THE HARDEST DECISION OF MY LIFE

When Elle Halliwell saw the tell-tale blue lines appear on her home pregnancy test, she had more than just a baby on her mind.

Only 48 hours earlier she had been diagnosed with blood cancer.

The diagnosis had been discovered through a routine blood test, which Elle underwent after deciding to start trying for a baby with her husband, Nick.

“I wanted to check my folate and vitamin D levels, which came back fine, but my platelets were unusually high,” Elle said.

Two weeks later, further tests found Elle had chronic myeloid leukaemia (CML), a type of cancer that affects the blood and bone marrow.

Still reeling from the shock of her devastating diagnosis, Elle had an urge to do a pregnancy test.

“When I looked at the test and saw two little blue lines I was just in shock,” Elle explained.

“How can someone with cancer carry a baby to full term?”

The 31-year-old faced an excruciating decision: continue with her pregnancy and risk her own life, or start treatment and miss the chance to become a mother.

“My specialist strongly advised me not to keep the baby because without treatment my slow-growing cancer could possibly turn aggressive and kill me before my pregnancy reached full term.”

But soon after Elle and Nick met with CML expert Professor Timothy Hughes, who gave the couple confidence the risk could be relatively low given the CML had been diagnosed so early.

“We made the decision to go through with having the baby, and then we reached out to the Leukaemia Foundation.”

Elle participated in the Leukaemia Foundation’s Blood Buddies program, where people recently diagnosed are matched with a ‘Buddy’ who has been affected by a blood cancer.

The program put Elle in touch with another mum who had been on a very similar journey to inspire and support her during pregnancy.

“It instantly gave me hope there was light at the end of the tunnel and a vote of confidence that, although there were risks, I could see the pregnancy through,” Elle said.

“I’m really grateful to the Leukaemia Foundation. It’s made a difference and meant I haven’t felt alone.”
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Elle gave birth to gorgeous baby boy Tor in December last year and in January started a new treatment regimen: nilotinib, a tyrosine kinase inhibitor.

Elle is hoping to be able to reach remission within five years, which could enable her to stop nilotinib provided her bcr-abl (the enzyme that leads to an excess of leukaemic cells) levels stay low.

The journalist and fashion editor is relishing her return to work.

"I’m hoping to balance my career and motherhood as best as I can," she said.

"I appreciate so many more things in my life now.

"You really don’t know how strong you are until you’re thrown into something like this.

"You survive and you do what you need to do. It’s as simple as that."

LIGHT THE NIGHT WITH ELLE

Elle now regularly takes part in the Leukaemia Foundation’s Light the Night, an event for Australia’s blood cancer community that raises money to provide support and services for families facing blood cancer.

“My first Light the Night last year was a deeply moving moment," Elle said.

“Seeing how many others were there in support was so comforting.”

Elle will again join thousands of others this October at Light the Night.

Events take place at locations all over Australia, where those impacted by blood cancer raise specially coloured lanterns to reflect on their own journey while lighting the way for others in their darkest hour.

Learn more at lightthenight.org.au.

2 BLOOD CANCER NEWS
Chimeric antigen receptor therapy (CAR T-cell therapy) has seen promising results in US studies and will now be trialled in Australia.

In our last issue of Blood Cancer News we introduced this experimental gene therapy, which alters the T-cells in a patient’s blood and boosts them with a cancer-targeting gene.

After the cells are given back to the patient, they multiply and turn into an ‘army’ that fights the disease.

The therapy was recently approved for use in the US, making history as the first genetically modified cell therapy to be approved by the Food and Drug Administration.

One US study showed the therapy eradicating tumours in eight out of nine chronic lymphocytic leukaemia patients; another study resulted in one third of non-Hodgkin lymphoma patients showing no sign of the disease six months after treatment.

Another clinical trial in Chicago reported that 94% of myeloma patients went into clinical remission and experienced only mild side-effects.

Now, Australia will be able to test the advancements in CAR T-cell therapy in a clinical trial that opened in August at Sydney’s Westmead Hospital.

The trial is a result of Leukaemia Foundation-funded research by Dr David Bishop at the Westmead Institute for Medical Research.

He said even though the therapy has seen very promising results overseas, access is currently limited due to the cost and complexity of the cell generation process.

“The manufacturing process of most CAR T-cells to date has utilised expensive systems but we have developed a process that has enabled us to reduce the cost of cell production by 10-fold,” he said.

Dr Bishop has a Leukaemia Foundation PhD Scholarship (Clinical), supported by the NSW Community Foundation N&P Pinter, of $60,000 per year from 2014-2017. He is researching immune cell therapies for lymphoma, leukaemia and post-transplant viral infections.

“It’s an incredibly exciting area of research to be involved in.”

The trial is open to both paediatric and adult patients with relapsed or refractory B-cell malignancies following allogeneic bone marrow transplant.

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A brand new cancer care centre has opened at the Sunshine Coast University Hospital (SCUH), giving blood cancer patients better support and access to treatment.

The Adem Crosby Centre provides services in haematology, medical oncology, radiation oncology and palliative care for people affected by cancer and blood disorders.

Sunshine Coast Hospital and Health Service Oncology Director Dr Jeremy Long said SCUH and the Adem Crosby Centre have added a new spectrum of care for patients and their families.

“The centre is a one-stop shop and that has massive benefits for patients by making their health care journey safer and easier with less travel and greater access to services and specialists,” Dr Long said.

The centre is named after the late Adem Crosby, an inspirational supporter of the Leukaemia Foundation who died from an aggressive form of blood cancer in 2013.

Adem’s father Brent said the facility means patients can now feel secure, knowing they’re receiving the best possible treatment close to home from exceptional staff.

“We are sure current and future patients will draw strength and inspiration from Adem and from each other at the new Adem Crosby Centre,” Brent said.
Regional families who need to move to the city for life-saving treatment will now benefit from improved accommodation facilities in Brisbane.

The Leukaemia Foundation’s Herston Village has now re-opened after closing in December for extensive refurbishment.

The 13 units have helped more than 1,700 people with blood cancer since 1989, giving families free accommodation near the Royal Brisbane and Women’s hospital.

The long-awaited renovations were made possible thanks to incredible support from the community and a $998,400 grant from the Australian Government’s National Stronger Regions Fund.

In order to ensure Herston Village continued to be a safe and low-risk environment to families it was vital extensive redevelopment took place.

“Like with any building or house, our accommodation centres need upkeep and maintenance so they are meeting the needs of our residents,” said Ron Bolton-Wood, the Leukaemia Foundation’s Manager of Accommodation Services in Queensland.

“Herston Village has always provided a vital service to Queensland families, helping to ease the burden of moving away from home for treatment. We’re pleased to be able to offer improved and more modern facilities, that will help more people beat their blood cancer in a comfortable home-away-from-home.”

The upgrades include the installation of an elevator and improved unit layouts, with new modern appliances.

Residents will also now be able to easily keep in touch with family back home with upgraded internet data cabling.

There’s also improved recreation facilities and a support area for people with blood cancer and their carers.

For more information about all of our accommodation centres, visit leukemia.org.au/accommodation.

PBS LISTING SAVING BLOOD CANCER PATIENTS THOUSANDS

Idelalisib was recently listed on the Pharmaceutical Benefits Scheme (PBS) for certain types of lymphoma and leukaemia, potentially saving patients thousands of dollars.

Prior to its addition to the PBS, idelalisib could cost individuals as much as $115,000 per year.

It will now cost eligible patients just $38.80 per script, or $6.30 per script for concession card holders.

People with relapsed or refractory chronic lymphocytic leukaemia, small lymphocytic leukaemia, and relapsed or refractory follicular lymphoma are eligible to access idelalisib on the PBS.

“People living with FL or CLL/ SLL have previously had very few treatment options available to them if they had failed to respond to, or were unsuitable for chemotherapy,” said Dr Chan Cheah, Consultant Haematologist at Sir Charles Gairdner Hospital, Hollywood Private Hospital and the University of Western Australia.
DON’T FORGET TO NURTURE YOUR MIND

People affected by myeloma are often encouraged to look after their bodies, but what about their mind and emotions?

At the recent National Myeloma Day seminar in Brisbane, Craig Smith spoke about adapting to the life changes that a blood cancer diagnosis can bring.

Although relaxation and mindfulness are often overlooked parts of dealing with blood cancer, Craig said incorporating them into everyday life can help people deal with the stresses that a diagnosis poses.

The first step is to calm the mind, Craig explained.

“When we think about the mind, we don’t actually think of it as something separate to us,” he said.

“We usually regard the ‘chatter’ within us as who we are. I like to introduce the concept to people that we have the ability to step back and be an observer of the busyness of our mind.”

Craig said taking a moment to reflect can help people become a little bit calmer and see life from a different perspective.

Another way to introduce a sense of calm during a time of change is by focusing on the breath.

“The breath is inextricably linked to heart rate and to our mind, emotions and nervous system,” he said.

Craig suggested simply slowing your breathing is a very easy way to bring relaxation and calmness to life.

“But remember, relaxation is like any activity in life – in needs to be practised! Luckily, it’s very easy to do,” Craig said.

“Breathing, learning to relax physically, and consciously taking time out to do the things you love and are passionate about – these things will all help us in life.”

You can watch Craig’s video at youtube.com/leukaemiafoundation.

Craig is a relaxation therapist and registered yoga teacher, who has worked with the Leukaemia Foundation for the past 12 years.

DARATUMUMAB GRANTED EXTENDED LICENCE

Daratumumab has been granted an extended licence in Europe for use in combination with other myeloma drugs, for treating relapsed patients who have had at least one prior therapy.

Previously the drug was licenced in Europe as a standalone therapy.

Myeloma UK Policy and Public Affairs Manager Kate Morgan said, “Substantial evidence exists for the effectiveness of combination treatments in myeloma, and daratumumab is an innovative new drug with great potential.”

KYPROLIS COULD IMPROVE SURVIVAL RATES

A trial has showed adding carfilzomib to the standard regimen of lenalidomide and dexamethasone reduced the risk of death in myeloma patients by 21%.

The study looked at Kyprolis (carfilzomib), a proteasome inhibitor that causes cancer cell death by promoting a very high amount of abnormal proteins.

The Amgen-sponsored trial was conducted at sites across the US, Europe, and Israel.

STUDY FINDS IDEAL ALTERNATIVE TO TRANSPLANT

A US study has found adding daratumumab to carfilzomib, lenalidomide, and dexamethasone is a feasible alternative to an autologous stem cell transplant for newly diagnosed myeloma.

Andrzej Jakubowiak of the University of Chicago said the drug combination was well-tolerated among study participants, and was associated with a 100% overall response rate.

At 12 months follow-up, the median progression-free survival rate was 94%.

Findings were presented at the 2017 American Society of Clinical Oncology in Chicago.
Nicole Cane is not your ‘typical’ myeloma patient.

Diagnosed when she was aged just 25, the Gold Coast resident is much younger than the average age of diagnosis – 70.

“Everyone has been quite surprised,” she said.

“The youngest person with myeloma I’ve met so far has been in their late 30s.”

In October 2015 Nicole had been experiencing some leg and back pain, but put it down to her physical job in a warehouse.

It wasn’t until she was on her way back home after a weekend away she realised things were more serious.

“I was on my way back to the airport and I was literally shuffling along; I was so slow,” she said.

Her sister encouraged her to go to the chiropractor, who also thought something was wrong.

“He barely touched my back and then told me to go to my doctor to get a referral for an MRI and x-ray,” she said.

Tests showed several tumours in Nicole’s body.

“I had one the size of a golf ball on the outside of my skull, one on my ribs, and one tennis ball-sized on my spine that was starting to grow inwards,” she said.

Nicole was immediately admitted to hospital where she had surgery to remove the tumour on her spine.

Shortly after surgery, a bone marrow aspirate showed she had myeloma.

“My doctors drew up a 12-month treatment plan, which shocked me. I couldn’t believe it would take so long,” she said.

The plan started with four months of chemotherapy but after just two cycles it was clear that chemo alone wasn’t doing the job fast enough.

Radiation was next, which had better results.

“It was amazing – within an hour of treatment, I could feel my legs getting stronger immediately,” Nicole said, referring to the severe nerve pain on her legs and feet she’d been feeling due to her tumours.

The nerve pain impacted Nicole’s mobility and she had to use a walking frame for two months.

“I had to go to the physio and re-train my foot to walk properly again. It was flopping around like a duck’s,” she said.

The next stage in her treatment plan was to get two transplants: an autologous and an allogeneic.

Two transplants would give Nicole the best chance of fighting her myeloma, given her young age.

“In June 2016 I had my autologous transplant, then in October I had my allogeneic transplant with donor cells from my sister,” she said.

It was during her allogeneic transplant that Nicole spent over three months staying at the Leukaemia Foundation’s Clem Jones-Sunland Village.

“Mum and my nanna stayed with me most of the time, so having family support close by really helped,” she said.

A participant in the Leukaemia Foundation’s Fit to Thrive program, Nicole also credits the exercise sessions as a source of support.

“I felt stronger and it was great to work out with people who were in a similar boat,” she said.

As a result of her treatment, Nicole also went into an early menopause. She was given the chance to freeze her eggs the weekend before chemotherapy started.

Nicole is now looking ahead to the future.

“I’m hoping to return to work soon, once my cyclophosphamide dose is reduced and I receive my vaccinations,” she explained.

“It will be good to get a bit of my life back.”
It’s been nearly a decade since her stem cell transplant for acute lymphoblastic leukaemia (ALL): 10 years that has dealt Roula Selinas a series of blows.

“I have not had an easy journey,” said 50-year-old Roula, who lives on the Gold Coast.

In April 2007, Roula had a blood test to determine the cause of lethargy, weight loss, and small lumps on her stomach.

The test revealed ALL and the search began for a bone marrow donor for an allogeneic transplant.

“We couldn’t find a match in my family but we found an unrelated donor in Germany,” Roula said.

Although the transplant was completed successfully, it sparked more health problems for Roula as the donor only had 80% compatibility.

“I got very bad graft-versus-host disease (GVHD), first in my skin then in my stomach.

“I was put on a high dose of steroids that gave me steroid-induced diabetes – twice!” Roula said.

The years following her transplant brought further health complications due to her weakened immune system.

“I contracted pneumonia in 2009 and got so sick I had a mild stroke,” Roula said.

Now, Roula says she feels fit and strong after building her health back up for the past few years, and is nearly off all of her medications.

“I’m thrilled, as doctors thought I’d never come off medication,” she said.

During her treatment for ALL Roula had to leave her Gold Coast home and come to Brisbane for treatment, staying in the Leukaemia Foundation’s ESA Village.

“I stayed there with mum, and while it was hard to be away from my children and husband, it was so good to have her close by while I was going through everything.

“Even the transport service was fantastic, since some days you’re so weak you can’t even walk down stairs let alone drive to appointments,” Roula said.

Inspired by the motivational books she read while in hospital, Roula recently penned her own: Stronger: You Can Overcome and Bounce Back from Adversity.

“I never planned on writing a book before I got sick, but I had such a tough journey that I wanted to try and help others in a similar situation,” she explained.

Roula also said resilience was key to helping her get through each day.

“I’ve been knocked down so many times, but you have to just keep on going - you have to keep getting back up.

Visit roulaselinas.com to find out more about Roula’s book.

GVHD is a common, and sometimes serious, complication of allogeneic stem cell transplantation. Some of the donor’s immune cells try to reject the patient’s own cells as foreign. The skin, liver and gut may be affected. It can occur in either chronic or acute forms and is treatable by immunosuppressive drugs.

In May the Australian Government announced Blincyto, a treatment for a rare form of acute lymphoblastic leukaemia (ALL), would be listed on the Pharmaceutical Benefits Scheme (PBS).

The listing means patients will save $127,700 per course of Blincyto.

Blincyto helps induce and maintain cancer remission to allow a stem cell transplant, targeting and encouraging the destruction of lymphocytic cells.

Researchers at the Australian National University in Canberra have reported that a new treatment for acute myeloid leukaemia (AML) has been outperforming standard chemotherapies.

The study, published in Blood, uses the compound CX-5461 to target the protein-making process within cancer cells.

Researchers found that CX-5461 reduced the number of cancer cells that tend to be resistant to chemotherapy.

The National University of Singapore has found new insights into the molecular mechanism that affects how genes can contribute to leukaemia formation.

Published in Leukemia, the study looked at the protein TAL1.

The research team discovered that TAL1 triggers a ‘molecular switch’ that activates a cluster of genes called GIMAP, which could lead to the development of T-cell ALL.
When Janelle Pritchard hit the 10-year mark for remission from breast cancer, she thought that would be the end of chemotherapy and hospital visits.

But two years later in July 2015, the Brisbane resident was diagnosed with acute myeloid leukaemia (AML).

“I was advised about the stem cell transplant program and we found a donor match in Barbara, my younger sister,” Janelle said.

Initially Janelle wasn’t sure about whether she’d be considered for a transplant, until she told her haematologist, Professor Geoff Hill, about her love for dragon boating.

“Professor Hill told me if I was fit enough to do all that in one day, I was probably fit enough to cope with a transplant,” the 60-year-old said.

Janelle took up paddling in 2005, joining Dragons Abreast Brisbane.

Dragons Abreast brings breast cancer survivors together to give hope of an ongoing active life post-diagnosis.

While Janelle was in hospital recovering from her transplant in October 2015, it was the thought of joining the group in Italy for the next international regatta that kept her going.

“I was lying in bed thinking, I’m going to get through this,” she told Blood Cancer News.

“I had to get well for my husband and family of course, but I gave myself a goal to get well enough to go to Florence,” Janelle said.

After her transplant Janelle was determined to build her fitness back up, joining the Leukaemia Foundation’s Fit to Thrive program in early 2016.

“Molly was my terrific personal trainer who would set a schedule of exercises for me that I could continue to do at home.

“I highly recommend Fit to Thrive to others affected by blood cancer – the team were fantastic and so understanding.”

After starting Fit to Thrive Janelle noticed other benefits that surprised her.

“Of course my fitness improved, but I also felt more alert and energetic. I started to become more enthusiastic about life and my whole demeanour changed.”

Now, Janelle is back to nearly the same activity level as before her AML diagnosis.

“I’m training twice a week in the boat and doing lots of walking and weights,” she said.

Janelle is also planning a return to work soon at charity YourTown.

“I’m slowly returning to a life of fulfilment, and it’s all because of my transplant, my sister’s stem cell donation and all the world class medical care I received. I’m so grateful for all the support.”

Find out more about Fit to Thrive at leukaemiaqld.org.au/thrive.
Q&A WITH DR SALLY MAPP

We sat down with Dr Sally Mapp to chat about some of the common questions asked by people affected by chronic lymphocytic leukaemia (CLL). Dr Mapp is a Clinical & Laboratory Haematologist at the Princess Alexandra Hospital in Brisbane.

What are some of the symptoms of CLL?

While many people with CLL feel very well, some people can feel quite sick. This can be due to the burden of the lymphocytes that are in your body. This can give you enlarged lymph nodes that can start to ‘squash’ things, and it can give you a big liver or spleen. It can also affect your immunity; people with CLL often have infections.

Which patients are more likely to progress from ‘Watch and Wait’ to developing symptoms and requiring treatment?

There are a few factors that can guide us to determine whether someone is likely to need treatment early or not. We can look at whether people have enlarged lymph nodes, or whether they have an enlarged liver or spleen. We often look at the ‘doubling time’, which is a measure of how rapidly the white blood cell count is increasing.

These measures and tests are not definitive, however, so people need to be monitored regularly by their clinicians to see where they’re at with their disease.

Are there any CLL trials running in Australia at the moment?

There are lots! I recommend the ‘ClinTrial Refer’ app, which is available for free in app stores. Once you’ve downloaded it you can enter your state and your disease, and it will show you any local trials that are going on.

Do we repeat trials run in the US, or do we adopt their findings and offer that treatment in Australia?

Most trials these days are multinational, so that as many people as possible can participate. Australia is often a part of these multinational trials, so we use the results from other country’s trials as well as our own to help determine the best appropriate treatment.

What do I need to be aware of prior to joining a clinical trial?

If you’re considering a trial it’s very important you understand what the trial entails. You need to ask lots of questions and find out the benefits and disadvantages for you.

Is there a link between CLL and skin cancer?

Yes – people who have CLL are more likely to develop skin cancers, so if you have CLL it’s really important you have regular skin checks and if there’s anything you’re worried about, see your doctor early on.

Are there any new CLL treatments on the horizon?

It’s an exciting time for new treatments and it’s changing very rapidly! Ibrutinib has been showing to be very effective for CLL. At the moment it’s just being used in relapsed and refractory CLL but hopefully that will change soon. Venetoclax is still in the early trial stages but it’s showing promising results.

Why can’t I access all of these new drugs I keep hearing about?

Many drugs you hear about in the news are still in the trial phase. We need to determine that drugs are safe and effective and that requires years of testing. It’s very important that we know the full spectrum of a drug’s side-effects before it’s made available to people.

WHAT IS CLL?

It’s the most common leukaemia in the Western world, and it’s a cancer of the B-cells. The B-cells are a type of blood cell, B-cells are normally made in the bone marrow, so this type of cancer is often found in the bone marrow. It can often spread through the blood into the lymph nodes.
Like most people with a physically demanding profession, Brisbane student nurse Rosie MacLeod initially assumed her sore neck was a result of just another day on the job. She went to her doctor thinking the golf ball-sized lump in her neck was simply a pulled muscle that could be massaged out.

“I had also been losing my voice and feeling really tired, but didn’t think it was all connected,” the 21-year-old said.

Her GP sent her for an ultrasound, which showed a tumour running down her sternum.

Last year, after an open neck surgical biopsy, she was diagnosed with lymphoma, although doctors initially couldn’t figure out what type.

“They couldn’t work out whether it was Hodgkin’s or non-Hodgkin’s, which lead to gray zone lymphoma,” Rosie said.

Gray zone lymphoma is a very rare and aggressive lymphoma that has features of both B-cell lymphoma and Hodgkin’s lymphoma.

“Doctors were really reluctant to start a treatment plan for me, so I was referred to a specialist,” Rosie said. Brisbane haematologist Dr Ashish Misra prescribed a unique and intense treatment gray zone lymphoma regimen for Rosie.

“It was five types of drugs for five days, with a 24 hour infusion via a pump that was attached to me.

“I’d have a two week break then it would all start again,” Rosie said.

In total Rosie went through six months of chemotherapy and one month of radiation.

“I lost my hair, had bone pain and bad mouth ulcers. Luckily I didn’t have any nausea,” Rosie said.

Four months into her chemotherapy regimen, Rosie started the Leukaemia Foundation’s Fit to Thrive exercise program.

"I found it really helpful with my fatigue, and the routine also really helped to motivate me. It was also nice hanging out with people who understood what I was going through," Rosie said.

Rosie found further support with 20/30 Chat, a Leukaemia Foundation-facilitated support group for younger people affected by a blood cancer or disorder.

“The hardest thing about having cancer as a 20-year-old is that none of your friends know what to say, so it was nice to meet other people on the same journey.”

Now, one year later, Rosie has returned in a limited capacity to both study and nursing.

“I do short, staggered shifts in low immunity wards, as it will be another year until my immune system recovers,” she said.

Although Rosie is slowly getting back into more of a routine, she is still very fatigued and finds it difficult to explain her limitations to people.

Despite her challenges, Rosie is determined to keep pushing ahead with her study.

At the time of her diagnosis Rosie had been close to finishing her dual degree in nursing and midwifery, a course that she had to defer while undergoing treatment.

“I’m hoping to finish my degree in December – and then take a very long holiday!”

The next 20/30 chat will be in Toowoomba on 14 October.
An Australian-led trial has shown a new drug works in almost five times as many patients, and has more durable benefits, compared to standard therapy for cutaneous T-cell lymphoma.

Around 130 patients across 52 international trial sites, including at the Peter MacCallum Cancer Centre in Melbourne, took part in the study and were randomly assigned into one of two groups.

One group treated participants with the drug brentuximab vedotin, and the other group received standard therapy.

Study participants had either CD30-positive mycosis fungoides or primary cutaneous anaplastic large-cell lymphoma, and had previously been treated.

The study results, published in *The Lancet* in June, reported that more than half of those treated with brentuximab vedotin showed a beneficial response that lasted four months or more.

Only 12.5% of the patients who received the standard therapy showed such a response.

Longer-term follow-up also showed a major improvement in progression-free survival – at 16.7 months for patients treated with the new drug compared to just 3.5 months for standard therapy.

“We saw both a large increase in the number of patients who responded well to the new drug and, importantly, their responses were durable and lasted a lot longer than expected for this hard-to-treat cancer,” said Professor Miles Prince, trial leader and specialist haematologist at Peter MacCallum Cancer Centre.

“These impressive results point to a new and more effective treatment option for these patients, for whom standard therapies have to date offered only unreliable or short-term benefits.”

The new drug was not associated with any new or unexpected toxicities compared to standard therapy.

In Australia, brentuximab vedotin is already approved for use in relapsed Hodgkin’s lymphoma and systemic T-cell lymphoma.

This study’s results could fast-track approval for the drug’s use in cutaneous T-cell lymphoma.
Most new retirees are busy planning trips and taking up new hobbies – not dealing with the diagnosis of a disease they haven’t even heard of.

Bill Stinson, 64, was just a few months into retirement when he visited a haematologist to find out why his white blood cell counts were dropping.

His counts had previously been low due to kidney cancer, but had recovered after surgery to remove his left kidney. So why were they dropping again?

In February 2012, a bone marrow biopsy revealed Bill had myelodysplastic syndrome (MDS).

“I didn’t know what MDS was, even though I read very widely and have long had a subscription to New Scientist,” Bill said.

“MDS was explained to me briefly and I was told my long-term prognosis was unknown. It could continue as it was or worsen. The worst scenario was the MDS could turn into acute myeloid leukaemia.”

After he received news of his diagnosis Bill turned to the Leukaemia Foundation for more information about his disease.

“I quickly found the Leukaemia Foundation’s website and requested copies of the MDS, Eating Well, and Living with Blood Cancer information books.

“They were very informative and I didn’t look at much else,” explained Bill, a retired university librarian.

Bill started a ‘wait and see’ program, with blood tests every six weeks, and enjoyed his retirement the best he could with a short trip to New Zealand.

But by early 2012, he had become dependent on blood transfusions, his blood counts were dropping and he felt exhausted walking to the shops.

After his third bone marrow biopsy, Bill was finally eligible to receive azacitidine under the Pharmaceutical Benefits Scheme.

“After my first cycle of azacitidine I had improved and my blood counts were all back to normal after the third cycle,” Bill said.

He started six weekly treatment cycles in December 2015, enabling him and his partner Genie to plan travel during his treatment breaks.

Since his diagnosis, the couple have travelled overseas six times.

“I travel the day after my last injection, so I get around 31 days before I need to be back for my next blood test,” Bill explained.

“I want to enjoy life as much as I can and finally do the things I have talked about.”

Turn to page 14 for more information about travel and blood cancer.

Improving the ‘wait and see’ approach to treatment

Australian researchers utilising valuable samples from an initial clinical trial funded with Leukaemia Foundation support have discovered why some MDS patients will not respond to a common treatment.

The discovery could form the basis for a world-first clinical test to identify early whether or not patients with high-risk MDS will respond to the frontline treatment azacitidine (AZA; Vidaza).

The findings could have potentially important translational outcomes, enabling for the early identification of such patients and will be incorporated into a clinical trial beginning next year.

AZA is not a cure for MDS, but about half of people who are treated with the chemotherapy drug will respond after four to six months, and may not progress to leukaemia.

Dr Ashwin Unnikrishnan, a Research Fellow at the Lowy Cancer Research Centre, UNSW, says the team have discovered the bone marrow hematopoietic progenitor cells of patients who were resistant to AZA therapy were dormant, and a smaller proportion were undergoing active cell cycle progression compared to the cells of patients who responded to treatment.

The multinational study was led by Professor John Pimanda’s team at the Lowy Cancer Research Centre, UNSW, and the Prince of Wales Hospital in Sydney.

“AZA is not a cure, and we are starting to understand why it does what it does,” said Dr Unnikrishnan.

Professor Pimanda received a Leukaemia Foundation Career Establishment Grant to identify genes that are abnormally switched off in myelodysplasia. Dr Unnikrishnan and Professor Pimanda were awarded a Leukaemia Foundation Grant in Aid to identify the differences between cancer stem cells and normal stem cell.
A lack of energy and feeling a bit “out of sorts” were the first indications for Caeleigh Hancock that things weren’t right.

She imagined something minor, perhaps a low iron count.

Instead in 2012, aged 40, she was diagnosed with a myeloproliferative neoplasm called Polycythemia Rubra Vera (PV).

Myeloproliferative neoplasms (MPN) are a group of disorders where bone marrow stem cells reproduce abnormally, producing excess numbers of red cells, white cells and/or platelets.

In many cases, people with PV have a ruddy complexion, and a reddening of the palms of their hands, the soles of their feet, ear lobes and their eyes. This is due to high numbers of red cells.

And because their blood is thicker than normal and cannot flow as easily, especially through the smaller blood vessels, those with PV have an increased risk of blood clots.

“At the time I could hardly even pronounce the name of the condition let alone work out what it would mean for my health,” Caeleigh said.

“It was very confusing and a little scary for me and my family but we took a great amount of comfort from the support and information supplied by the Leukaemia Foundation.

“Through them I’ve been able to form a support network with other blood cancer patients and access advice like how to combat the debilitating fatigue.”

Like many people with PV, Caeleigh has high white cell and platelet counts, which requires regular checks of her blood counts and having blood taken out from time to time to bring her red cell count down.

Caeleigh has also had to come to terms with giving up her goal of performing at an elite level at masters sports.

“The good thing is I’m still able to work and do some of the active things I’ve always loved, like jogging and playing hockey. I just have to be careful not to overdo it.

“My husband, Ian, and I have taken the attitude that we should try and live life to the fullest and get out and explore the world while I’m still well.”

This year Caeleigh and Ian completed the Leukaemia Foundation’s 55 for 5 – a 55km charity hike through the Sunshine Coast hinterland – for the fifth time.

“Given the difference that the Leukaemia Foundation has made to me and my family, we plan to keep doing the 55 for 5 walk as our annual fundraiser for as long as we are able to.

“I’ve met some great people with amazing attitudes and stories through the walk.”

PEGASYS UPDATE

In our last edition of Blood Cancer News we highlighted the work Nathalie Cook has been doing in advocating for Pegasys (pegylated interferon alfa-2A) to be listed on the Pharmaceutical Benefits Scheme (PBS) for MPN patients.

People living with MPN are now a step closer to accessing Pegasys through the PBS after the Pharmaceutical Benefits Advisory Committee (PBAC) held a special meeting last month to consider the proposal calling for unrestricted access to Pegasys.

The Leukaemia Foundation congratulates Nathalie for spearheading this campaign and we will continue to work with Roche and the PBAC to ensure MPN patients get access to Pegasys on the PBS.
Many people affected by a blood cancer think they’ll be unable to continue many of the activities they enjoyed prior to diagnosis, like travelling.

While travel isn’t advisable for some treatment plans and conditions, it can be possible with a little extra planning and by taking some factors into consideration.

You may find the below tips useful for before and during your trip — but remember, you must always talk to your doctor first if you are considering any type of travel. They will be able to advise what is suitable for you.

It can be very uplifting to focus on a future holiday while you’re having treatment. Work with your treatment team and take a few simple precautions to ensure you look after yourself while you’re away.

BEFORE YOUR TRIP

Research your medications. Make sure that the drugs you are taking with you are not controlled substances in the countries you are visiting, as there may be restrictions on what and how much you can travel with. You should also ensure you have enough medication to cover your trip, plus a little extra in case of transport delays.

Take a doctor’s note with you. Ask your doctor for a letter outlining the details of your condition, your treatment history, and a list of medications. It will come in handy if you need to seek medical help while you’re away.

Check your vaccinations. Ask your doctor if your vaccinations are up to date, and see if you need to get inoculated (e.g. hepatitis, typhoid, tetanus). You will need to avoid any live vaccines for the six months following chemotherapy.

Research travel insurance. It can be difficult to find a travel insurance company that will cover a pre-existing condition like blood cancer. However, there are some companies that will cover you depending on your general health, your blood counts and where you are at in your treatment plan. At the time of writing ‘All Clear Travel’ covered some blood cancers; visit allcleartravel.com or phone 02 9333 3922 to see if they can cover you. Otherwise, you can get travel insurance through a multitude of companies to cover other complications that aren’t related to your cancer – for example, if your flight gets delayed, or if the airline loses your luggage.

Talk to your doctor about your plans. Find out if, when, and where you can travel, and what precautions you need to take. Don’t get discouraged if they advise you against going abroad just yet; you may be able to take a mini break interstate instead.

DURING YOUR TRIP

Get moving! If you’re going to be sitting for long periods of time (like on an aeroplane or a train), you should take some measures to prevent blood clots. Some people with a blood cancer have an increased risk of developing blood clots, as they may have a high level of the proteins and platelets that help the blood to clot. Take short walks as often as possible; do simple leg exercises if you can’t leave your seat too much; wear compression stockings; and have plenty of non-alcoholic drinks.

Remember to slip, slop, slap. Your skin may be more sensitive and drier after treatment. Wear sunscreen, loose cotton clothing, and a hat.

Keep up good hygiene practices. Some people are at a higher risk of infection after treatment, plus illnesses like gastro and the flu can ruin even the healthiest person’s holiday! Proper hand washing, eating food that has been properly and freshly cooked, and (in certain countries) drinking bottled water can minimise your risk.
Lynn Simpson is now the carer for her son, Darrin, after his shock blood cancer diagnosis. It’s a role hundreds of parents take on each year as leukaemia remains Australia’s most common childhood cancer.

But Lynn can offer a unique perspective on blood cancer most carers don’t have: Darrin is 40 years old and intellectually disabled. Lynn knew one of her biggest challenges was working with healthcare staff to tailor Darrin’s induction to a haematology ward so he was introduced to the new environment and routine in a nurturing and gentle way.

“You could see the panic in his eyes – he didn’t know exactly what they were talking about. He doesn’t process information the same way we do so he was scared.”

Lynn says she broke it down to Darrin in simple, clear steps.

“I told him that his blood wasn’t working properly so he had to have chemo to kill off the bad bugs in his system,” she said.

“When the transplant came around, I told him that the chemo didn’t work so we have to get something from someone else’s body to help make some good bugs.”

Lynn says that throughout their experience, Darrin has amazed everyone with his positive attitude – and thinks ultimately that has helped him handle his treatment and side-effects so well.

“He endeared himself to everyone at the hospital and tolerated treatment really well,” Lynne told Blood Cancer News.

“It’s hard to sometimes keep those feelings locked up and to try to be positive for him.”

“But now that he’s gone through it, and he’s looking good, I’m doing fine. We know he will make it through.”

It’s hard to keep your emotions locked up

Lynn has shared five tips she found helpful for her and Darrin.

BE HONEST

If they ask hard questions, answer them – by being honest, it can take away some of the fear. It will be hard for you to talk about things like death, but you need to have that conversation. You can’t hide things; the fear will build as they know you’re being secretive. Darrin also needed to understand what was happening as some of the treatments were going to make him feel sick.

BE POSITIVE WHERE APPROPRIATE

Darrin feeds off me so I try to show a positive and strong front for him. However, I also make sure to always address any concerns he has.

FIND A TALKING POINT

Darrin loves the Broncos, so hospital staff would often talk to him about the team when they first met him. It was a great starting point to make Darrin feel comfortable.

USE CLEAR LANGUAGE

I broke it down into parts. Part 1 was chemo. Part 2 was the transplant. Part 3 was coming home and us building him up and getting fit and healthy again. Part 4 would be him going back to his house. By breaking it down into little small steps, he understood it a lot better.

DON’T CHANGE HOW YOU ACT

Everyone in our family has acted normally. No one treated him differently – his brother still riles him up!

The Leukaemia Foundation offers a variety of support services for carers, including counselling and informal support groups. Contact us on 1800 620 420 or email info@leukaemia.org.au for more information.
**WHAT’S ON**

Find out more about an event near you by contacting us on 07 3055 8233 or qldsupport@leukaemia.org.au. We will send out invitations closer to each event.

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**UPDATED BOOKLETS NOW AVAILABLE**

Updated educational booklets on chronic myeloid leukaemia, chronic lymphocytic leukaemia, autologous transplants, and non-Hodgkin lymphoma are now available.

These booklets have recently been revised with help from haematologists and nursing staff across Australia.

To order a booklet, contact us on 1800 620 420 or download them from our website: leukaemia.org.au.

**CONTACT US**

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

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

**TOWNSVILLE**
- 41/100 Angus Smith Drive, Douglas Qld 4814
- Support, accommodation and information: 07 4727 8000

**CAIRNS**
- 52B Comport Street, Portsmith Qld 4870
- Support and information: 07 4051 3355

We don’t receive any direct government funding and rely on the generosity of the community to support patients when they need it most. If you would like to make a donation to help others affected by blood cancers, visit leukaemia.org.au.

Would you like to receive this newsletter or invitations to our seminars via email? We would also love to know what you think about Blood Cancer News.

**Contact us:**
- 1800 620 420
- leukaemia.org.au
- qldsupport@leukaemia.org.au

Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist. If you do not wish to receive future editions of this publication please contact the Leukaemia Foundation Support Services Division on 07 3055 8233.