Double diagnosis: amyloidosis and myeloma

Janette Elson and her husband, Charles, were living what they described as a very happy life in the sleepy beachside haven of Woodgate near Bundaberg when life took an unexpected turn.

“I had never heard of amyloidosis or myeloma until three-and-half years ago,” Janette said. “I probably had the same attitude as most people about getting a life-threatening illness – that won’t happen to me!”

In early 2012 Janette experienced a range of unrelated symptoms: pain in her skull, dizziness, a series of infections and a general feeling of being unwell.

Fortunately Janette’s doctor took her symptoms seriously and did a series of blood tests and scans.

“He thought I had an auto-immune issue, but when he eventually suspected myeloma he sent me to a haematologist in Brisbane,” she said. “The day before my 66th birthday I had my diagnosis - smouldering myeloma.”

Because her immune system was compromised, the haematologist started Janette on monthly rounds of Intragam P, as well as Zometa to help avoid the bone disease issues associated with myeloma.

“We made the 800km round trip to Brisbane every month and nothing really changed until May 2013 when a scan revealed a diffuse infusion in my lungs that resembled ‘ground glass’.

“At first it was diagnosed as interstitial lung disease, a separate but untreatable illness.

“However, further lung tests and scans revealed deterioration in the condition and the decision was made to do an open lung biopsy. This revealed that the ‘ground glass’ was in fact both myeloma and amyloidosis.”

The decision was made to start chemotherapy immediately followed by an autologous bone marrow stem cell transplant if Janette responded well to the chemotherapy.

Treatment went very well apart from a hiccup with Janette’s pacemaker on the 14th day of each cycle when she became dizzy, her heart rate fluctuated and she had to be admitted to coronary care. Both the protein and long chain cell count fell to nothing and her transplant took place on 25 January 2014.

“There were some difficult times throughout the transplant process but the process worked wonderfully,” she said.

Since her diagnosis, Janette said the Leukaemia Foundation has been a great support for her and Charles.

“We were so grateful that they provided free accommodation for both of us, firstly in a motel and then in a two bedroom unit at...
A message from the editor

Welcome to the second edition of Amyloidosis News for 2015. Thank you to everyone who gave feedback on the last edition of Amyloidosis News. We appreciate your comments and are always happy to accept suggestions for future articles and topics.

I’d like to thank Pat Neely, the Volunteer/Honorary Amyloidosis Patient Education and Support Officer at the Amyloidosis Centre, Princess Alexandra Hospital Brisbane who contributed two articles on an exciting new research trial which is giving new hope to amyloidosis patients (page 3) and an overview of what amyloidosis services are available in Australia (page 9).

Earlier this year we said farewell to our National Amyloidosis Coordinator, Kaye Hose, who left the Leukaemia Foundation to take up a position in palliative care. On behalf of patients, families and colleagues I would like to thank Kaye for her hard work and commitment to supporting patients, her contribution to Amyloidosis News and for facilitating the telephone forums.

We wish Kaye all the best in the future.

We would like to thank those of you living with amyloidosis who supported Light the Night which was held at various locations around Australia on 9 October. As always it was a very special evening and a great opportunity for those who have been affected by blood cancers and related blood disorders like amyloidosis to join together and raise awareness and funds.

These funds will enable us to continue to support patients and their families who are going through the difficulties associated with having amyloidosis, as well as invest valuable funds into research and finding a cure.

Remember that we are here to support people living with amyloidosis in any way we can, whether newly diagnosed or months or even years down the track. I’d like to wish you all a very safe and happy festive season.

Sheila Deuchars
Support Services Coordinator - Amyloidosis (Queensland)

Continued from pg 1

Clem Jones – Sunland Leukaemia Foundation Village in Brisbane.

“Not only was the unit first class but the staff were totally committed to the welfare of the patients and their family members. It was amazing.

“I am also so thankful to my haematologist and the staff at the Greenslopes Hospital in Brisbane who were fantastic throughout the whole process. They cared not only for me, but also for Charles.”

Janette described Charles as her tower of strength throughout her illness.

“He has attended every medical appointment and procedure with me, and after each appointment we had long discussions which were really helpful.

“He was always there by my bed during the transplant and nursed me through the darker days of chemotherapy,” she said. “He now introduces me as his bionic lady as I now have a porta-cath on one side and a pacemaker on the other.”

In mid 2014 scans and a lung biopsy showed no detectable myeloma cells in Janette’s lungs and the amyloidosis protein had also responded very well to treatment, although her haematologist said it might take four years to disappear completely.

The amyloid protein in Janette’s lungs has created cysts which have reduced her lung gas exchange to 56%, although her total lung capacity has been unaffected.

“I have been very fortunate as no deterioration has occurred in nine months of testing and I now only have to see the lung specialist once a year.

“In early 2015 my haematologist gave me the great news that I was in remission from the myeloma as no cells could be detected.

“I am feeling absolutely great. Charles and I have just returned from a five-week holiday in the United Kingdom.

“The air travel tired me out more than I anticipated and I got a chest infection, but it was well worth it,” she said.

Janette and Charles have resumed their volunteer work with the
New hope for amyloidosis patients

Over the last few years research has provided a much better understanding of the group of different rare diseases referred to as amyloidosis in which an abnormal protein known as amyloid is produced.

A Phase I trial conducted by the National Amyloidosis Centre (NAC) in London and funded by GlaxoSmithKline has given great hope that a future treatment will be available to withdraw amyloid out of the body at diagnosis in all types of amyloidosis.

The findings were published in an article in the New England Journal of Medicine (July 2015) entitled, ‘Therapeutic Clearance of Amyloid by Antibodies to Serum Amyloid P Component’.

The open label Phase I trial involved 19 NAC patients with different types of systemic amyloidosis and varying organ damage. Patients with cardiac involvement were not included for safety reasons.

The trial focused on the non-fibrillar normal plasma protein, serum amyloid P (SAP) which is always present in the amyloid fibrils that cause the organ damage.

A drug referred to as CPHPC appears to reduce SAP from the plasma leaving some SAP in amyloid deposits. These deposits can be specifically targeted by therapeutic IgG anti-SAP antibodies. These antibodies bind to the residual SAP and trigger the rapid clearance of amyloid.

The trial participants were given fully humanised monoclonal IgG1 anteSAP antibody by infusion after first receiving CPHPC to deplete circulating SAP, with no serious adverse events.

The outcomes were very promising. The article reported that “at six weeks those who had received a sufficient dose of the antibody in relation to their amyloid load had decreased liver stiffness and improved liver function with substantial reduction of the hepatic amyloid load”.

The conclusion was that “treatment with CPHPC followed by an anti-SAP antibody, triggered clearance of amyloid deposits from the liver and some other tissues”.

In the next trial phase the NAC will include patients with significant renal and cardiac amyloidosis. This exciting trial has the potential to change the face of amyloidosis treatment in the future.

To read the full article go to http://bit.ly/1k3KHVI

Amyloid is an unusually stable material with a unique chemical structure, which is formed when certain proteins fold in a particular way. These diseases are systemic, meaning the amyloid proteins can deposit in any organ and tissue of the body disrupting organ function that may lead to death without treatment.

In about 20% of cases, the monoclonal plasma cells in the bone marrow behave in a cancerous fashion, in which case the underlying bone marrow disorder is multiple myeloma. A patient with myeloma may have or develop AL amyloidosis, but it is rare for a patient with AL amyloidosis (who does not have myeloma at presentation) to progress to full blown myeloma.

Janette during her stem cell transplant

State Emergency Service (SES): Charles as Acting Local Controller Bundaberg and Janette as a trainer in both her local group and the regional area.

Janette has also started singing again with the Woodgate choir and will return to fitness classes once her chest infection goes.

“I am very content with my life. I still have the 800km round trip each month to Brisbane for Intragram P and Zometa but this is a small price to pay.”

Continued from pg 2
David Hutt is Lead Nuclear Medicine Technologist at the National Amyloidosis Centre (NAC) in London. He presented at a Leukaemia Foundation education session in the New England region while he was in Australia visiting his family in August. His core responsibility is to oversee and provide a nuclear scintigraphy service for the department, which includes both SAP and DPD scans. These scans are performed on both clinical patients and patients participating in drug/research trials. David’s father, Don, has myeloma and regularly attends our Tamworth Support Group.

How did you get into amyloidosis treatment?
I first started working at the NAC in 2008 as a locum nuclear medicine technologist to assist in performing the SAP scans. Until then, I had never heard of the disease called amyloidosis or even knew what a SAP scan was.

Why does this type of blood cancer interest you?
AL amyloidosis (which an estimated 15% of myeloma patients in the United Kingdom go on to develop) accounts for a large proportion of our patients in the NAC. However, there are many different types of amyloidosis, and they are a group of diseases that most people haven’t heard of despite being very serious.

How many people with amyloidosis would your treatment centre treat in a year and how does this compare with 10 years ago?
In 2000, 286 patients were newly diagnosed with amyloidosis (all types), and in 2012, this number had increased to 900. In terms of scans performed at the NAC, in 2004 we performed a total of 819 SAP scans (no DPD scans). In 2014 we performed 1935 SAP scans plus 526 DPD scans.

What do you see as the most promising area of research for treating amyloidosis in your specialty area?
There are currently several pharmaceutical companies working on treatments for amyloidosis using different strategies. Most recently, the Phase I clinical trial results of a treatment designed to directly remove amyloid deposits from the body have just been published in the New England Journal of Medicine and are very promising. (See more information about this trial on page 3)

If Australians wanted to learn more about the work you are doing in your area of expertise, how could they access this information?
Our websites at www.ucl.ac.uk/amyloidosis/nac and www.amyloidosis.org.uk contain lots of useful information about amyloidosis (including patient information leaflets), the NAC, and ongoing research trials.

A SAP scan is a whole body scanning procedure, called SAP scintigraphy, that can show the distribution and amount of amyloid within the body’s organs without the need for biopsies.
A DPD scan is a type of scan, called DPD scintigraphy, to image the heart in patients with hypertensive heart disease, that potentially avoids the need for a cardiac biopsy.
Many patients with AL amyloidosis should limit their fluid intake

This advice is extremely important, but is often overlooked. Patients receiving chemotherapy for other conditions that are not AL amyloidosis are often told to drink plenty of fluid to avoid dehydration. But in AL amyloidosis, this well-meaning advice is inappropriate and can prove dangerous.

Many patients with AL amyloidosis have amyloid deposits in the kidneys and/or in the heart. These two problems mean that the body is unable to cope well with excess fluids. The combination of kidneys that are unable to sufficiently clear the fluid into the urine and a heart that is too stiff to pump efficiently may be problematic. Even if just one of these organs is affected by amyloidosis, excess fluids can make matters worse.

Patients with fluid overload may develop swelling in the legs (oedema) or difficulty breathing due to heart failure.

The ALchemy (AL amyloidosis chemotherapy) study is a large, ongoing, ‘real world’ study of chemotherapy in AL amyloidosis, started at the National Amyloidosis Centre in 2009. In this study, fluid overload has been clearly identified as the number one serious side effect experienced by patients with AL amyloidosis. It is far more common than infection, neuropathy or any other severe side effects reported. Fluid overload comprised nearly 40% of all the episodes of toxicity. Nearly one in three of the patients who were hospitalised because of toxicity had fluid overload.

Fluid excess can be avoided by careful attention to the 3 Ds:
- Diet
- Diuretics
- Daily weigh-ins.

Diet
Fluid intake should be steady and should usually not exceed 1.5 litres per day.

Salt intake should be limited. This includes attention not just to salt added to the food but also to food with high salt content such as chips, bacon, canned meats, sausages, canned soups and smoked fish. It can be very helpful to meet with a dietitian for precise and personalised dietary advice.

Diuretics
Doctors will often prescribe diuretics (fluid tablets) which increase the amount of urine produced and help the body to lose excess salt and water in the urine. This can help to reduce ankle swelling and breathlessness. Taking these drugs is not a substitute for avoidance of excessive dietary salt and water.

Patients should follow their doctors’ advice carefully regarding the dose of diuretic and the time of day when the tablet should be taken.

Daily weigh-ins
Some patients benefit from recording their weight regularly, usually daily or weekly. It is important that weight should be measured consistently using the same scales, at the same time of day. This is usually best done first thing in the morning after passing urine, just wearing underclothes.

Several litres of fluid can accumulate in the body without it being very noticeable. An increase in weight can be an early sign of fluid excess. Your doctor can then recommend appropriate measures such as increased diuretic dose, before the patient even feels unwell because of the fluid overload.

National Amyloidosis Centre, London
A STEP WORTH TAKING

Exercise should be viewed as an important additional treatment to the current medical interventions for amyloidosis. A specially developed individual exercise program has the ability to improve:

» injury management and prevention
» pain levels
» weight management and triglyceride levels (cholesterol)
» strength and flexibility
» circulation and heart function
» lung function
» immune function
» mood levels, self esteem, cognitive function
» cellular regeneration
» sleep cycles and lethargy
» bone density
» muscular and joint function, and mobility
» balance
» quality and enjoyment of life.

Remember, you should always talk to your doctor before beginning an exercise program.

Why bother?
The effects of AL amyloidosis on the body will depend upon which tissues and organs have been affected. Symptoms may be global like fatigue, or more localised to affected organs like neuropathy, shortness of breath, increased oedema and raised cholesterol levels. This will vary from patient to patient, and hence treatment options will also vary between individuals. Each treatment subsequently brings along its own set of side effects and these too are unique to each patient. Many of the effects occur at a cellular level but can produce physical changes to endurance, strength, fitness, balance, motor function and energy levels. An understanding of this will help develop realistic expectations and goals for exercise prescription. This will lead to so many improvements and benefits for quality of life and longevity. Remember it is better to move it than lose it.

How will an exercise program impact upon my daily life?
The best mantra or affirmation for exercise is 'little bits, but often!' Exercises are best performed at low levels with few repetitions, a couple of times a day. Regardless of your condition, research is now indicating that a daily routine of small amounts of frequent activity is a far better key to a long and healthy life.

The old adage of ‘move it or lose it’ has now been proven scientifically! Extended periods of inactivity (lying around or sitting, e.g. office job) were linked to higher levels of morbidity, regardless of the inclusion of a daily hour of high activity such as a one hour jog.

I am unable to perform physical activities for more than a few minutes at a time. Are there any exercises that I could do that would help me?
Incidental and low repetition exercises are the best way to reap benefits. Slowly, as you begin to see improvements, exercises can be modified, increased or changed to suit your needs. Isometric or static exercises (working a specific muscle without moving) are among the best ways to see improvement in function and mobility. These exercises can be performed even if you are in hospital or bed-ridden for a period of time.

How can I go about assessing what exercises I should be doing?
After consulting your doctor, you can visit a physiotherapist or clinical exercise physiologist. They are trained in therapeutic exercise prescription and can liaise with your doctor. They are trained to undertake a full medical history and physical assessment, and have been trained in movement analysis. They are also able to prescribe exercises that complement your particular history, presentation, goals and biomechanics. These exercises can be performed in your home or in a group setting.

Do you have any results from others who have started an exercise program that show the benefits?
Yes we do. A clinical exercise physiologist from our Fit to Thrive program said she has seen many examples of the way an exercise program has improved not only fitness but also quality of life while decreasing feelings of fatigue and depression.

“There was one lady aged in her 70s with myeloma who was so weak when we first met her that she couldn’t hang washing on the line. She needed a stem cell treatment to fight the cancer, but she wasn’t strong or big enough to undergo the procedure. On the Fit to Thrive program she improved out of sight. After six months she had the strength to receive the stem cells and has continued to grow stronger and healthier.”

Can I claim physiotherapy through Medicare?
Physiotherapy in private practice is generally covered by your private health insurance. There are some circumstances, however, which may entitle you to physiotherapy as a Medicare benefit and this should be discussed with your general practitioner.
Fit to Thrive, the Leukaemia Foundation’s successful exercise program has been modified to create an at-home resource for people affected by blood cancers all over Australia.

Our free *Fit to Thrive* DVD contains 28 different strength and flexibility exercises, as well as useful information like how to measure your exercise intensity and how to create your own at-home exercise program.

Exercise physiologists Molly Shevill and Sam Hall present the DVD, guiding patients through how to perform the exercises properly, as well as how they can modify the exercises depending on their fitness and strength levels.

The DVD was developed in partnership with Aspire Fitness and Rehabilitation, and builds on growing evidence of the benefits of exercise for people affected by a blood cancer.

“Patients have found a regular exercise program has strengthened not only their body but their mind, making them feel better equipped to tackle their cancer and their treatment regimen,” Director of Support Services Barbara Hartigan said.

*Fit to Thrive* may be suitable for anyone affected by amyloidosis, leukaemia, lymphoma, myeloma, and related blood disorders. You can order your free copy of the DVD by visiting leukaemiaqld.org.

You can order your free copy of the DVD by visiting leukaemiaqld.org.au/thrive or phone us on 1800 620 420.

The videos are also accessible on the Foundation’s Queensland YouTube channel at youtube.com/leukaemiaqld.

Always seek the advice of your doctor before starting any exercise program.
Embracing life despite a diagnosis

Maryanne Skarparis, one of our Support Services Coordinators, has helped many patients deal with their diagnosis, giving them tools to help them embrace life even in the face of adversity.

A blood cancer diagnosis is a life-changing event, where patients have to deal with treatment, side effects, a new routine, and health worries.

Fear, anxiety and anger are all normal reactions to being diagnosed with a blood cancer. Picking yourself up on those bad days and unhooking from the negativity weighing you down can be very difficult.

I suggest taking a few moments to think about the three Ps: purpose, passion and perspective. This exercise can be done by anyone whether they’ve just been diagnosed or are further down the track.

Purpose
What is your purpose in this life? You don’t have to change the world or be famous. It may be simply to be a good person; a good partner; a good friend or a good parent. Perhaps it’s to be a diligent worker or a positive role model. By concentrating on what your purpose is, you can use your gifts and talents to better the world around you.

Purpose gives our life direction, and presence allows us to make the most of the journey.

Passion
Thinking about what you’re passionate about is often harder than people think it will be. What is it that truly satisfies your soul and feeds your spirit? What drives you? What do you simply LOVE to do?

Good perspective
Life can deliver the unexpected and unwanted, but we can still acknowledge and embrace the good that we see in life. In the midst of life’s greatest trials, like a diagnosis, we can still be grateful for the beauty that exists in our day-to-day life.

What does this look like? It is different for everyone. It could be being grateful for the love of those around you. It could be admiring the blue skies of a beautiful day. It could even be enjoying and being grateful for the loyalty of a pet. Often it’s the simple things that can give us so much pleasure.

Mindfulness
Mindfulness is a bit of a buzzword at the moment, with people spruiking everything from mindful eating to mindfulness in the workplace – and even mindful sleeping! But mindfulness doesn’t need to be complicated. In fact, you can employ a few simple principles of mindfulness in your everyday life to help you find some peace in a stressful situation.

Mindfulness is essentially about bringing your complete attention to the present. Not thinking about what happened this morning or what you’re doing tomorrow but simply focusing on what’s happening right now.

Practising mindfulness can help you feel more calm and peaceful; become less reactive to unpleasant experiences; feel more connected to the people and the world around you; and feel more balanced, and less emotionally volatile.

Here are a few easy mindfulness exercises to help bring you some calm in this hectic world.

1. Mindful bites
At your next meal focus on the first two bites. Pay attention to the sensory experience; the taste, the smell, the texture of the food, even the sounds you make when you chew. It’s not necessarily about savouring the food, but paying attention to the sensory experience of eating the food.

2. One breath
Pay attention to what taking a breath feels like. Feel your diaphragm expand and your chest fill with air. Focus on what it feels like in your mid-section, your chest, and finally your throat. Then exhale and note how your stomach expands and your shoulders relax.

3. Give your brain a break
During down-time, it is easy to whip out our smart phones or turn on the TV. Instead, take a couple of minutes to just look out of a window. Watch the leaves on the trees; pay attention to sounds you can hear; think about how the breeze feels on your skin. This exercise can give your brain a much-needed break.

For more information about the support the Leukaemia Foundation offers, contact us on 1800 620 420.
Australia’s amyloidosis centres

There are three centres in Australia which specialise in amyloidosis diagnosis and treatment:

» Westmead Amyloidosis Clinic in Sydney was established in 2007 as a multidisciplinary service;

» Princess Alexandra Amyloidosis Centre in Brisbane was established in 2009 and is now a multidisciplinary centre;

» Victorian and Tasmanian Amyloidosis Service in Melbourne was established in September 2014.

Amyloidosis is not a reportable disease so it is not known how many patients are treated by specialists outside of these three centres.

New diagnoses and types of amyloidosis

Between 1 June 2014 and 30 May 2015 approximately four new cases of amyloidosis were referred to each service per month. There were 114 newly diagnosed patients seen in the three centres – 51 at Westmead Amyloidosis Clinic, 36 at Princess Alexandra Amyloidosis Centre and 27 at the Victorian and Tasmanian Amyloidosis Service.

The types of amyloidosis diagnosed included 47 cases of AL amyloidosis (41.2%), 17 cases of localised amyloidosis (14.9%), 14 cases undergoing investigation (12.3%), nine cases of hereditary amyloidosis (7.9%), five cases of genetic counselling (4.4%), three cases of AA amyloidosis (2.6%) and LECT2 amyloidosis (1.8%).

What services do the centres provide?

Referral patterns and models of care differ between each of the three centres although they work together to offer a national diagnostic, treatment and consultation service.

Westmead Amyloidosis Centre offers genetic screening while Princess Alexandra Amyloidosis Centre offers laser capture microdissection and tandem mass spectrometry to determine the types of amyloidosis. Each centre accesses cardiac MRI and are establishing DPD scintigraphy.

All centres provide advice to doctors outside the centres when requested.

All three services access the nonsteroidal anti-inflammatory drug diflunisal for transthyretin amyloidosis (TTR).

What’s in a name?

Different types of amyloidosis are named according to the proteins which form the amyloid fibrils. All have the initial ‘A’ denoting amyloidosis and letter(s) identifying the particular precursor protein which forms amyloid fibrils within the amyloid deposits. For example:

**AL AMYLOIDOSIS:** Light chains (fragments of monoclonal immunoglobulins [antibodies]) are the amyloid precursor protein. This is the most common form of amyloidosis and was formerly known as ‘primary amyloidosis’.

**AA AMYLOIDOSIS:** Serum amyloid A (SAA) protein is the amyloid precursor protein. Levels rise when there is prolonged inflammation. This was formerly known as ‘secondary amyloidosis’.

**ATTR AMYLOIDOSIS:** Transthyretin (TTR), a normal blood protein, present in everybody, is the amyloid precursor protein.

**Aβ2M amyloidosis:** Beta 2 Microglobulin (β2M) is the amyloid precursor protein.

**AFIB AMYLOIDOSIS:** Fibrinogen is the amyloid precursor protein.

A wide variety of other proteins can form amyloid in the various rare, hereditary types of amyloidosis.
Common misunderstandings about palliative care

- Palliative care is not end of life care. Palliative care is often provided at the end of life but it can also be provided at any time for a person with a life-threatening illness.
- Being referred to a Specialist Palliative Care Service does not mean that the doctors think a person will die soon. Many people are referred when they have troubling symptoms or when they are first diagnosed with a life-limiting illness. Being referred early enables a Specialist Palliative Care Team to support a person easily throughout their illness depending on their needs.
- Palliative care is not about stopping all treatment. People who receive palliative care also continue to receive other medical treatments such as chemotherapy, antibiotics, investigations and surgery. The care provided to a person is suited to their needs and wishes, and the particular circumstances of their illness.
- Receiving palliative care treatments and taking strong pain relief medications such as morphine does not speed up a person’s death. Palliative care treatments are given to relieve suffering and are managed carefully by the health care team.

Palliative care is actually not about dying; rather it is about living as well as possible with serious illness. The word palliative means to reduce the severity or intensity of an illness.

What is palliative care?
The aim of palliative care is to help people with a life-threatening illness and their family to live as well as possible within the limitations of their illness. The focus of palliative care is on improving the quality of a person’s life by helping them to manage any physical, emotional, social, cultural or spiritual problems they may have as a result of their illness or its treatment. Practical and emotional support is also provided for families and carers. Particular focus is placed on managing pain, nausea and other troubling symptoms. Often times, palliative care is provided at the end of a person’s life. Although it is very beneficial at this time, palliative care is not only for people who are dying. It can be provided and is beneficial at any time for a person with serious illness, even while they are getting other treatments.

Who provides palliative care?
Palliative care is a type of care and can be provided by a haematologist and the wider health care team or a general practitioner. Haematologists or general practitioners will often seek the advice and support of a Specialist Palliative Care Service depending on a person’s needs and the resources of their family.

Specialist Palliative Care Services are made up of a team of health care professionals who are very experienced in treating people with serious illness. This includes:
- doctors
- nurses
- allied health professionals (physiotherapists, occupational therapists, dietitians)
- social workers, counsellors or psychologists
- pastoral care workers
- volunteers.

Where can care be provided?
Where a person receives palliative care is dependent on their needs, their preference, how well they can function physically and how much support is available. Specialist Palliative Care Services can be provided in many places including in:
- the home
- hospital
- the out-patient department
- a palliative care unit or hospice
- an aged care facility.

A Specialist Palliative Care Service can support people who would like to die at home rather than in hospital. While supports can be put in place to help this to happen, where a person receives care at the end of their life is often dependent on their specific needs and how much help family and carers can provide. The Specialist Palliative Care Service will help guide patients and their families to make decisions about the best place care can be provided.

Can a person still receive other medical treatments if they receive palliative care?
Yes. Palliative care from the haematology team or a Specialist Palliative Care Service can be provided alongside treatment that aims to prolong life or cure an illness. People who see Specialist Palliative Care Service teams can also receive chemotherapy, antibiotics, investigations, surgery and other treatments as needed. The care provided is suited to the patient’s particular situation, needs and wishes, as well as their family and carer’s needs.

When is palliative care best provided?
Since palliative care is focused on managing troubling symptoms and promoting quality of life, it can be introduced at any time depending on the needs of the patient and their family. In many cases palliative care is introduced as people are nearing the end of their life as it is vital people are comfortable and receive dignified care at this time. Palliative care can also be introduced while people are receiving other treatments such as ongoing chemotherapy.
People with haematological cancers often experience fluctuating levels of health and can get sick very quickly. For this reason it is recommended that palliative care is introduced early for people with a haematological cancer. It is best if patients and their family have ample time to think about their wishes, know what resources are available and are supported to make treatment plans that are right for them.

**What is Advance Care Planning?**
A key goal of palliative care is to help patients and their family to understand and actively participate in decisions about their health care. Advance Care Planning is an important process where patients and those close to them can have open discussions with their health care team about their illness and the potential for them to become very unwell. Patients can talk about their wishes for future care in case they become too unwell to make decisions or speak for themselves; for example, if they were unconscious. As well as having conversations, patients may choose to make a legal record of their wishes using an Advanced Health Care Directive form or Statement of Choices Form.

Another important part of Advance Care Planning is giving someone you trust the legal right to make decisions about your health care if you are unable to do so. This is called appointing an Enduring Power of Attorney. It is important for all people to engage in Advance Care Planning, but more so if they have a serious illness such as cancer. If a person with a haematological cancer has any of these documents, it is important their haematologist is aware of them.

**Why should people do Advance Care Planning?**
For people with serious illnesses, having open conversations with family members and health care professionals about the way they wish to live and be cared for is important. These conversations help health professionals and families understand a person’s goals and preferences, and what an acceptable quality of life is to them. This will allow health care professionals and families make better decisions for a person who is unable to make decisions for themself.

**Where can I get more information about palliative care and Advance Care Planning?**
If you have any questions related to palliative care or want to know about the services that are available to you, talk to your haematologist or your general practitioner. They can refer you to or put you in contact with your nearest Specialist Palliative Care Service. You can also search the National Palliative Care Service Directory to find a service in your area (www.palliativecare.org.au). On this website you will find links to more information and resources regarding palliative care. If you would like to complete an Advanced Health Care Directive, Statement of Choices form, or nominate an Enduring Power of Attorney, speak with your general practitioner or haematologist. Alternatively you can find more information at http://www.publicguardian.qld.gov.au/adult-guardian/health-care-decisions/advance-health-directive

Elise Button - PhD Candidate, Queensland University of Technology A/Nurse Researcher, Cancer Care Services, Royal Brisbane & Women’s Hospital

Allison Lovell - Clinical Nurse Consultant, Palliative Care Service, Royal Brisbane and Women’s Hospital
Amyloidosis Support Groups

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<tr>
<th>EVENT</th>
<th>DATE</th>
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<tr>
<td><strong>Queensland Amyloidosis luncheon.</strong></td>
<td>Tuesday 24 November</td>
<td>11.30am</td>
<td>ESA Village – 41 Peter Doherty Street, Dutton Park, Queensland</td>
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<td>Assoc Prof Nicole Isbel, will speak about Amyloidosis and the kidney</td>
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<td><strong>South Australian Amyloidosis Support Group</strong></td>
<td>Monday 7 December</td>
<td>10am</td>
<td>The Bridgestone Australia Leukaemia Foundation Village – 39 Folland Ave, Northfield, South Australia</td>
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<td><strong>Western Australia Amyloidosis Support Network</strong></td>
<td>2nd Tuesday of the month (every two months)</td>
<td>12 - 1.30pm</td>
<td>Matilda Bay Tearooms, 5 Hackett Drive, Crawley, Western Australia</td>
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<td><strong>New South Wales Amyloidosis Education and Support meetings</strong></td>
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<td>Western Sydney. Contact Lauren Walker: <a href="mailto:lwalker@leukaemia.org.au">lwalker@leukaemia.org.au</a></td>
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Thank you for lighting the night

Thank you to everyone who joined us at Light the Night in October. We hope it was a special time for you as you joined others affected by blood cancers, remembered loved ones lost and supported the work of the Leukaemia Foundation. Seeing so many lanterns raised across Australia on a single night was truly inspiring. The money you raised during Light the Night is still coming in and will ensure we can continue to provide Australian families with free emotional and practical support on their blood cancer journey, and fund vital research to find better treatments for patients.

Support Services team

QUEENSLAND AMYLOIDOISIS COORDINATOR
» Sheila Deuchars

VICTORIA/TASMANIA BLOOD CANCER SUPPORT MANAGER
» Tennille Lewin

NEW SOUTH WALES/ACT BLOOD CANCER SUPPORT MANAGER
» Snezana Djordjevic

SOUTH AUSTRALIA/NORTHERN TERRITORY BLOOD CANCER SUPPORT MANAGER
» Peter Diamond

WESTERN AUSTRALIA BLOOD CANCER SUPPORT MANAGER
» Tanya Harris

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10-13 March 2016
worldsgreatestshave.com

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 1800 620 420.