

Amyloidosis news.

For people with amyloidosis & their families



Leukaemia
Foundation
VISION TO CURE
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Carole's in remission after seeking a second opinion

Carole Bartlett chose not to 'watch and wait', as suggested by a renal specialist in hometown Perth, after being diagnosed "very early" with AL amyloidosis in mid-2011.

"I was very nervous about waiting," said Carole, 64, a research assistant at the University of Western Australia (UWA).

So she travelled across Australia for further tests and advice that suggested having a stem cell transplant as soon as possible.

Her symptoms were minor – changes in her hair and nails, feeling more tired than normal, some weakness in her arms, and losing a bit of weight – "not something I'd go to the doctor for on their own".

Carole's diagnosis took eight months and began when her GP noticed changes to her cholesterol and albumin from regular blood tests taken to monitor menopause. When urine tests showed Carole's protein was higher than normal, she was referred to a renal specialist who did a free light-chain test.

"It came back positive for paraprotein, then a kidney biopsy showed amyloid in the kidneys," said Carole.

Next, she saw a haematologist and had a bone marrow biopsy. A clone of cells producing excess levels of lambda free light-chains confirmed AL amyloidosis.



Carole Bartlett at work at the UWA's School of Biological Sciences

"It's important to know what kind of amyloid you are dealing with and I'd been picked up pretty early which is unusual," said Carole.

"Being in medical research, I wanted to find out as much as possible about the disease, and I have access to research journals and scientific papers, which I delved into.

"Initially, I was shocked. A lot of articles said prognosis was very poor but the more I read, I realised... that's not the case for everybody. There are people who are picked up earlier, and the message – 'early diagnosis and early treatment resulted in the best outcomes' – came out again and again.

"This reassured me, but at the same time my renal physician was saying we'd just watch and wait and see what my protein levels did.

"I'd been handed back to the renal physician for treatment and it seemed he was waiting for my kidneys

to get significantly worse before doing anything.

"He talked about eventually going on to chemotherapy but I couldn't see the point of waiting and didn't have a lot of confidence in this approach," said Carole, and she was concerned about having a blood disease but not being treated by a haematologist.

"After my diagnosis, I contacted the Leukaemia Foundation and was put in touch with a patient advocate in Brisbane who specialised in support for people with this disease.

"She became my life jacket, keeping my head above the water. She was always at the end of the phone line, gave me family counselling, information and perspective. In fact, she completely changed my life.

"She also put me in touch with my local Leukaemia Foundation office and another patient in Perth who I started meeting up with for coffee and a chat*. He was very supportive

Sophie is Jenny's '1%' bundle of unexpected joy

A lot has happened to Jenny Andrich since her story in the last issue of *Amyloidosis News* – she fell pregnant unexpectedly and last month gave birth to baby Sophie.

“Our little girl is a bit of a miracle and most definitely the best and happiest of surprises ever,” said Jenny.

She was diagnosed with AL amyloidosis in 2015, aged 26, and two years ago, Jenny and her husband Michael had embryos frozen, ready for when they planned to start a family, perhaps this year.

Jenny's fertility levels had been “almost knocked out” by high dose chemotherapy prior to a stem cell transplant in November 2015.

When she was told her odds of conceiving were less than 1% she decided to go off the pill, which she'd been taking as a precaution while giving her body a break from medication.

A month later, Jenny noticed some pregnancy symptoms and at first didn't believe the result of a home pregnancy test.

“I found somewhere on the internet that ‘protein loss can cause a false positive pregnancy test’, so we thought that was the reason, but a blood test confirmed I was pregnant a few days later,” said Jenny.

“As our chances of having a baby naturally were extremely low, we were shocked, excited and very happy.



Jenny Andrich and her little miracle, Sophie

“There were lots of times I'd think about the future and all the different possibilities, but at the end of the day we can't predict what will happen, so we're enjoying every moment together and looking forward to the future with Sophie.”

New and updated information guides

Having access to credible and current information can be empowering, and helps with understanding and coping with practical and emotional issues.

The Leukaemia Foundation has developed a new guide in its extensive series of information booklets, titled *Living Well After Treatment – A guide for patients and families*.

This booklet, developed by healthcare professionals who work in cancer care, helps to provide support when treatment has finished. The information is largely research-based and is divided into three main topics:

- » finding a new normal;
- » staying healthy; and
- » moving on.

Transitioning from ‘cancer patient’ to ‘normal life’ is a process that takes time and is a journey that differs for each individual and may involve a mix of emotions, from feeling happy and relieved, to worried or sad. Some people say they appreciate life more, while others are anxious about their



health and concerned about the future. All these feelings are normal. Some people may find aspects of the post-treatment phase complex or challenging, such as staying healthy, returning to work, coping with feelings or fatigue, and follow-up care.

This booklet has been written to help you and your family to be aware of what to expect after treatment, and to be active in the ongoing management of your health.

Our booklets are regularly reviewed and updated editions of *Amyloidosis* and *Autologous Stem Cell Transplants* are now available.

Latest editions of these publications are available from our offices Australia-wide and can be downloaded from the ‘Resources’ section at leukaemia.org.au

Our Jo takes on Everest Challenge

Jo Beams couldn't pass up the call for a Leukaemia Foundation staff member to join the Beat Blood Cancer Everest Challenge in April.

For our National Myeloma and Amyloidosis coordinator, this was another opportunity to provide support... inspiring participants on their personal quests to raise funds and trek to the gateway of the world's highest peak. For more than a decade, Jo's had “the privilege” of delivering support services; on a local level to Tasmanians, and since July 2016 on a national level.

“I see first-hand the difference our organisation makes to Australians living with a blood cancer such as amyloidosis,” said Jo.

“Our team is coming together from all over Australia and includes people touched by blood cancer and the support we provide. We're still recruiting participants, so spread the word to anyone who likes a physical challenge and who has Everest base camp on their bucket list.”

Clinical trials in amyloidosis

By Dr Simon Gibbs

Director, Victorian and Tasmanian Amyloidosis Service

Ixazomib-dexamethasone versus physician's choice

Open to recruitment now

The Australian Amyloidosis Network is still offering the Millenium ixazomib-dexamethasone vs physician's choice trial for patients with relapsed or refractory systemic AL amyloidosis. This trial is somewhat difficult to recruit to, as patients must not have previously been exposed to bortezomib (Velcade®). Any patient who has not previously received bortezomib but has relapsed disease should contact a doctor at the Australian Amyloidosis Network to enquire further. Ixazomib is a once-per-week oral tablet in the same class of drugs as bortezomib, but with far less side-effects, especially neuropathy (pins and needles in hands and feet, diarrhoea, dizziness upon standing).



Dr Simon Gibbs

Daratumumab with VCD chemotherapy

Coming soon

The pharmaceutical company, Janssen, is establishing a trial of daratumumab with bortezomib, cyclophosphamide and dexamethasone (VCD) for newly diagnosed systemic AL amyloidosis. Daratumumab is a monoclonal antibody that attaches to the CD38 protein on the surface of plasma cells and helps the immune system clear these cells. Thus, daratumumab should decrease the production of the abnormal light chains that make amyloid fibrils. Results of this drug

in myeloma have been impressive with high response rates and long remissions. The drug is usually given as an IV infusion over several hours, but in the amyloidosis trial Janssen is looking at using a subcutaneous form (injection in the skin), meaning less time in hospital. The trial should be offered at the three Australian Amyloidosis Network sites, and we hope that this will open in the second quarter of 2018.

Anti-SAP monoclonal antibody

A trial of the GSK anti-SAP monoclonal antibody is underway in the U.S. and UK for the treatment of TTR amyloidosis. We hope this trial will be extended to Australian shores in 2018 and involve patients with AL and other amyloid disease types.

Patisiran

The agent, patisiran (made by Alnylam, marketed in Australia by Sanofi) recently had positive results in its trial in patients with hereditary TTR amyloidosis with neuropathy. We hope this agent will be available either in a clinical trial or on a compassionate access basis in 2018. Patients with neuropathy and TTR amyloidosis should keep in touch with physicians in the Australian Amyloidosis Network as access to this drug on a compassionate access scheme may be limited.

Pomalidomide and dexamethasone +/- venetoclax

This trial for relapsed and refractory systemic AL amyloidosis is on hold due to some poor results with pomalidomide (Pomalyst®) in the U.S. as upfront treatment with bortezomib. We are still keen to run a trial with venetoclax (Venclexta™) in AL amyloidosis and are in ongoing discussions with the manufacturer, Abbvie. Half of patients with systemic AL amyloidosis have the t(11;14) genetic mutation that seems to respond best to venetoclax.

Systemic amyloidosis (AL or TTR) study

If you have AL or TTR systemic amyloidosis there's a phone interview research study about how systemic amyloidosis affects

health-related quality of life and you may be able to help provide valuable information that will be used to develop a questionnaire for future studies. No medical treatment is being provided as part of this study. The interview takes around 75 minutes, and those selected to participate will be compensated for their time. For information, email 0018-0665-AmyloidQual@iconplc.com

Australian Amyloidosis Network

Victorian and Tasmanian Amyloidosis Service, Melbourne

- » Weekly Monday morning clinic at Box Hill Hospital
- » Fortnightly multi-disciplinary team meeting with cardiologists, neurologists, nephrologists, radiologists and histopathologists

Contact/referrals:

simon.gibbs@monash.edu
1300 342 255

Westmead Amyloidosis Clinic, Sydney

- » Monthly Friday morning clinic at Westmead Hospital
- » Clinic attended by haematologists, immunologists and neurologists, with support from cardiologists, rheumatologists and nephrologists
- » Provides genetic testing for hereditary amyloidosis

Contact/referrals:

linda.mekhael@health.nsw.gov.au
02 9845 8738

Princess Alexandra Hospital Amyloidosis Centre, Brisbane

- » Monthly Friday afternoon clinic at Princess Alexandra Hospital
- » Clinic staffed by a team of health professionals including cardiologists, haematologists, neurologists, renal physicians, pathologists, specialised nurses, social workers, and a support and education officer.

Contact/referrals:

amyloidosis@health.qld.gov.au
07 3176 5772

GP and psychotherapist, Dr Louella Crawford's presentation, The Science and Health of Mind and Spirit, captivated attendees at the Leukaemia Foundation's Annual Blood Cancer Conference in Sydney in June. Her focus was mind/body therapies and how they can help drive the healing process and provide emotional and psychological support during a standard cancer treatment regimen, thereby contributing to the best emotional and physical outcome.

The mind/body connection in healing

Twelve years ago, when Dr Louella Crawford* was being treated for stage III breast cancer, she had a “full frontal” realisation – the mind plays an enormous role in your health.

She started to meditate, to have massages, and embarked on more study – enrolling in an arts degree majoring in philosophy of the mind and an advanced diploma in holistic counselling and psychotherapy.

“Fascinated by how the mind is involved in health, I began reading widely on everything I could get my hands on to do with psychology, the role of religion in health, spirituality, quantum physics, physics, quantum biology, neurobiology, neuroplasticity, neuroscience, psychoneuroimmunology, and epigenetics,” said Dr Crawford.

“Medicine is very objective. It’s about fixing things that can be measured and observed, and is pharmacologically focused.

“Few doctors have the time or training to really inquire about what’s happening more broadly in a patient’s life... how is it for you, what is happening at home, what’s going on? And by and large they don’t recognise that stress, or more importantly how one deals with the vagaries of being human and having human experiences – good or bad, affects health. That is changing, but very slowly.

“I was looking for a bridge that spoke the language of science (medicine) and the wonderful and complex story of a person’s inner life... for want of a better word, ‘The Spirit’.”

Dr Crawford came upon meditation, an Eastern spiritual practice dating back tens of thousands of years that,

put simply, makes people feel better. Meditation came to the attention of the West in the 60s when the Beatles, who were interested in Eastern philosophies, went to the U.S.

“Some interested scientists and doctors decided there was something to meditation but realised no one would take an Eastern spiritual practice seriously unless there were some tangible studies.”

According to Dr Crawford, there are now thousands of “good studies” on the effects of meditation on all kinds of people, from beginner meditators to Buddhist monks and nuns. Using fMRI machines that look at functional brain anatomy, and EEGs (electroencephalography), measuring brain waves, they have found definitively that meditation changes the brain.

“What these studies show is that meditation, and as little as 10 minutes a day for three weeks, actually changes a lot of parameters physiologically including the way your brain functions¹,” she said.

Meditation has been proven to reduce depression and anxiety and increase empathy, compassion and meaning in life. It increases the depth of grey matter and changes brain waves, increasing coherence. It also increases high-level thinking and the capacity to focus.

“We all have cancer from time to time; cancer cells rise up and fall away. They disappear because our immune system is functioning well,” said Dr Crawford.

“I think what is interesting and important for people who have a cancer, is that meditation actually changes your immune system and has been found to increase the number

of natural T-killer cells (a type of white blood cell) and one of their functions is to mop up metastatic cancer.

“Meditation also reduces inflammation and there’s a lot of science indicating inflammation is possibly the underlying pathogenesis (development) of a large number of illnesses including cancer, Alzheimer’s and heart disease.

“Meditation also reduces pulse rate and blood pressure, and a small but good study of Afro-Americans practicing transcendental meditation showed it reduced the incidence of heart attack and stroke by 30%.

“So here we have a practice that is not only free, it has no side-effects, and as a medication, it does an enormous amount of good.

“If meditation was a drug, you’d have pharmaceutical companies falling over each other trying to get it to market.”

In 2009, Tasmanian-born Elizabeth Blackburn won a Nobel Prize for discovering an enzyme, called telomerase, that repairs the telomeres² on the ends of DNA. As we age, our telomeres shorten.

Professor Blackburn teamed up with psychiatrist, Elissa Epel, who had a theory that stress might have a role in reducing the level of telomerase. Together, they designed a study showing that stress actually did reduce the level of telomerase, which Dr Crawford described as “paradigm changing”.

“Not content with this, they then decided to see if reducing stress via meditation actually increased telomerase levels. They looked at two groups of people – those who meditated and those who didn’t,” said Dr Crawford.

“The results were stunning. Not only did meditation increase telomerase levels, it also reduced neuroticism (the propensity to worry constantly), increased mindfulness (living in the present moment; a very spiritual attribute) and increased one’s sense of meaning in life. Meaning⁴ can be the simplest moment or action in life; something that gives a person a reason to go on despite the most terrible circumstances.

“What was even more extraordinary was that the increased levels of telomerase were purely and directly related to an increased sense of meaning in life. In other words, having a sense of meaning in life increases the repair of our DNA.

“To me this is an absolutely extraordinary and significant study³ that directly links the qualitative spiritual value of our inner world with our objective measurable physiology.

“How wonderful would it be to combine and marry treatment of our measurable physical problems with understanding and caring for our amazing, complex inner worlds? The best of everything... that’s the way forward. It’s not an either/or thing,” said Dr Crawford.

“More than 20 years ago, in the U.S., Marc Barasch and Caryle Hirschberg⁵, were fascinated by the concept of spontaneous remission from cancer; when someone outlives a dire cancer diagnosis by many, many years or completely recovers.

“Their study on spontaneous remission found a series of human qualities, including resilience, termed ‘hardiness’ in 1979 by Suzanne Kobasa, one of the first people to look at positive psychology. These qualities enabled people to respond appropriately and cope under stress.

“They had a sense of control about how they responded to a situation (different to being a control freak); they lived wholehearted lives (they had spiritual qualities like gratitude, forgiveness, living in the present moment, a sense of awe); they had a sense of meaning in life; and they had a sense of not feeling alone... in other words, they felt connected to something, be it friends, family, animals, the divine, or even nature.

“What I find fascinating,” said Dr Crawford, “is the huge crossover here between the study of positive psychology and resilience, and what they found in spontaneous remission in cancer”.

Dr Crawford now works as a GP concentrating on mind/body medicine through the practice of ‘process work’⁶ – a form of psychotherapy that sprang from Carl Jung’s work and believes the mind and body are not separate, but simply different sides of the same coin.



Dr Louella Crawford at the Leukaemia Foundation’s Annual Blood Cancer Conference in Sydney in June.

“The more I practice, the more I absolutely know this to be true... the mind and the body are completely in sync. Obviously, it’s also what you eat, whether you exercise and what genetic predispositions you have.

“I focus on trying to speak the language of science and there is now an overwhelming number of studies in the area of psychoneuroimmunology that joins up psychology, the immune system and neurology, as well as epigenetics that says genes aren’t the only things that determine people’s health.

“Bruce Lipton⁷, one of the pioneers of epigenetics, says our beliefs, thoughts and feelings are entwined and affect the expression of our DNA.

“Epigenetics teaches that the DNA is like a set of architect’s plans that needs a builder to decide which parts of the plans to implement. This is incredibly empowering, to think that we may have some input or control over the expression of our DNA,” said Dr Crawford.

“Epigenetics is a burgeoning field that needs to be incorporated into medicine. It explains and looks at how we interact with our environment on every level, including nutrition, exercise, thoughts, beliefs and feelings, and how these affect the expression of our DNA.

“Nothing is the complete answer... it’s a very broad collection of a whole lot of things.

“In my practice, I advise people to meditate, but you’ve got to do the work on the stuff that you bring with you, and we’ve all got it – baggage.

“I have lots of anecdotes about people who changed how they viewed the world and how they existed within the world and environment, and it made a dramatic difference to both their psychological wellbeing and health.

“For me, it took the drama of being diagnosed with cancer before I thought – what’s going on here?

“When I had breast cancer, it was terrible. We had four children under 15 and I thought I was going to die. It was a traumatic experience,” said Dr Crawford.

“I felt very grief-stricken on a whole series of levels. I’d get in the shower every morning because it was the only place I could cry without upsetting my children and husband.

“I was lucky. Friends gave me interesting books such as *The Tibetan Book of Living and Dying*⁸ and intriguing books on the mysteries of quantum physics. These stimulated my interest in areas of thought I never knew existed and began my quest into understanding the mysteries of our minds.

in terms of telling me what he'd been through.

"The most important thing to me was to make a decision about treatment," said Carole, who was becoming increasingly concerned as her monthly renal tests showed her kidney function was dropping.

"Things were getting worse but no treatment was being instigated.

"A problem with amyloidosis is that it is a rare disease and not all doctors are up to speed with current developments. Getting to see the right people is very important.

"I knew there was a specialist amyloidosis clinic at the Princess Alexandra Hospital in Brisbane and asked my GP for a referral to go there for a second opinion," she said.

In November, Carole made the trip to Brisbane. More tests confirmed her diagnosis and she saw three different amyloidosis specialists.

"They said they would get me straight on a stem cell transplant (SCT) regimen because I was young enough, healthy enough and that was the best option for me. I felt empowered by that," said Carole.

Back in Perth, she set the wheels in motion. She got a referral to a haematologist she'd heard

was running a clinical trial for an amyloidosis treatment, and contacted him personally, asking his advice and opinions.

"He agreed I should get treatment as soon as possible and felt I was a good candidate for a SCT. The trial was not my best option as it was randomised; with only a 50% chance of getting the new drug combination."

On Boxing Day 2011, Carole started chemotherapy – three rounds of cyclophosphamide, dexamethasone and thalidomide over nine weeks. After a break, her stem cells were harvested and she had an autologous stem cell transplant on 15 April 2012. Her husband, Peter, took charge of the home environment and cooking, drawing up a menu of sterile meals for when she was neutropenic.

"We were anal about cleanliness, knowing the main problem was infection post transplant. We changed sheets, towels and pajamas and wiped down surfaces with alcohol, initially every day.

"I remained infection-free, so it was worth it," said Carole.

She returned to work in July 2012, has since "got better and better", and is now five years post transplant.

"It took a while for the free light-chain levels to come down and they are

now in the normal range. My kidney function has improved over the years, but is still not quite normal," said Carole.

Her life though is back to normal.

"I really enjoy my work, being with friends, getting out and walking, cooking, photography and spending time with my family."

She has three grown children, recently became a grandmother and hopes to retire at the end of next year.

Having amyloidosis has changed Carole's outlook on life.

"I'm really grateful to be where I am. Even when things are a bit tough, I'm grateful to be here to experience them. It could have been a very different story.

"I look at the positive side of any situation and I don't like to waste time. I appreciate that time is short, so you have to make the most of every day."

** These get-togethers progressed into an informal amyloidosis group, and now the Leukaemia Foundation facilitates the group that meets every two months at Matilda Bay. Carole has been involved with Light the Night since 2015 and also is a trained Blood Buddy.*



Carole Bartlett, right, at last year's Light the Night at UWA, with (from left) her daughter Elora and her partner James Webster, her son Craig Bartlett with his fiancée Shawn Borlagdagan, and husband, Peter

Workshops highlighted exciting developments in all aspects of amyloidosis

By Carole Bartlett

The Australian Amyloidosis Network's workshop series – *Amyloidosis: Are We Any Nearer To A Cure?* – was held in Brisbane, Melbourne and Sydney in February to promote understanding of the disease.

There were separate sessions for patients and practitioners with Australian experts and two international specialists addressing both audiences.

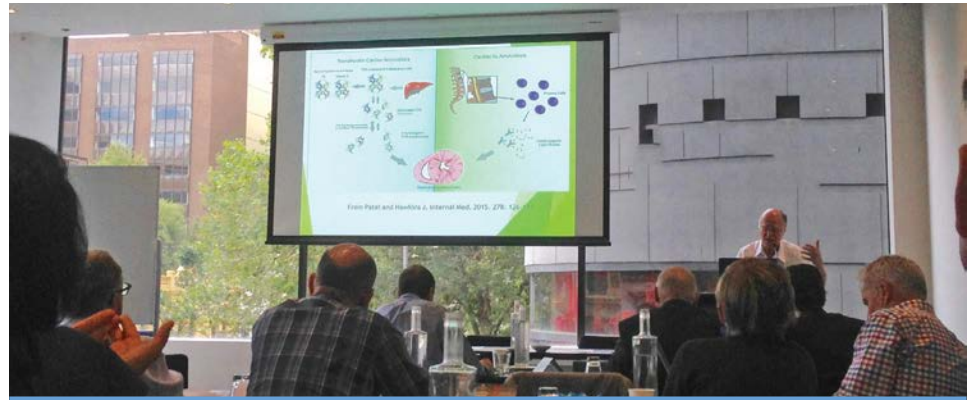
Having a good 'lay' understanding already, I registered for the clinician's program in Melbourne, opened by Dr Simon Gibbs. He returned to Melbourne in 2014 after spending time at the National Amyloidosis Centre (NAC) in London and establishing an Amyloidosis Service at Manchester.

Associate Professor Peter Mollee from the Princess Alexandra Hospital Amyloidosis Centre (Brisbane) explained amyloidosis, the different disease types and how they differ depending on the protein involved.

After giving details on how to correctly diagnose and stage the disease (essential for correct, appropriate and timely treatment) NAC director, Professor Phillip Hawkins, spoke of new techniques involving biomarkers, histology, proteomics, and laser micro-dissection. These are available in Australia.

Dr Gibbs then focused on amyloidosis in Australia and the growing expertise and experience available at the specialist amyloidosis centres.

Cardiologist, Dr James Hare, said cardiac amyloidosis could be missed, as some traditional tests



One of the international presenters, Professor Rodney Falk, talking about cardiac amyloidosis at the amyloidosis workshop in Melbourne

for cardiac function can appear normal. He talked about different techniques for examining the heart (echocardiography, MRI) and how the presence of amyloid can be detected.

Assoc. Prof. Mollee discussed PET imaging using florbetaben, an amyloid-specific radiotracer. This technique, developed in Australia, indicates amyloid load in both TTR and AL amyloidosis.

Victorian and Tasmanian Amyloidosis Service haematologist, Dr Nora Lee, discussed bone scintigraphy, and also an imaging technique to distinguish TTR from AL in the heart, that could avoid the need for cardiac biopsies. Many techniques can aid diagnosis and she said getting it right was critical.

Amyloidosis legend, Professor Rodney Falk, director of the Cardiac Amyloidosis Program, Boston (U.S.), detailed challenges when assessing the heart and lesser-known physical signs of the presence of amyloid, and said more than one disease may be present; an older patient may have both ATTRwt and AL amyloidosis.

The afternoon session focused on treatment and management options and quality of life issues.

Treatment in AL amyloidosis has traditionally reduced the free light chain protein that makes up the fibrils by killing cells that produce it, with chemotherapy or SCT. Dr Gibbs described novel approaches across the amyloidoses that interfere with genes that make the protein, influence the ability of the protein to misfold, or even attack and remove the deposited amyloid, as well as new drugs being developed and clinical trials underway or about to start.

The kidneys often are involved, especially in AL amyloid, and Professor Lawrence McMahon, director of Nephrology at Eastern Health (Melbourne) addressed problems associated with amyloid in this organ. Declining kidney function often necessitates dialysis and he discussed kidney transplantation and when this may be a good option.

Dr Fiona Kwok, a haematologist at the Westmead Amyloidosis Clinic (Sydney), addressed quality of life issues during treatment including pain relief, oedema, neuropathy and gastrointestinal problems, the importance of supportive care, and the need to support the organs – both healthy and affected by amyloid.

Professor Hawkins talked about some of the newest approaches to treatment where antibodies to inflammatory markers or to part of the amyloid protein are used to stimulate the body's natural immune system to attack and get rid of the amyloid protein. He also discussed new generations of drugs, such as proteasome inhibitors and drugs being developed that interfere with the way the cells make proteins from the genetic instructions, which is exciting.

Finally, Prof. Falk gave case studies illustrating some of the challenges faced when diagnosing and treating the amyloid diseases. A speakers' panel then took questions and there was active discussion around the day's topics.

I was greatly encouraged by the enthusiasm and commitment of the scientists and clinicians dedicated to improving diagnosis, treatment and outcomes for amyloid patients. There is a lot of hope for the future.

Support near you

For information about Leukaemia Foundation events and amyloidosis support programs please visit leukaemia.org.au or contact:

NATIONAL	
Jo Beams	National Myeloma & Amyloidosis Coordinator
	jbeams@leukaemia.org.au
QUEENSLAND	
Sheila Deuchars	Support Services Coordinator
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VICTORIA/TASMANIA	
Tennille Lewin	Blood Cancer Support Manager
	tlevin@leukaemia.org.au
NEW SOUTH WALES/AUSTRALIAN CAPITAL TERRITORY	
	Inquiries: 1800 620 420
SOUTH AUSTRALIA/NORTHERN TERRITORY	
Peter Diamond	Blood Cancer Support Manager
	pdiamond@leukaemia.org.au
WESTERN AUSTRALIA	
	Inquiries: 1800 620 420

◀ continued from page 5

“However, it’s those hidden emotions – sadness, grief, anger, powerlessness, etc., and their expression that is the beginning of what is not an easy journey, but one that is so important to take... to find the peace that at the end of the day is all any of us wants. It is my belief that it is this peace that also allows our physical body to function and heal as best it can.

“I began to listen to myself and to my intuition, and to do what did and didn’t feel right for me. I learnt to say “no”. This is not being selfish, as we so often think – it’s about self-care.

“Before cancer, I always did what other people wanted me to do. I was completely disconnected to my

own inner world and never listened to what I wanted or what I felt. “I went into my healing space, and if people rang me and said ‘can I come and visit you?’, I’d think to myself, I don’t have to say ‘yes’ to this, so I could say ‘no’ without guilt. And it was like – oh my god, this is so fabulous. I’d never realised you could say ‘no’ and it felt so good.

“Of course, this was my journey. Everyone has a different path to travel but whatever it is, it is important.

“The difference between me now, and 12 years ago, is the awareness I have about my mind.

“In my practice, I teach three things you need. Firstly, you need awareness about how you exist in

the world (this is where my practice as a psychotherapist is enormously helpful), secondly, a will to want to change, and thirdly, you’ve got to practice it.

“Practice is what changes your brain and your physiology.

“In my view, how we exist within and respond to our world and environment and how we incorporate every aspect of our mental and physical worlds, including our genetic makeup, nutrition and exercise, is what determines our health. And that is what science is starting to tell us. This is a truly holistic approach to living a long, healthy and happy life.”

1. This is explained in Richard Davidson’s bestseller, *The Emotional Life of the Brain*.

2. These small structures are thought to provide important clues for fighting chronic diseases and slowing down the aging process.

3. *The Telomere Effect* by Elizabeth Blackburn and Elissa Epel.

4. Described in Austrian psychiatrist, Viktor Frankl’s book, *Man’s Search for Meaning*.

5. *Remarkable Recovery: What Extraordinary Healings Tell Us About Getting Well and Staying Well* by Marc Barasch and Caryle Hirschberg.

6. Quantum physicist, Arnold Mindell, developed process-oriented psychology in the 1970s.

7. A developmental biologist and author of *The Biology of Belief*, who promotes the idea that genes and DNA can be manipulated by a person’s beliefs.

8. Written in 1992 by Buddhist meditation master, Sogyal Rinpoche.

*** Dr Crawford runs a weekend program at the Southern Highlands Private Hospital oncology unit, Bowral (NSW).**

Contact us

If you need support or would like to make an enquiry please contact the Leukaemia Foundation on 1800 620 420 or go to leukaemia.org.au or leukaemiaqld.org.au (Queensland patients).

