Remission can be bittersweet

For many years the Leukaemia Foundation of Queensland has recognised the importance of offering ongoing support for patients and families long after treatment finishes.

Supporting blood cancer survivors became such an important part of the Foundation’s work that we funded survivorship research in partnership with the International Program of Psycho-Social Health Research (IPP-SHR) which explored blood cancer survivorship issues and how patients can best be supported by the Foundation following treatment.

According to the program researcher, Associate Professor Pam McGrath, the response to becoming a blood cancer ‘survivor’ can vary over time and will depend in part on the individual’s life circumstances.

‘Our research showed that for some patients, remission can be a bittersweet experience. This is evident in Linda Hennessey’s very honest account of her experience following lymphoma treatment. Many of you will be able to relate to what Linda is saying.’

‘It is so important for blood cancer survivors to understand that these feelings are totally normal and that there is support available from the Foundation – you are not alone.’

‘Remission. It’s a funny thing. A little over a year ago, the idea of being in remission was exciting! Cancer free? Hell yeah! However, it’s not quite like that.

First, there’s relief. It washes over you. Wow. I did it. I actually did. I beat cancer. I survived six rounds of chemo; 18 sessions of radiation; six sessions of total body irradiation; high, intense, soul crushing chemo; and a bone marrow transplant. Side effects you’ve never heard of. Preparing a Will at 23 because you’re afraid that at any moment the clot in your heart from your PICC line might dislodge and kill you. Waking up in ICU, shocked and confused. Not understanding what has happened and to be told that you nearly died. You actually nearly died and didn’t wake up because your lungs filled with blood. The treatment that was needed to save you, nearly killed you, without the chance of a goodbye. That’s what still scares me. That’s what sticks with you long after.

Remission...I fought hard for this. If I knew what I was in for in the beginning a part of me wonders if I’d run screaming from the hospital. Another part knows that we are all capable of so very much more than we ever thought possible.

After that short moment of relief, comes that tightening in your stomach - fear. How safe am I really? Is that breast a bit bigger than the other? Is that headache a tumour? What if it comes back? Or when will it come back? No one can say. Some do...some don’t. I take comfort in the fact that I have the best possible chance of staying in remission. I took a risk for a second chance at life - the best chance. I didn’t have a choice, and for that I’m somewhat angry.

Continued over page
A message from the editor

Welcome to our first edition of Lymphoma News for 2015. Our biggest fundraising event, World’s Greatest Shave, is over again for another year. We are hoping to reach our target of $5 million thanks to the fantastic support of Queenslanders who shaved and coloured their hair or donated to those who did. It’s not too late to make a donation at worlds greatest shave.com

Our two Coffee, cake and chat events in March were great opportunities for people with lymphoma to get together, support each other and share information. Don’t worry if you missed out, there will be another lymphoma Coffee, cake and chat on Thursday 6 August, and a Waldenstrom’s Macroglobulinemia session on 2 November. We will also be having guest speakers for World Lymphoma Awareness Day on Tuesday 15 September. For younger lymphoma patients, we are holding 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 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 12-week program is also being rolled out on the Gold Coast, Cairns and Townsville.

I’m sure Linda’s honest account on the front page of her experience with lymphoma will strike a chord with many of you who also understand the difficulties associated with adjusting to life following a lymphoma diagnosis. While there is definitely a place for positive thinking, there are times when feelings of anger, fear and sadness are a reality and need to be acknowledged as normal. This theme also follows into the ‘Living as a cancer survivor’ article on pages 8 and 9.

Every experience is different but I would like you to remember that you are not alone and can contact the Leukaemia Foundation any time you require support or a friendly listening ear.

Nicole Douglas
Support Services Coordinator (Lymphoma)

Continued from pg 1

I was 23 years old! I see 60 year old men and women, standing on the street smoking and I feel the anger bubbling up inside me. Why me? Why not them? I never had a chance. Lymphoma doesn’t discriminate - young, old, black, white, gay, straight. It doesn’t matter. I was a nurse. I helped people every day. I tried to make a difference. Part of me felt betrayed. Where was my good karma? I wasn’t supposed to be the patient. I was a nurse. Why did I get cancer when others didn’t? Why did I survive when others didn’t? I’d like to think it was my attitude, that I was tough. But the truth is, sometimes it doesn’t matter. One of the most positive people I ever met died. She was a good person, tough - but it didn’t matter.

Cancer is not a blessing. It’s a horrible curse. It took my health, my time, my fertility, but mostly, it took away my carefree life. I didn’t need to get cancer to appreciate life. Before I was diagnosed, I’d already skydived twice. I’d travelled, and planned to travel more. I had a university degree, a black belt in karate, trained hard and fought in a boxing match (and won!). I’d surfed - badly - been zorbing, parasailing, paragliding, got my motorbike license. I never needed my second chance at life. I was making the best of it the first time round.

I am not grateful. I am angry. And that’s ok. I have a right to be. We all do. I strongly believe it’s ok to feel anger. Cancer is an emotional roller coaster. We shouldn’t fight what we feel. Anger is just the stage I’m currently in, but I won’t let it consume me.

If I think just a little harder though, I can see the positives - the overwhelming support; crying from all the love I was shown; the moment my girlfriend’s conservative Vietnamese parents brought food to me in hospital and cried for me. The moment my own parents, who previously weren’t ready for my partner to stay over, suggested she move in as I would need her support. Those little moments you never forget, like going outside for the first time in weeks and lying in the sun on the lush grass. Just being thankful to be able to sit up, walk and eat. You can never truly appreciate these things until they’ve been taken away.

Cancer has been a journey I’ll never forget. The shortest and yet the longest year of my life. The worst and best experience in some ways. I’m certainly not grateful for cancer, but if I had to be grateful for anything, it’s that I know now how truly loved I am. And that is a blessing!’
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 in coming months, and a second live cooking session is currently being planned.

Our thanks go to ICON Cancer Care and Chris’ IGA for supporting Cooking for Chemo.

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 almost $2000 to help those with blood cancer.

Proudly supporting his daughter’s efforts was her dad, Dr Matthew Hourigan, a clinical haematologist and haemat-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.
A day in the life of
Nicole Douglas

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 Nicole Douglas.

Nicole’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 Nicole to give you a glance into the important role of Support Services Coordinators.

8.30am – I arrived at our accommodation and support village, and spoke briefly to our two volunteer bus drivers working this morning before they left to take patients and families up to the hospitals. Free transportation is 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 and allowance, and lodged the form. Filling out forms and lining up at Centrelink can seem like an overwhelming task. I also discussed schooling options for the couple’s two young children who will also be staying at the village for the next six months. We discussed financial assistance as both parents have had to give up work to come to Brisbane, so finances are a big concern for them.

10am – I attended a staff meeting to discuss our education program for the following 12 months. This includes organising guest speakers and coordinating dates and times for Coffee, cake and chat groups, as well as planning for the new Cooking for Chemo program.

11am – I received a phone call from a woman in Rockhampton who will soon be coming to Brisbane for a bone marrow transplant. We talked about her fears about undergoing the transplant process and facing a potentially life-threatening disease. We spoke about an ‘enduring power of attorney’ and practical matters such as ensuring her husband knew how to access bank accounts in order to pay the household bills which she normally does. We talked about our villages where she can receive free accommodation. I posted our DVD and booklet on allogeneic stem cell transplants, and arranged to meet her at the hospital when she is down for her work-up appointments.

11.30am – I received a phone call from a psychologist in Bundaberg who was seeking information about our grief services and support available for a father whose seven year old son has recently passed away. I posted information to her including our referral forms and further information about our services, including the Bereaved Parents’ Weekend.

12pm – I made a home visit to a gentleman in Sunnybank who is newly diagnosed with lymphoma. We discussed chemotherapy side-effects and symptom management, as well as concerns about having to stop work, financial difficulties, and telling his children and family about the diagnosis. I provided information booklets and children specific resources, and told his wife about our Caring for the Carer program.

1pm – Lunch time with my lovely colleagues at the village! We talked about about her fears about undergoing the transplant process and facing a potentially life-threatening disease. We spoke about an ‘enduring power of attorney’ and practical matters.

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 – I helped co-facilitate a lymphoma telephone forum in which patients from all over Australia call up to talk to each and share experiences from the comfort of their own home.

3.15pm – I spent some time talking to one of our residents whose brother was readmitted to hospital by ambulance this morning following a high temperature. It was quite a shock for him to see his brother become so unwell so quickly.

4pm – I wrote a support letter to the principal of a private school requesting assistance with school fees, as the parents do not want their children to move schools at a time when they are already dealing with a huge amount of change and stress.

4.30pm – Tomorrow I will spend most of the day at the hospital, so I started putting together some information packs for some new patients I have been asked to see. Providing useful information is an important way we support patients and families.

5pm – Home time!
Beating blood cancers for 40 years
by Beverley Mirolo OAM, President of the Leukaemia Foundation of Queensland

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.
New lymphoma therapy a step closer

A potential new treatment for lymphoma and leukaemia 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.
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 assessed 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 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

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**Would you like to meet other patients with Waldenstrom’s?**

We have organised coffee/tea, cake and chat events where you can:

- meet others with Waldenstrom’s macroglobulinaemia
- relax in an informal setting
- and share your story if you would like to.

**When:** Wednesday 1 October 2pm  
**Where:** ESA Village Conference Room  
41 Peter Doherty Street, Dutton Park  
**RSVP:** 07 3055 8233

Refreshments provided by Leukaemia Foundation of Queensland  
Limited 2 hour street parking is available.
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.
Assisting patients to re-enter the workforce

Assisting people to re-enter the workforce when they feel well enough or when they complete treatment for blood cancers is an important element of support offered by the Leukaemia Foundation of Queensland.

According to Support Services Coordinator, Maryanne Skarparis, the ability to return to work was identified as an important issue for many people living with blood cancers in survivorship research funded by the Foundation.

‘One of my roles as a Support Services Coordinator is to guide and assist people in exploring avenues for them to be able to get back into the workforce, and talking through the obstacles that may be hindering them,’ Maryanne said.

‘Being able to work again is obviously important for most people from a financial point of view, but also to give them a sense of normality, regain their identity, and give them companionship and personal satisfaction.’

‘However, how to move back into work can seem overwhelming especially after having to deal with the trauma of treatment and the physical and emotional effects that may linger long after treatment stops.’

‘While many people living with blood cancers are motivated to return to work, there may be obstacles that need to be overcome such as physical effects from the disease and treatment, especially fatigue. Some patients are unable to continue with the same amount of work or the same type of work they did prior to their diagnosis.’

‘They may be unable to maintain physically demanding positions or work outside due to sun sensitivity, and these issues force them to retrain or do further study.’

‘These obstacles can seem overwhelming and it may affect a person’s feelings of confidence and competence, however being able to talk through these issues and have someone who can help you to look at alternative avenues can be really helpful.’

The Leukaemia Foundation of Queensland works with a number of organisations to assist patients wanting to re-enter the workforce including Centrelink, TAFE, Open Minds and other employment agencies.

‘It is really a matter of helping people tap into the opportunities that are out there and showing them that there are resources available to them and they don’t have to do it on their own,’ Maryanne said.

Twenty-six-year-old Rohan Gray has been affected by blood cancers for nearly his whole life, yet during those years he has been motivated to work and study as an important way of maintaining a level of normality.

‘I was first diagnosed with leukaemia when I was three and have relapsed several times, have had many rounds of chemotherapy, radiation and a stem cell transplant. My treatment has caused serious neuropathy and I needed corrective surgery on my feet, although I still have limited movement.’

‘During that time I missed a lot of school and I had to work hard to keep up, which I did because I didn’t want to be kept back to repeat a year.’

Despite these difficulties Rohan finished a business degree and has had a number of jobs including his current position in a newsagency.

‘I have spoken to Maryanne from the Leukaemia Foundation several times between working and having treatment. While I was lucky and didn’t need Maryanne to find me a job, it was really worthwhile being able to chat with someone who understood the challenges I was facing and who could assist me in really thinking about what my passions were, what options were out there for me and what my future goals were.’

If you would like more information about seeking assistance in returning to work, please call Maryanne on 07 3055 8233 or email mskarparis@leukaemia.org.au
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

Thank you IGA for a brighter Christmas

Christmas hampers were delivered to every patient and their family staying at the Leukaemia Foundation of Queensland accommodation and support centres in Brisbane and Townsville in December.

The hampers were overflowing with sweet and savoury goodies, and vouchers, to help make Christmas a little brighter for families whose loved ones were going through blood cancer treatment. Thank you to Chris’ IGA at Carina in Brisbane for donating the hamper food at cost prices and for their generous donation of $2000. Thanks also to our branch network for funding the hampers.

Order your new 2015/2016 Entertainment™ Membership now!

Choose from the traditional Entertainment™ Book or the NEW Entertainment™ Digital Membership, which puts the value of the Book into your iPhone or Android smartphone! Each membership has hundreds of 50% off and 2-for-1 offers for restaurants, cafés, attractions, hotels, shopping, groceries and travel and contain over 2000 offers that you can use whenever you like until 1 June 2016.

Don’t forget, Leukaemia Foundation of Queensland retains 20% of the price of every Membership sold which goes straight to the Foundation!

To order your copy of the Entertainment Membership, contact us on 07 3318 4418 or call in to our office on 213-217 St Pauls Terrace, Fortitude Valley QLD or order online now at www.entbook.com.au/220058f

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.

Cath Blanch and Nick Nicolaou from Chris’ IGA Carina

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.

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Support Services seminars

**MAY**

**SAT 16**
Information for blood cancer patients in their 20s and 30s
Time and location to be advised.

**JUNE**

**THU 18 10am**
Caring for the Carer: The role of the carer

**THU 25 10am**
Caring for the Carer: Burnout, how do I recognise it and how do I deal with it

**JULY**

**THU 2 10am**
Caring for the Carer: Types of communication – being heard and feeling valued

**THU 9 10am**
Caring for the Carer: Strategies for coping in the longer term

**AUGUST**

**TUES 4 2pm**
Nuts and Bolts of Allogeneic (Donor) Transplants, Dr James Morton

**THU 6 11.30am**
Lymphoma Coffee, cake and chat

**SEPTEMBER**

**TUES 15 11.30am**
World Lymphoma Awareness Day, Dr Jason Butler (haematologist/oncologist) and Dr Steve Mattarollo (researcher)

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
» Maryanne Skarparis
» Nicole Douglas
» Natalie James
» 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 WANT TO RECEIVE THIS NEWSLETTER OR INVITATIONS TO OUR SEMINARS VIA EMAIL? PHONE MARIAN ON 07 3055 8233.