Venetoclax (Venclexta™) is a treatment that aims to induce cell death of the CLL cells that would otherwise not be able to be destroyed. It works by targeting a specific protein in your blood called BCL-2 which is a protein that may build up in your body when you have CLL and prevent CLL cells from self destruction naturally. This is a drug that targets the BCL-2 protein and is given in the form of a tablet.

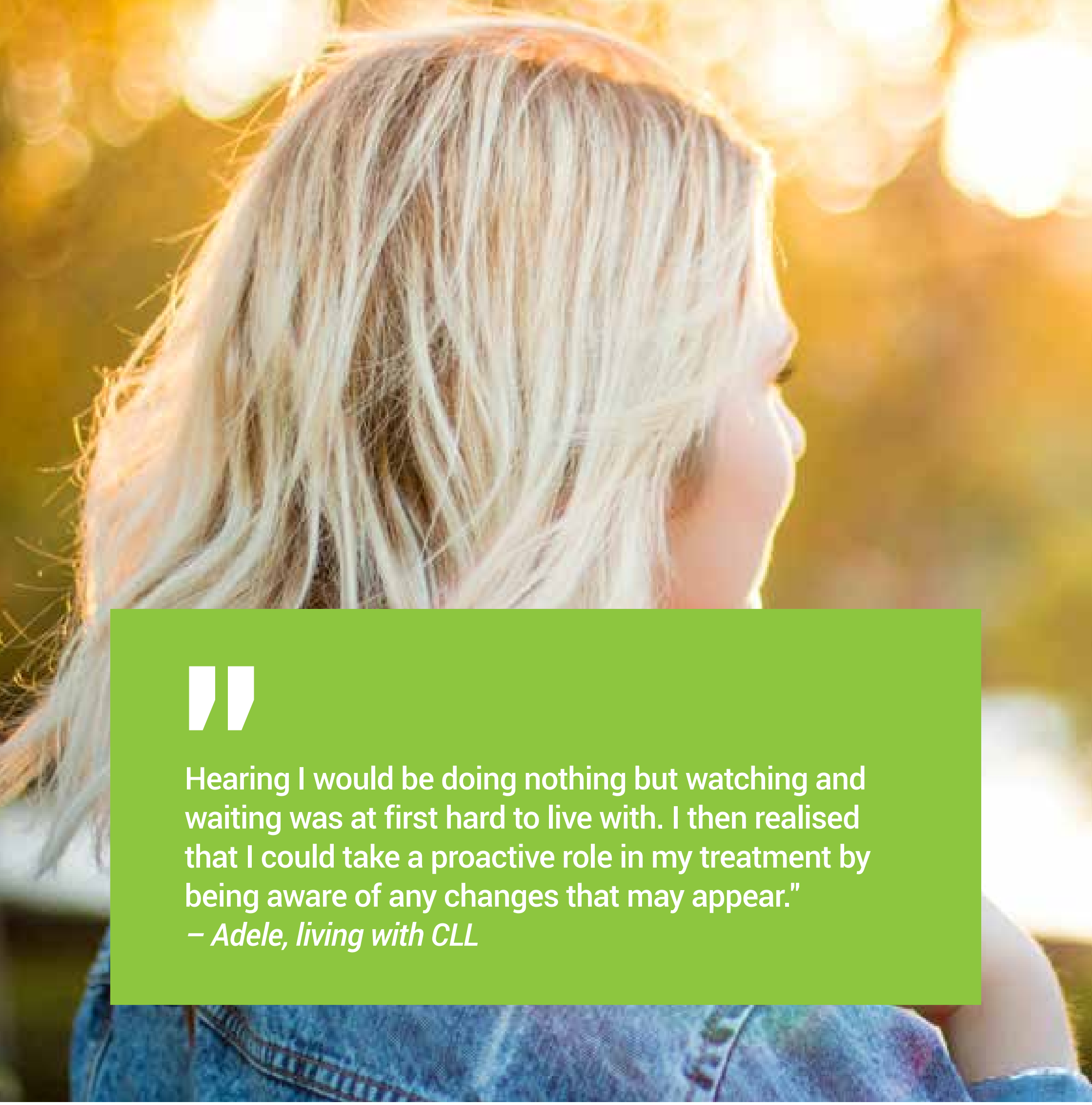
These are great advancements in the treatment of CLL with new drugs being made available to people with CLL all the time so please talk to your doctor and ask if there are any new treatments that would be available for you.

My follow up care plan

These next sections are for you to manage your follow up care. We encourage you to take control of your care and seek out the information from your health care team. Fill in these sections and make sure that all the necessary checks and tests are done. You can obtain this information through your haematologist, specialist nurse, GP or any other staff member who has authority and access to your medical history. Sections for you to record your care in are:

- My CLL overview
- My health and family history
- Symptoms to watch out for
- My follow up tests and checks
- My follow up appointments
- Subsidised visits to allied health professionals
- My CLL treatment overview
- My current medication list

As life changes you may not always have the same GP so be aware of any health risks you may have and know that it is OK to tell your doctor what tests you may need. You do not always have to wait to be told by a doctor what needs to be checked!



> Hearing I would be doing nothing but watching and waiting was at first hard to live with. I then realised that I could take a proactive role in my treatment by being aware of any changes that may appear."
> *– Adele, living with CLL*

You may need to also check with your health care team before seeing other health care provider's such as dentists, gynaecologists, podiatrists and so on. This is because you may have a reduced immune system due to the CLL or treatments which means certain exams, tests and treatments should not be performed at certain time periods.

My CLL overview

Describe your CLL type (including stage/grade):

CLL location:

Date of diagnosis:

Age at diagnosis:

Symptoms experienced at diagnosis:

My health and family history

It is important when seeing the medical team to identify any other health issues you have had in the past including diabetes, past injuries, asthma, heart related conditions, lung issues, other cancers, high blood pressure, cholesterol and so on as well as any family health history.

My health history:

My family health history:

My treatment overview

It is important to have a record of the types of treatments you have received and any other significant events or complications. This information can come in handy in the future when seeing other health professionals who may need to know your history. It is also useful to take this information with you when travelling under the unexpected circumstance of being admitted into a hospital who may not have immediate access to your history.

Date	Treatment category	Treatment type
May 2019 to Nov 2019	Chemotherapy	FCR – Fludarabine, Cyclophosphamide, Rituximab

Above is an example

Treatment category may include: Chemotherapy, Radiation, Autologous transplant, Allogeneic transplant, Clinical trial, Biologic therapy which includes immunotherapy and targeted therapy.

Additional treatment notes	Complications or significant events during this period	Treatment centre
Cycle 5 delayed 3 days due to infection and low blood counts	Admitted to hospital while my blood counts were low with a chest infection after cycle 4	The Austin Hospital

Date	Treatment category	Treatment type

Additional treatment notes	Complications or significant events during this period	Treatment centre

Date	Treatment category	Treatment type

Additional treatment notes	Complications or significant events during this period	Treatment centre

My current medication list

Medications are constantly reviewed and changed so this section may get a little messy! Use this table initially to fill in your current medications however you may prefer to use a mobile phone application to update as you go along.

Name of medicine	Dosage/strength	How much to take and when
Resprim Forte	160mg/ 800mg	1 tablet a day

Above is an example

This is particularly useful for those who are still on lots of medication who may find it difficult to keep track of everything.

Additional instructions or comments	Date started	Date to stop or review
Take after food	2019	Ongoing until reviewed

My follow up tests and checks

It is important to understand the tests and check-ups that you may need to undertake in the coming months and years. Discuss this with your doctor and fill in the sections relevant to you so you are aware of all the tests and follow-ups that need to be done.

	Type of test/check	Test method
Blood Tests	Full Blood Count Examination (FBE) test	Blood sample
	Lactate dehydrogenase (LDH) & other tumour markers	Blood sample
	Liver function test	Blood sample
	Kidney function test	Blood sample
	Thyroid function test	Blood sample
	Cholesterol test	Blood sample
	Hormone function tests for women (may need to be referred to specialist)	Blood sample

There may be some instances where the doctor cannot give you exact time frames, some of these tests will need to happen less often as more time passes but the most important thing is to know what tests should be getting done and reviewing the time periods when necessary.

Is this relevant to me?	How often do I need this done?	How long I need to continue getting this done

	Type of test/check	Test method
Blood Tests	Hormone function tests for men (may need to be referred to specialist)	Blood sample
	PSA tests for men (Prostate Specific Antigen test)	Blood sample
Physical Examinations	Physical exam	Feel for lymph nodes, swelling of the liver & spleen
	Skin check	Observation especially in irradiated areas
	Breast check	Self-check plus have health professional feel for abnormalities (see screening for breast screens)
Other checks	Urinalysis (urine test)	Urine sample
	Blood pressure	Routine BP check
	Dental (get medical clearance first before seeing dentist)	Routine mouth & dental checks
	Eye examinations	Routine eye checks with optometrist or specialist
	Glucose intolerance test (diabetes)	Finger prick & blood sample
Screening	Lung function test	X-ray if required, breathing test
	Heart tests	Echo, ECG
	Bone health	Bone density scan

Is this relevant to me?	How often do I need this done?	How long I need to continue getting this done

	Type of test/check	Test method
Screening & other examinations	Other screening methods if required	CT/CAT Scan, PET scan, MRI, X-Ray
	Colon & rectal cancer screening	Colonoscopy
	Cervical cancer screening	Pap smear
	Breast check	Ultrasounds and/or mammograms. MRI (if premenopausal)
Vaccinations	Flu shot	Needle injection
	Pneumococcal shot	Needle injection
	Immunisation shots (for transplant recipients only)	Schedule of various needle injections

Is this relevant to me?	How often do I need this done?	How long I need to continue getting this done
	10 years after radiation or at age 35 (whichever is later), followed by colonoscopy every 5 years	
	Annual mammogram &/or ultrasound beginning at age 25 or 8 years after chest radiation (whichever is later) Yearly mammograms &/or ultrasound for women over 40 years of age	
	Annually	Commence 6 months post treatment
	Once every 5 years	Commence 6 months post treatment
	You should receive a schedule of what immunisations you need & in what month	Commence 6 months post treatment

My follow up appointments

Based on the tests which are relevant to you from the above table, use this section to fill in all of your follow up appointments and add reminders into your calendar. Be sure to include the appointments that happen less often or annually, even if you can't set a date and time for them just yet.

Appointment Type	Location	Date and Time
Clinic appointment	The Austin Hospital	Thursday 14th November 2019
Flu shot	GP office	May 2019 (call to make appointment closer to date)

Above are examples

Appointment Type	Location	Date and Time

Notes

Lymphoma
Nurse Support Line

1800 953 081

We are here to help.
Please call, as fear of the unknown should not be part of the Lymphoma experience.

Lymphoma Australia would like to give a very special thank you to sponsors, hospitals, doctors, nurses, patients, families and friends that make our educational resources possible. Taking the fear of the unknown out of the Lymphoma journey can make a huge difference.

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