Belinda loses her locks for Charli

Cairns Mum, Belinda Francis, said shaving her long hair was a small price to pay to support her daughter Charli and other children who have lost their hair while undergoing chemotherapy.

‘I also wanted to give back to the Leukaemia Foundation and was so excited to raise over $12,000 during World’s Greatest Shave to say thank you for supporting my family through our experience with leukaemia’ Belinda said.

‘I don’t know how we would have coped without the help of the Leukaemia Foundation. Our horrifying journey would have been even more stressful without the emotional and financial support we received.’

The Francis family’s world was turned upside down when their two-year-old daughter Charli was diagnosed with acute lymphoblastic leukaemia in June 2013.

‘Charli seemed to have the symptoms of a virus – high temperatures, lethargic and not eating very much – a fairly normal thing that kids can pick up at day care,’ she said.

‘However I decided to take her to the GP when she complained of a sore mouth and I discovered a blister on her tongue. She also had a few light bruises but I still was really not concerned.’

‘The doctor told me Charli was anaemic from the colour of her eyes and skin and that I should rinse her mouth with salt water to treat the blister and give her an iron supplement.’

Belinda said that by the next day her gut was telling her that something wasn’t right.

‘I returned to the doctor that morning and insisted on blood tests – and I’m so glad I followed my instinct,’ she said.

‘Within an hour of the blood test I was told that our precious Charli had leukaemia.’

Charli and her Dad, Steven, were rushed to the Royal Children’s Hospital in Brisbane the morning after the diagnosis. Belinda soon followed once she had made arrangements for their older daughter, Sienna, to stay with someone while they were in Brisbane.

‘It was so hard for the whole family as we were separated by 1700 kilometres,’ Belinda said.

‘Steven runs a family concreting business and couldn’t be away for long periods of time. We desperately needed to keep his income as we had just moved into a newly built home a week before Charli was diagnosed.’

‘I really think that was Steven’s way of helping our family as it really tore him to pieces to see Charli in hospital. He would come and visit us every second weekend and my mum would come on the other weekend which gave me a break.’
We have already had a Coffee, cake and chat event for CML patients and carers in February, which was a great opportunity for those affected by CML to get together, support each other and share information. Don’t worry if you missed out, there will be other leukaemia Coffee, cake and chat events in coming months. For younger leukaemia patients, we will also be having our first “20/30 chat session” for young blood cancer patients on Saturday 16 May. There are also events on the Gold Coast and in north Queensland which give an opportunity to connect with other patients and carers. Please see the back page for details or call 1800 620 420 for more information.

We are still encouraging patients to sign up for our free Fit to Thrive exercise program and are excited to share that the program is also being rolled out on the Gold Coast, Cairns and Townsville. This 12 week program is an individually-tailored exercise program for those living with leukaemia and other blood cancers to help promote positive outcomes during and after treatment.

The Leukaemia Foundation’s annual Doorknock collection is on again from 20 June to 3 July, so please give generously if someone knocks at your door. I’d also like to encourage you to mark Friday 9 October in your diary for Light the Night 2015. This very special event aims to raise funds and awareness of leukaemia and other blood cancers. Stay tuned for more information later in the year.

Thank you so much to Belinda and Charli Francis and John Scholes for sharing their stories about their experiences with leukaemia. Every experience is different and I would love to hear from any of our readers who have ideas for articles or who would like to share their stories.

Take care.

Kate Arkadieff
Support Services Coordinator
(Acute and Chronic Leukaemia)
Cooking for Chemo

The first Brisbane session of Cooking for Chemo was held on April 11, with patients and carers gathering at Brisbane's The Golden Pig Cooking School for an afternoon of learning more about nutrition and meals during treatment.

2014 Masterchef finalist Ben Macdonald and Brisbane chef and restaurateur Ben O'Donoghue cooked several dishes for attendees, with an emphasis on creating easy and nutritious meals that are palatable for someone experiencing the typical side effects of chemotherapy.

Ben Macdonald could identify with many of the issues some of the attendees were facing – in 2002, while living in the UK, he was diagnosed with acute lymphoblastic leukaemia. While Ben has been in remission for more than 10 years, he remembers how his tastebuds and feelings about food changed while he was in treatment, which meant he was able to offer a unique perspective in designing the Cooking for Chemo program.

Dietitian Peter Rhodes co-hosted the cooking session, giving participants handy tips for adding more nutritional punch to their meals in the form of whole foods.

“Often patients are told to just eat whatever they can, but we wanted to also give them options for enjoying food and getting adequate nutrition, while still meeting the unique needs of a patient and carer going through treatment,” says Barbara Hartigan, Director of Support Services.

Cooking for Chemo videos will be posted on the Foundation’s YouTube channel next month, and a second live cooking session is currently being planned.

Dominique does something amazing to beat blood cancers

There aren’t too many 10-year-old girls who would be willing to part with their hair to help people with blood cancers, but Dominique is brave beyond her years.

Dominique cut short her beautiful waist-length blonde locks to not only help the Leukaemia Foundation raise $5 million in Queensland during World’s Greatest Shave in March, but also make wigs for kids going through chemotherapy.

With the help of her family and school friends, Dominique surpassed her goal by raising $2000 to help those with blood cancer.

Proudly supporting his daughter’s efforts was her dad, Dr Matthew Hourigan, a clinical haematologist and haemato-oncologist who treats blood cancer patients and participates in clinical research. Dr Hourigan has also given presentations to patients at our villages and trains medical students at University of Queensland.

Over 40,000 kind-hearted Queenslanders coloured, shaved or supported those who did during World’s Greatest Shave.

For those who didn’t get a chance to shave or colour this year, donations can still be made at worldsgreatestshave.com or by calling 1800 500 088.
John’s unexpected CLL diagnosis

Like many other chronic lymphocytic leukaemia (CLL) patients, John Scholes’ diagnosis resulted from a routine blood test which showed an elevated white cell count.

John was 53 at the time and had a complimentary medical which was offered while working in the New South Wales public service.

‘I was told that my white cell count was slightly elevated, but that it was nothing to worry about,’ John said.

‘Twelve months later I had another blood test which showed that my white cell count had risen again and my doctor told me I shouldn’t ignore it.’

He sent me to a haematologist although at no stage did he talk about leukaemia.’

‘So when I got the diagnosis of CLL I was really shocked. I didn’t know there were different types of leukaemia - I just thought of leukaemia as a death sentence.’

However, John’s haematologist eased his fears and told him that he probably would not need any treatment for years.

Unfortunately, things did not go as smoothly as John had hoped.

‘My white blood cell count continued to climb and by early 2009 I needed to begin treatment. In March 2009 I started three rounds of oral chemotherapy,’ John said.

‘While the chemotherapy made me very sick, my doctor was delighted with the results.’

The following year John decided to retire from his job and moved with his wife Kerrie to the Sunshine Coast.

‘When we moved state I went to see a new specialist and although I had regular blood tests my results were all over the place. I felt like my doctor wasn’t confident about how to treat me.’

‘At that stage I was having low dose chemotherapy but my blood results were not good and I was feeling unwell and fatigued.’

By late 2013 John said his health had declined and he began seeing a new haematologist as the previous doctor had left.

‘My new haematologist was concerned with the blood test results and ordered a bone marrow biopsy which revealed a chromosomal issue called deletion 17P, which my doctor indicated made my case more complicated to treat.’

‘I began another three doses of chemotherapy along with Mabthera just after Christmas 2013 and although I wasn’t as sick as I had been when I first had chemotherapy, I was very glad I wasn’t working. I felt incredibly lethargic.’

‘The treatment was very successful and by mid 2014 I was feeling well and my blood test results had improved dramatically, however they still couldn’t get my platelet count up.’

‘My doctor told me that a stem cell transplant was my best chance of a good outcome, so we went ahead with finding a donor. In the meantime I had a number of skin cancers that I needed to have removed before they would go ahead with the transplant.’

In November 2014 John had an allogeneic (donor) transplant with stem cells taken from his brother who fortunately proved to be a near perfect match.

‘During my transplant Kerrie stayed at a motel near the hospital as there were no vacancies at the Leukaemia Foundation villages.’

‘Eighteen days after my transplant I came out of hospital and we moved to Clem Jones – Sunland Leukaemia Foundation Village – a fantastic facility.’

‘We were so grateful to have free accommodation in such a wonderful place where we had support staff on hand and which provided free transport to the hospital. If we’d had to pay for accommodation it would have made things a lot tougher.’

John said he feels very fortunate that the stem cell transplant went very smoothly even though he said he was incredibly lethargic after it.

‘Now I am only on a small amount of medication and my blood results are fantastic. My energy has returned.’

John is now 100 days post transplant and looking forward to returning home to the Sunshine Coast very soon where he plans to get back into the surf again as soon as possible.
A day in the life of Kate Arkadieff

A huge part of the support we offer blood cancer patients and their families comes from our team of dedicated and professional Support Services Coordinators like Kate Arkadieff.

Kate’s role at the Foundation is definitely not a nine-to-five job, delivering emotional and practical support to patients and families when they need it most - throughout diagnosis and treatment and in the months and even years that follow. We spent a day with Kate to give you a glance into the important role of Support Services Coordinators.

8.30am – Arrived at the village and spoke briefly to our two volunteer bus drivers before they left to take patients and families up to the hospitals – offering free transportation means one less thing our patients have to worry about.

8.45am – I helped one of our residents with her Centrelink application for the Carer’s Payment as well as her husband’s Sickness Allowance. Once all paperwork is gathered we send it off to Centrelink. Centrelink staff visit our ESA village fortnightly and assist with any questions or paperwork lodgements.

10:30am – I had an AYA (adolescents and young adults) patient drop in and we chatted about some survivorship issues (fatigue, chronic graft-versus-host disease (GVHD), and living with the daily reminder of the disease and transplant). He was diagnosed four years ago and had a transplant two years ago. We discussed issues around returning to work and judging his physical limits. He was concerned about how his return to work might affect his Centrelink payment and health care. We also spoke about our 20/30 chat that the Foundation is hosting in May for young cancer patients and he was excited about meeting people of a similar age who would understand what he is going through.

12pm – I received a phone call from the social workers at the Princess Alexandra Hospital wondering if we would be able to give financial assistance to a patient for the purchase of a wheelie walker to use at home after being discharged from hospital. We do all we can to reduce extra stress so that patients and their families can concentrate on their treatment and recovery.

12.20pm - A local patient phoned and asked if I could post him some information on chronic lymphocytic leukaemia (CLL). We had a chat regarding his disease and how we could assist him. I told him that his wife was welcome to attend our Caring for the Carer program and that she may be eligible for the Carer Payment from Centrelink. We arranged a home visit for next week so I could come and meet with him and his wife. Home visits are a great way to provide emotional and practical support in the comfort of the patient’s home.

12:40pm – I received a phone call from a psychologist in Bundaberg who was seeking information about our grief services for a father whose seven-year-old son had recently passed away. I posted information to her including our referral forms and further information about our services, including the Bereaved Parents’ Weekend.

1pm – Lunch time with my lovely colleagues at the village!

2pm – I organised a meeting with one of our volunteer Financial Counsellors for a family seeking guidance on approaching their bank to negotiate a repayment deferral on their mortgage. Unfortunately when you are diagnosed with blood cancer, the bills still keep coming. Being able to help families with these types of issues is so important in relieving some of the stress they are under.

2.15pm – A carer phoned whose husband is quite unwell at the hospital and asked if I could come and visit with her today. Being that listening ear or providing words of encouragement during this tough time is such an important part of this role. I feel privileged to be able to support patients and their families in any way I can.

2.45pm – I met with a carer and her daughter in the hospital cafe to provide emotional support and comfort over a cup of coffee. I spoke with her about her husband’s wishes, the financial implication of a loved one passing such as access to the bank accounts and whether he had a Will and an advance health directive in place. Providing emotional care for the families of our patients is so important as they go through such a difficult time.

4.15pm – I responded to some emails and queries that had come through the website. Tomorrow I will spend most of the day at the hospital, so I started putting together some information packs for new patients I have been asked to see, and collate some flyers for upcoming education seminars that I can take to the wards and outpatients department. Providing useful information is an important way we support patients and families.
New leukaemia therapy a step closer

A potential new treatment for leukaemia and lymphoma patients is being progressed at the Walter and Eliza Hall Institute of Medical Research (WEHI) in Melbourne with funding support from the Leukaemia Foundation of Queensland.

The research project is one of 14 additional blood cancer projects across Australia that will share almost $4 million through the latest round of the Foundation’s National Research Program.

Dr Stephanie Grabow will receive $200,000 over two years for her Postdoctoral Fellowship to continue the work that she and others at WEHI have been doing to develop a new anti-cancer treatment for lymphoma and leukaemia. One of the avenues under investigation is to target MCL-1, a protein that is critical for the survival of many cell types.

Up to 70% of human cancers, particularly leukaemias and lymphomas, show deregulated MYC protein which allows cells to divide abnormally and (together with other genetic defects) can cause tumour development.

In previous work, Dr Grabow and her colleagues discovered that leukaemia and lymphoma cells that arose due to deregulated MYC are dependent on MCL-1 for their survival. In fact, many tumour cells are more dependent on MCL-1 than normal healthy cells, suggesting that a drug targeting MCL-1 may be feasible for cancer therapy.

To determine the therapeutic potential of MCL-1 inhibitory drugs and their possible adverse effects on patients, Dr Grabow will gather vital information about the amount of MCL-1 protein required during lymphoma development and continued growth of tumour cells, and compare this to the extent of MCL-1 reduction that normal tissues can tolerate.

‘The data I gather will help us understand what concentration of MCL-1 inhibitory drug is needed to effectively kill leukaemia and lymphoma cells without causing adverse side-effects,’ Dr Grabow said.

‘We have highly promising preliminary results testing a potential drug in laboratory models of various human lymphomas and leukaemias.’

‘I am also looking at the role of key ‘pro-death’ proteins to understand how they interact with MCL-1 to control the survival of cancer cells and the normal tissue cells.’

Another component of Dr Grabow’s research is to identify gene mutations commonly found in leukaemias and lymphomas that correlate with high dependency on MCL-1 for survival. This work is geared to identify diagnostic biomarkers for these cancers that will benefit the most from drugs that inhibit MCL-1.

Knowledge gained from Dr Grabow’s studies will contribute to the development of novel drugs that specifically target MCL-1 or regulators that control its level and activity for anti-cancer therapy.

The Leukaemia Foundation also awarded a $120,000 PhD scholarship to Dr Grabow’s colleague Margs Brennan who is investigating the mechanisms that control the expression of MCL-1 and the potential of drugs that inhibit MCL-1 for the treatment of leukaemias and lymphomas. The Foundation has previously part-funded this laboratory’s ground-breaking research into MCL-1.

The 2015 research allocation brings the number of research projects currently funded by the Foundation at leading research institutions across Australia to 49.

For more details about the Foundation’s latest research investments, please visit leukaemiaqld.org.au

The Leukaemia Foundation is investing $1.65 million over three years in the ALLG Discovery Centre in Brisbane (formerly the ALLG Tissue Bank) to ensure this vital infrastructure continues and tissue samples remain available for blood cancer research.
2015 is a very special year for the Leukaemia Foundation of Queensland as we celebrate our 40th anniversary. I look back with tremendous pride and gratitude at the small band of men and women who began our organisation intent on one purpose – beating blood cancers with love, sweat and tears.

The late 1960s saw significant advances in the treatment of blood cancers with the introduction of new chemotherapy treatments and medical equipment that improved patient survival.

The dedication of haematologist Dr Trevor Olsen to make these new technologies available in Queensland became the driving force behind the establishment of the Lions Leukaemia Foundation in 1975 which later became known as the Leukaemia Foundation of Queensland in 1980.

As is the case today, a blood cancer diagnosis put patients and their loved ones under enormous emotional and financial stress, especially those from rural and regional areas who had to travel to Brisbane for treatment. Unbelievably we heard stories of families sleeping in their cars while their loved one underwent treatment as they had nowhere to stay and no support in Brisbane.

I was a registered nurse in the 1970s at the Royal Brisbane Hospital, and saw how desperate life was for people affected by blood cancers such as leukaemia, lymphoma and myeloma. Family members were only allowed restricted visits and physical contact. As a young mother of four children I understood how heartbreaking it was for a mother not to be able to hug her child.

During those early days many dedicated members of the Foundation did all they could to offer emotional and practical support to patients. They worked tirelessly to raise funds and in 1977 Hollydene, an old Queenslander, was purchased and renovated to become our first accommodation facility.

This was just the beginning! Branches were established throughout Queensland. The decades that followed saw many major achievements for the Foundation including raising $1.5 million to open Queensland’s own Bone Marrow Transplant Unit in 1987; the establishment of the Foundation’s Support Services division; the opening of the first of four purpose-built patient accommodation villages, Herston Village in 1989; and the establishment of the Leukaemia Foundation Research Unit at the Queensland Institute of Medical Research in 1992, at what is now the QIMR Berghofer Medical Research Institute.

The Foundation has never been timid in our resolve to achieve the best possible outcomes for patients and their families regardless of how insurmountable the problems may have seemed at the time. The partnership between the Foundation, health professionals, government and the community has been one that has and continues to make a tangible difference. Since 1975 many thousands of people have donated funds, participated in events and fundraisers, provided a gift in their Will, and volunteered their time. The generosity of each and every one of these people has saved lives and made the journey for those living with blood cancers a little easier.

I have been privileged to be involved in the work of the Leukaemia Foundation since the late 1970s and have seen the amazing difference our work has made in the lives of countless patients and their families.

Today, beating blood cancers and improving the lives of patients and their families remain our top priorities. Despite the many breakthroughs in treatments, our work is not done and we urgently rely on donors and volunteers to continue to support the growing number of patients and families who still desperately need our care.

As we enter our 40th anniversary year, we haven’t lost sight of our organisation’s history. We are determined to never accept the status quo. We will not rest until we have beaten blood cancers.
Living as a cancer survivor
by Professor Miles Little

Back in 2001 the Foundation invited Professor Miles Little to speak at one of our seminars about the groundbreaking research he was conducting into cancer survivorship.

Following is an article written by Professor Little which provides valuable insight into the challenges faced by people who are getting on with their lives following cancer treatment.

According to the Leukaemia Foundation’s Support Services Director, Barbara Hartigan, while cancer survivorship has in recent years become a ‘hot topic’, the Foundation has been active in this area for over a decade and has invested in research into how we can best support patients in the months and years following treatment.

“The results of the survivorship research we funded has helped form the basis for our model of care and a range of support programs we have developed to support people physically and emotionally following blood cancer treatment,” Barbara said.

‘Many of you will be able to relate to Professor Little’s article and we hope it helps you to understand that you are not alone – many people feel the same way and there is help available.’

Life may be unpredictable, but most of us expect to lead our daily lives with at least some semblance of order. We value that order in many ways. We inhabit bodies that we accept and trust, and whose functions we scarcely notice. We know dimly that we’re all mortal, but we don’t think too much about our own deaths. Instead, we try to work, play, learn and have enriching experiences.

But what happens when we experience something that really threatens our own lives, something like cancer: Our valued order takes a real battering. Our trusted, familiar body has turned against us, and could do it again. We no longer have a comfortably dim knowledge of our own mortality, instead we confront the reality of our own death and there’s not much comfort in that. It’s frightening and for many people it’s not something they can forget. When treatment is over and the cancer seems to have gone, the cancer survival story is just beginning. Life can look different. Things that mattered before cancer may not seem so important. People who were good friends before can seem not such good friends now.

If we’ve had cancer, the cancer label sticks. Even those who’ve survived cancer for many years go on thinking of themselves as people who’ve had cancer. Cancer won’t just go away out of our lives. As one of the cancer survivors we interviewed years after her cancer said, ‘Every time I get a headache or a backache, I think, ‘is it back?’’ We fear recurrence. The fear may grow less with the years, but it doesn’t usually vanish altogether. There may be too many reminders. There may be long-term physical changes, or less obvious things like infertility, fatigue or shortness of breath from chemotherapy. It can be hard to get life insurance or a credit card or even a job if we’ve had cancer. And then there are the regular medical appointments that bring our fears back to the surface each time.

It’s hard to communicate these things to other people who matter to us. We can tell them what cancer was like, but we can’t get them to have the same experiences of fear or pain or loss or loneliness that we’ve had. That’s pretty tough because we want support and understanding from those we love and respect. As one of our survivors says of her family, ‘you just want them to understand, but they can’t’.

Life for survivors is made harder because of the things that people in our kind of society expect of them. People tend to think things like this: ‘If you’ve survived cancer, you’re lucky’, and ‘you ought to appreciate your luck’. They think you should get on with it, go back to normal. Or even get yourself a bigger, richer life, or become a hero like Lance Armstrong.

Some people can do these things. Some even claim that cancer was the best thing that ever happened to them. But that response is not for everyone. Most find the survival experience very mixed, with highs and lows in varying proportions. Many people – perhaps a quarter to a third – find all the troublesome aspects of cancer and its survival affects their quality of life in significant ways. They find themselves driven to give up their jobs, drop university courses, or fall out of love. They may find it hard to talk to old friends. They want help too but it can be hard to know where to get it.

One of the big problems for survivors is their close relationships. Good friends, partners and families are all involved. These people are members of society, like everyone else, and they have the same kinds of expectations. They want to get back the person they knew before the cancer. They want them to be ‘reasonable’, ‘glad to be alive’, ‘grateful to be cured’. They want survivors just to ‘get on with it’. Yet none of these things are possible. Survivors may have demons to battle, issues to resolve, and a big
need to make meaning for their chaotic and unsettling experiences. Those processes can take a long time. When they’re happening, close relationships are stressed, and may fall apart. Furthermore, survivors often feel guilty because they have to ask for understanding and special consideration for so long, and that just makes things worse.

Things are even harder if close friends, family members or partners also cared for survivors when they were ill with cancer. You generally know how to relate to someone who is sick. You expect them to be unable to do the things they normally do, to be sad, frightened, in pain, nauseated and so on. You cut them some slack, let them lie around, wait on them, protect them from stress. But what are you supposed to do for a survivor? The survivor is ‘better’ and all that special understanding you reserve for illness seems irrelevant. The survivor wants your understanding, but finds it hard to tell you what there is to understand. We have ways to talk about illness, but not about survival. That increases the sense of loneliness on both sides.

Perhaps now we can begin to understand that, for some survivors at least, survival can be a downward spiral.

As survivors, we feel different – different to the way we were before the cancer and different to others who haven’t had cancer."

Confronting the reality of death makes us view life and other people in new ways. We may not have the same interest and commitment to the things that seemed important before cancer. We may therefore not perform as we used to, whether working in a job, being a lover, running a household, looking after a family or playing sport. When we don’t perform well, we lose the respect of others and then we tend to perform less well. And so the cycle goes, toward an increasing loss of self-respect, and a decreasing willingness to take on challenges, and eventually toward what seems like depression. We can break the cycle by finding things that we do well and enjoy, that seem important and worthwhile. But that’s easier said than done. It takes time and may take help from others with similar experiences, or from professionals who understand the issues.

Most people adapt to the stresses of life after cancer pretty successfully, but there are many whose lives contain real unhappiness. It’s an unhappiness that doesn’t usually fit the patterns of ordinary, clinical depression, or post-traumatic stress disorder. It’s a condition of sadness, isolation and diminished self-respect. For many, help comes from understanding what’s happening, from recognising that it’s normal, from realising that it’s happening to many others, from being given ways of talking about the experiences, and being offered opportunities to talk about them. Most people have the capacity and desire to heal themselves. All they may need is advice about resources to use for that healing, and some help in finding out how to use them. There is no ‘one size fits all,’ no single solution for everyone’s difficulties. Each person must find their own way to heal, to recreate an identity from the mixed and often chaotic experiences of survival.
Tips for healthy eating during chemo

If you're undergoing chemo, you may be faced with gastrointestinal symptoms, including bloating, diarrhoea, nausea and constipation that can leave you unable or unwilling to eat. Luckily, there are things you can do to alleviate these symptoms and get back to feeling your best.

With the help of Director of the Johns Hopkins Integrative Medicine & Digestive Center, Dr Linda Lee, we’ve collected some chemo-friendly tips on how to help with some of those symptoms.

TRY MINI MEALS
If you’re running short on calories, try eating small but frequent meals that include plenty of lean meat, vegetables, fruits and whole grains. While you may think you need rich or fried foods to keep your calorie count high during treatment, foods that are really high in fat and calories can slow stomach emptying, which may worsen bloating and nausea and leave you unable to eat at all.

STOCK UP ON EASY SNACKS
Chemo treatments may sometimes leave you feeling too exhausted to cook. Avoid letting fatigue lead to malnutrition by stocking your house with easy, nutritious snacks you can grab with little or no prep work. Nuts, muesli bars, plain popcorn, meal replacement shakes, hard cheese and whole-wheat crackers, yoghurt, bananas, berries, carrot sticks and hummus, or peanut butter and whole-wheat toast are just a few tasty options.

ADJUST TO NEW FLAVORS
Confused that a food you once loved is suddenly unappealing to you—or even tastes bland or metallic? No need to worry, this is a common chemo side effect, and it’s only temporary.

For now, you might do better eating milder foods and may even be surprised by how good they taste. Consulting a dietitian or nutritionist can be helpful for getting new recipe ideas and making sure you’re meeting your daily calorie and nutrient needs.

“Consulting a dietitian or nutritionist can be helpful for getting new recipe ideas and making sure you’re meeting your daily calorie and nutrient needs.”

KEEP MOVING
If possible, try to go for a medium or slow-paced walk after meals. Just 10 minutes is enough to get your food digesting and your energy up. Lying down after meals can sometimes cause stomach acid to rise back up your esophagus, leading to heartburn, indigestion and more. If you’re too fatigued to walk or stand after meals, try to sit as upright as possible, using pillows to prop up your back.

ADD GINGER TO MEALS
Recent studies suggest that encapsulated ginger may help reduce the nausea associated with some types of chemotherapy even more effectively than OTC antinausea meds. Try adding some of the fresh, zesty root to stir fries, soups or fish dishes, or steep 1/8 tsp of fresh grated ginger in hot water to make a therapeutic tea. Alternatively, you can take a 200mg supplement three times per day. You can find the supplements in health-food and natural-food stores, as well as some supermarkets.

BE CHOOSY ABOUT DAIRY
Milk drinkers are often surprised when they become lactose intolerant during chemo and experience bloating, gassiness, cramping or diarrhoea after eating dairy. The reason? Chemo drugs can prevent the small intestine from producing enough of the enzyme needed to break down the lactose found in dairy foods. The effect is temporary, but it's best to avoid milk, creamy cheeses and ice cream until treatment is over. In the meantime, stick to almond or rice milk and harder cheeses.

MAKE VEGGIES EASIER TO DIGEST
Raw vegetables contain lots of good vitamins and minerals and are an essential part of a balanced diet, whether you’re undergoing chemo or not. Unfortunately, most uncooked veggies are also very high in fibre that can be challenging for your stomach to break down. But that doesn’t mean you shouldn’t eat them—try blending veggies into a ‘green’ smoothie (carrots and beets taste great blended with fruit juices) or adding them to soup. Puréed and cooked vegetables are easier for your body to digest.

Consulting a dietitian or nutritionist can be helpful for getting new recipe ideas and making sure you’re meeting your daily calorie and nutrient needs.

STICK TO WATER AND JUICE
Conventional wisdom aside, soft drink and soda water do not help settle a stomach. Although some people believe the bubbles make them burp and feel better, the effect is only temporary—and the bubbles and caffeine in some soft drinks can actually aggravate gassiness, bloating and heartburn.

STAY HYDRATED—THE RIGHT WAY
It’s best to not drink water while you’re eating—it can dilute stomach acid and make it more difficult for your stomach to process your meal. However, dehydration can worsen symptoms of nausea, vomiting and fatigue, so be sure to drink plenty of water between meals. If you’re too nauseated to drink a whole glass of water, sucking on ice cubes can help. Talk to your doctor if you experience diarrhoea, as this can sometimes cause life-threatening levels of dehydration.

Puréed and cooked vegetables are easier for your body to digest.
Try blending veggies into a “green” smoothie or adding them to soup.

**PICK THE BEST FRUIT**

Your small intestine can sometimes struggle to absorb too much fructose, the main sugar found in fruit. Because of that, it’s best to limit high-fructose fruits, such as melons, papaya, mango, apples and pear, to one a day to avoid discomfort. Or, stick to fruits like berries, peaches, plums, ripe bananas and citrus that are lower in fructose and easier to digest.

**SUPPLEMENT WISELY**

It's best to get your nutrients from food if you can, although in most cases taking a multivitamin or vitamin D is fine—just let your doctors know you’re taking them. Be careful about using other supplements during your therapy, as some may thin your blood or interfere with the efficacy of your treatment.

**LET FAMILY HELP**

When loved ones offer to cook for you, by all means, accept! This allows them into your life and able to feel connected to you. With everything else you’re managing right now, there’s nothing wrong with letting someone else help you out.

However, because your tastebuds or ability to process food may have temporarily changed, don’t be afraid to advise them, ‘Sure, I’d love it if you cooked dinner for me, but right now salads are kind of upsetting my stomach, so could we skip them?’

[guide2chemo.com](http://guide2chemo.com)

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**CLL update**

A new treatment option for CLL patients became available on the PBS from 1 April 2015. Arzerra® (ofatumumab) used in combination with chlorambucil may be an option for patients who have not had any treatment and for whom fludarabine-based treatment is not appropriate.

A clinical trial for CLL patients will be funded from 2015 to 2017 to investigate the efficacy and safety for dose reduced fludarabine, cyclophosphamide and intravenous obinutuzumab compared to oral chlorambucil and intravenous obinutuzumab in previously untreated, co-morbid elderly (65 years or older) patients. The trial will be managed by the Australasian Leukaemia & Lymphoma Group with $300,000 in funding from the Leukaemia Foundation.
Understanding your blood count

WHERE DO BLOOD CELLS COME FROM?
Blood cells come from the bone marrow, a spongy layer that is found inside the long and flat bones of the body, for example the long bones of the arms and legs, the breast bone, the shoulder blades and the pelvic bones.

The bone marrow provides a home to protect immature blood cells (or stem cells) as they grow and develop into mature cells. When cells are fully mature and able to do their normal job, they are released from the marrow to circulate in the blood stream.

WHICH BLOOD CELLS ARE CHECKED BY YOUR BLOOD COUNT?
A blood sample is used to count - literally - the numbers of mature blood cells in the circulation.

Doctors are mostly interested in the number of white blood cells, red blood cells and platelets that you have.

WHAT DO WHITE CELLS DO?
There are several different types of white cells, all of which function in various ways to protect the body from infection. A group of white cells called neutrophils, for example, protect the body by eating microbes and other potentially risky particles. They produce pus and help to alert you to the fact that an infection may be present, for example by causing pain, swelling and redness.

White blood cells are important as they provide the body’s main protection against infection. When the number of white cells, specifically neutrophils, is low, this is commonly known as neutropenia.

ARE WHITE CELLS AFFECTED BY TREATMENT?
Yes, very much so. White cells normally only live for between seven or eight hours in the blood stream, after which they need to be replaced by the stem cells in the bone marrow, which grow to produce new white cells. Because of this need for billions of neutrophils to be made each and every day, some of the marrow cells have to be continuously dividing.

When you are given chemotherapy the marrow cells are affected and are not able to keep up with the demand for new white cells.

WHAT DOES HAVING A LOW WHITE CELL COUNT MEAN TO ME?
Having a low white blood cell count means that you have very few white cells in circulation. This can make it unsafe to give chemotherapy because of the risk of infection. When your white cell count is very low, simple infections that you would normally shrug off can become very serious very quickly. For this reason, it is very important that you alert your doctor or nurse if you have a temperature or feel unwell. If you have had previous problems with infections please tell your doctor before starting treatment.

WHAT DO RED BLOOD CELLS DO?
Red blood cells give the blood its deep red colour. Their most important role is to carry oxygen around the body. Oxygen is needed by every cell in the body and red blood cells transport it to them. If the number of red blood cells is low, then less oxygen is circulated and you may begin to feel tired, short of breath or light-headed.

ARE RED CELLS AFFECTED BY TREATMENT?
Red cells live for about three to four months and therefore the marrow doesn’t need to divide very often to make new ones. For this reason, although some may be destroyed by treatment, it usually takes several courses of chemotherapy before your red cells become affected. When the number of red cells is low, this is known as anaemia. Anaemia is usually corrected by having a blood transfusion or can correct itself.

Participants needed for research study
The University of Queensland is conducting research on the wellbeing of adult blood cancer survivors. Participants will need to complete a 10-15 minute online survey (hard copies are available via post), about their physical activity, counselling preferences, motivators, and barriers. The study findings will help support the development of new programs for the wellbeing of adult blood cancer survivors.

To participate, you will need to:
» be 18 or older
» have or have had a blood cancer, specifically acute myeloid leukaemia, acute lymphoblastic leukaemia, Hodgkin lymphoma AND/OR be a recipient of an allogeneic or an autologous bone marrow transplant in Brisbane.

If you would like to help with this research study visit http://bit.ly/1zlZPm8. If you would like a hard copy of the survey mailed to you instead contact Vanessa Allen at v.allen@uq.edu.au
WHAT ARE PLATELETS AND WHAT DO THEY DO?
Platelets help your blood to clot. You have seen how when you cut your finger the bleeding stops after a short while. This happens because platelets stick together and form a “plug”. In just the same way as you would use a plug to keep water in the sink, platelets are there to keep the blood in our arteries and veins by stopping any leaks if we damage ourselves.

ARE PLATELETS AFFECTED BY TREATMENT?
Yes. However, platelets have a slightly longer life span than white cells, so it is a little less likely to see severe drops in numbers in the blood count. On average, platelets live for about a week, so bone marrow replaces them by dividing from week to week - the daily demand is not as high as it is for white cells. There are about 1400 million platelets in your bloodstream - lots more than white cells.

HOW WOULD I KNOW IF I HAD A LOW PLATELET COUNT?
Since platelets are designed to stop us from bleeding, you might notice that you bruise more easily or, more commonly, that your gums bleed more than normal when you brush your teeth. There are no medicines that can help your platelet count to recover but if you needed one, you could have a transfusion of platelets. A low level of platelets in the bloodstream is called thrombocytopaenia.

HOW LONG MAY IT TAKE FOR MY COUNTS TO RECOVER?
In most cases, blood counts are usually at their lowest about 7-14 days after chemotherapy. Before having a further cycle of chemotherapy, your blood count will be checked to see if it has recovered sufficiently and it is safe to give you chemotherapy. If the blood count is still low, your hospital may recommend postponing your treatment for a short time (usually a few days or a week) until your blood count has recovered. Sometimes, it is necessary to give you a small injection, or course of injections, under your skin to stimulate the production of blood cells in your bone marrow. These injections are called "growth factors" and have very few side effects.

THE IMPORTANCE OF BLOOD COUNTS
A blood count allows your doctor to check how many blood cells you have available, and therefore to decide whether you can receive your next course of chemotherapy safely. Very importantly, the blood count also helps your doctor to decide whether you need antibiotic treatment to prevent or fight infection, a platelet transfusion to prevent bleeding, or a red blood cell transfusion to help you feel better and have more energy. A small syringe of blood can reveal a great deal.

Join the Leukaemia Foundation's telephone discussion forums!

WHY JOIN US?
It can be hard for people who aren’t living with a blood cancer to understand what it’s like. In the telephone discussion forum you can share your experiences, tips and become part of a support network in the comfort of your own home. Each discussion is facilitated by a trained Leukaemia Foundation health professional.

FORUMS FOR PEOPLE AFFECTED BY CLL
When: The 4th Monday of each month at 2pm– 3.30PM EST / EDST (or as advised) April 27, May 25, June 22, July 27, August 24, September 28, October 26, November 23.
Duration: 1-1/2 hours

FORUMS FOR PEOPLE GOING THROUGH A STEM CELL OR BONE MARROW TRANSPLANT
April 21, May 19, June 16, July 21, August 18, September 15, October 20, November 17.

FORUM ESPECIALLY FOR MEN
April 22, June 24, August 26, October 28.

To find out how you can be part of the next telephone forum phone Freecall 1800 620 420 or email info@leukaemia.org.au

IT’S ALL ABOUT ME!
You’re invited to a two-part workshop for those living with, through and beyond blood cancer, giving survivors and their carers the skills, support and confidence to get the best out of their lives and take control.

Part 1 Saturday 9 May
Speakers: Peter Rhodes (Dietitian) and Julie Allen (Physiotherapist and former lymphoma patient)

Part 2 Saturday 16 May
Speaker: Arthur Alexander (Life Coach)

To RSVP or find out more information phone Marian on 07 3055 8233.
Fit to Thrive program continues to grow

In our last edition we told you about our *Fit to Thrive* program – a 12 week personalised exercise program we offer free-of-charge to patients. The program has been so successful that the Foundation has decided to roll it out in Cairns, Townsville and the Gold Coast.

Here is another letter we received from a patient who is experiencing the benefits of the program. If you would like more information on *Fit to Thrive* please phone us on 07 3055 8233.

Dear Maryanne,

I have recently completed the 12 week *Fit to Thrive* program. I wanted to write to tell you of my appreciation and immense gratitude to the Leukaemia Foundation and particularly the Sylvia and Charles Viertel Trust for making the program possible.

After being diagnosed with stage two lymphoma I went through six months of chemotherapy and then a stem cell transplant. Following that I ended up with a viral infection, turning to myocarditis which affected the muscles in my heart.

In my younger years I played A grade rugby and also did a lot of rowing. For 16 years I worked in a very physical profession as a commercial deep sea diver on the oil rigs in the North Sea. All of this kept me at a very high level of fitness. So following the chemotherapy and post viral fatigue I had been really struggling for some time with exhaustion after any exercise.

*Fit to Thrive* has been the perfect thing for me. Aspire Fitness is the ideal partner - they ran an excellent tailor-made program and were efficient and very professional. It was great to be training with and meeting people who had been through similar and often far worse experiences than me. Sam the exercise physiologist accessed me and worked out a program to gradually build me up over the 12-week period.

The result has been extraordinary. I have recently returned from an 11,500 kilometre motorcycle journey through the centre of Australia with a group of mates. I have just been asked by a couple of mates to join them in doing a team half ironman triathlon. I have just started training to do the swim leg of 1.9km, something I would never have been able to contemplate before *Fit to Thrive*.

A HUGE thank you to everyone involved in putting the program together. It has turned my life around. I had my 60th birthday in January and I’m striding forth into life with a very positive attitude, so thank you all most sincerely for what you have done for me and for so many others!

Yesterday is history
Tomorrow is a mystery
But today is a gift
That’s why it’s called the present.

Cheers
Scott Foote

Order your new 2015/ 2016 *Entertainment™* Membership now!

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To order your copy phone 07 3318 4418 or order online now at www.entbook.com.au/220058f
Children and adolescents needed for speech-language study

Dr Fiona Lewis, speech-language pathologist from the School of Health and Rehabilitation Sciences, at The University of Queensland, has been researching language development in children following treatment for acute lymphoblastic leukaemia (ALL) since 2008.

Fiona is keen to hear of the experiences and opinions of parents of children treated for ALL between the ages of 2-5 years. These children can now be aged up to 16 years.

Fiona would also like to hear from children and adolescents currently aged 12-16 years who were treated for ALL between the ages of 2-5 years.

The information will be gathered through a brief questionnaire which can be sent by email or by reply-paid post.

Please contact f.lewis@uq.edu.au or phone 0450 435 297 or 3365 6161 for further information on the research or how to be involved.
## Support Services seminars

### MAY

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<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tr>
<td>SAT 16</td>
<td>Information for blood cancer patients in their 30’s and 40’s</td>
<td>Time and location to be advised.</td>
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<tr>
<td>SAT 30</td>
<td><strong>2pm</strong> CML Coffee, cake and chat</td>
<td>West End Coffee Club</td>
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### JUNE

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<tr>
<td>FRI 12</td>
<td><strong>2pm - 4pm</strong> Gold Coast Coffee, cake and chat</td>
<td>50 Fairway Drive, Clear Island Waters</td>
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### AUGUST

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<tr>
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<tr>
<td>TUE 4</td>
<td><strong>2pm</strong> Nuts and Bolt of Allogeneic Transplant</td>
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</tr>
<tr>
<td>FRI 14</td>
<td><strong>2pm - 4pm</strong> Gold Coast Coffee, cake and chat</td>
<td>50 Fairway Drive, Clear Island Waters</td>
</tr>
<tr>
<td>SAT 29</td>
<td><strong>2pm - 4pm</strong> CML Coffee, cake and chat</td>
<td>50 Fairway Drive, Clear Island Waters</td>
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### LOCATION

Unless otherwise stated, all Brisbane information seminars are held at:
Leukaemia Foundation of Queensland
ESA Village Conference Room
41 Peter Doherty Street, Dutton Park

**RSVP IS ESSENTIAL**

Please phone Marian on 07 3055 8233 or email ssreception@leukaemia.org.au.

## Doorknock collection

**20 June – 3 July**

When one of our volunteers knocks on your door please give generously. You can also donate online or raise funds by doing an online doorknock. Go to leukaemiaqld.org.au/doorknock

Demand for our services and the urgent need to find a cure is relentless – and growing. We will not stop until we beat blood cancers, but we need your support!

## CONTACT US

**BRISBANE**
Support and information: 07 3055 8233
Accommodation booking and enquiries: 07 3055 8200

**TOWNSVILLE**
Support, accommodation and information: 07 4727 8000

**GOLD COAST**
Suite 4, 36 Harvest Court, Southport Qld 4215
Support and information: 07 5503 1270

**CAIRNS**
Suite 6, Virginia House, 68 Abbott Street, Cairns Qld 4870
Support and information: 07 4051 3355

**FREECALL 1800 620 420**
GPO Box 9954, Brisbane QLD 4001
lfq@leukaemia.org.au
www.leukaemiaqld.org.au

## QUEENSLAND SUPPORT SERVICES TEAM

**Director of Support Services**
» Barbara Hartigan

**Support Services Coordinators**
» Sheila Deuchars  » Kate Arkadieff
» Maryanne Skarparis  » Kathryn Huntley
» Nicole Douglas  » Amanda Ferguson
» Natalie James  » Michele Leis
» Claire Smith

**Regional Support Services Coordinators**
» Donna Vrancken - Cairns and Far North QLD
» Karen Szymanski - Townsville/Mackay North QLD
» Ann Scholz - Gold Coast/Hinterland

**Grief Support Services Manager**
» Shirley Cunningham

**Support Services Administration Officer**
» Marian Marshall

## WOULD YOU LIKE TO RECEIVE THIS NEWSLETTER OR INVITATIONS TO OUR SEMINARS VIA EMAIL? PHONE MARIAN ON 07 3055 8233.