Welcome

Happy New Year to everyone, and welcome to the first issue of AL amyloidosis Matters of 2017.

This year, the regular Medical Matters feature will be replaced with articles on living well with AL amyloidosis - this will allow inclusion and consideration of different topics, which we hope you will enjoy and benefit from.

In this issue we focus on coping with anxiety and depression, and exercising with AL amyloidosis. Throughout 2017, we will also be featuring extracts from a book written by patient Richard Thompson in our special feature section.

I hope you enjoy this issue.

Jude Leitch
Editor

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Watch 2016 Infoday videos

If you didn’t manage to get to our annual Patient and Family Infoday last year, or would like to refresh your memory about what was discussed, videos from the day are now available to view at: www.youtube.com/user/MyelomaUK/playlists

The videos include Dr Ashu Wechalekar talking about treatment strategies for AL amyloidosis and Dr Helen Lachman (pictured) giving an update on the management of complications and side-effects of treatment.

The 2017 AL amyloidosis Infoday will be held on Friday 17 November 2017 at Friends House, Euston Road, London. For further information or to book please contact Zara on 0131 557 3332 or visit www.myeloma.org.uk/infodays

Fatigue – self help

- Maintain a well balanced diet
- Eat regularly
- Take gentle exercise
- Use the time when you have energy and rest when you don’t
- Tell friends and family and ask for help
significant life expectancy gains in AL amyloidosis

A population based study of 1,430 AL amyloidosis patients diagnosed between 1995 and 2013 in Sweden has shown that life expectancy has markedly improved over the last 20 years. Using the nationwide Swedish Patient Registry, the study found that from 1995 to 1999, 43% of patients were alive one year following diagnosis. Over the years, that number steadily increased and, between 2010 and 2013, the 1-year survival rate was 70%. Similar improvements were seen in 2-year survival rates which jumped from 30% for 1995 – 1999 to 61% for 2010 – 2013. “In the past, outcomes in AL amyloidosis were very poor,” the lead researcher stated. “These survival gains are likely due to newer, highly-effective chemotherapies, improved supportive care, and possibly earlier diagnosis, all reasons to hope for continued improved outcomes in this disease.”

new heart imaging test may help guide transplant decisions

Researchers have reported in the European Heart Journal - Cardiovascular Imaging that a new heart imaging test can determine whether cardiac AL amyloidosis patients are expected to benefit from high-dose therapy and stem cell transplantation (HDT-SCT). Following HDT-SCT, cardiac patients are currently closely monitored using blood biomarkers and echocardiograms to assess improvements in their heart function. The research team evaluated the echocardiograms of over 60 cardiac AL amyloidosis patients, following HDT-SCT, to determine if applying a new measure, called a longitudinal strain, would be predictive of survival at one year after HDT-SCT. They found that it not only predicted survival, but outperformed other conventionally measured biomarkers found in the blood. “Having these additional data will allow us to make more informed decisions about which treatments would be most beneficial for our patients” the lead study author stated.

new drug in the pipeline for AL amyloidosis

A company has been set up in the US to advance the development of a new ‘anti-amyloid’ monoclonal antibody drug for AL amyloidosis. The drug, called CAEL-101, has demonstrated its ability to specifically bind to amyloid deposits and promote their elimination from the body in patients in an ongoing Phase I trial. Early and sustained organ improvement in patients with cardiac, renal, gastrointestinal, skin and soft tissue involvement have also been demonstrated following both a single infusion of CAEL-101 and once-weekly infusions for four weeks. Interim data show CAEL-101 promotes amyloid elimination in 67% of patients. Full results are expected in the first half of 2017 with a view to initiating a Phase 2 trial in early 2018.
Meeting Amy - a cautionary tale (PART ONE)

BY RICHARD THOMPSON

Richard Thompson noticed swelling in his left ankle on Boxing Day 2014. Thinking it related to his prostate troubles, he thought not much of it and underwent a prostate operation in April 2015. In every issue of AL amyloidosis Matters in 2017, we will publish extracts from his book Meeting Amy - a cautionary tale about what followed.

April 2015

Naively, I had thought that once the prostate thing had been sorted out, my swollen ankles and legs would go down. No such luck. In fact, the swelling, or oedema to give it its proper name, was getting worse. Why?

When I’d first noticed the swelling in my left ankle and gone for blood tests, my GP hadn’t seemed too concerned. That is, except, for the albumin levels in my blood which appeared to have been dropping consistently over the previous three years.

A pre-op ultrasound and CT scan showed a blur around the right kidney suggesting hydronephrosis - swelling due to urine not draining properly to the bladder - which is why getting the op sooner rather than later made sense.

Then he does the most extraordinary thing. He writes one word on a piece of paper in front of him, turns it round and shows me: Amyloidosis.

“Amy…loid…osis…? I mumble. What’s that?”

He shifts in his seat, contemplates a moment, looks me in the eye with a kindly stare and says, “It’s a bone marrow condition.”

Silence.

“But what does that mean?”

“At this stage it is difficult to say as you need to attend the National Amyloidosis Centre for further tests.”

May 2015

My renal consultant looks relaxed. “Take a seat,” he says amiably. “How are you?”

“I’m OK,” I nod feebly, waiting for him to say “It’s all been a huge success... your legs are going to get better and you can look forward to a long, happy, healthy life.”

But he doesn’t say that. Instead he waits for me to ask him questions. Now, I’ve never been a shrinking violet, but there’s something about the clinical distance between Big Doctor and Little Patient in situations like these that addle one’s brain and lowers your self-confidence.

I wandered around like a headless chicken for a while trying to figure out how a successful prostate op had somehow morphed into a death sentence.

6 June 2015

I get the letter from the National Amyloidosis Centre with the results. “Dr Thompson is a 69 year old gentleman with probable systemic AL amyloidosis and kappa light chain dyscrasia. He has dominant renal involvement with nephrotic syndrome though with preserved renal function...”

Blimey, I thought. Is this really happening?

I don’t really remember what happened after that. The mistake I made was to Google Amyloidosis and read:

Amyloidosis is a group of rare, but serious conditions caused by deposits of abnormal protein, called amyloid, in tissues and organs throughout the body...

Without treatment to address the underlying cause, the amyloid deposits can eventually lead to organ failure and death - sometimes within only a year or two.

I wandered around like a headless chicken for a while trying to figure out how a successful prostate op had somehow morphed into a death sentence. All good dramatic stuff, but hopeless if you start feeling sorry for yourself.

Read the second instalment from Richard’s book in the next issue of AL amyloidosis Matters.
Coping with anxiety and depression

AL amyloidosis patients and their carers can both be affected by anxiety and depression. This can be due to any number of reasons including the unpredictable nature of AL amyloidosis, complex treatment decisions, complications of the AL amyloidosis or just the feeling that life has turned into an endless series of doctors’ appointments and treatment schedules.

What are anxiety and depression?

Anxiety is a feeling of unease, worry or fear. It can be mild or more serious. Some people find anxiety difficult to cope with, which can often have an effect on their daily lives.

Depression is an ongoing feeling of hopelessness or despair which can cause a loss of interest in most activities, including those you previously enjoyed. Other symptoms of depression include difficulty sleeping, trembling and tearfulness.

At times I have felt very down and depressed and always wondered if others felt like this too or if it was just me?

Emotional wellbeing is as important as physical health. The following tips can help both patients and carers coping with feelings of anxiety or depression.

Inform yourself and talk to others

AL amyloidosis is a complex disease to understand - learning more about it and the different treatment options available may make you feel more in control and help to relieve associated anxiety. It is essential to use reputable sources of information. Myeloma UK provides a range of information covering all aspects of AL amyloidosis. For a full publication list visit www.myeloma.org.uk/publications

It is important to be frank about how you are feeling. Depression and anxiety are common side-effects to long-term illnesses and can be effectively managed by your doctors and nurses. Your doctor may refer you to a counsellor or psychologist to talk through your feelings. You can also talk to one of our Information Specialists by calling the Myeloma UK Infoline on 0800 980 3332.

You may find it useful to visit an online forum or attend a support group with other patients and their carers. Speaking with people who understand what you are going through can be very helpful in relieving feelings of isolation and anxiety.

Don’t be afraid to talk to someone - this can be a counsellor rather than a friend or family member, sometimes it’s easier to talk to someone outside of your immediate family and friends.

Work out

Even gentle exercise such as gardening or a short walk around

The block releases endorphins that may ease feelings of depression or anxiety.

Exercise as often as you can. I try and do a bit every day, it makes me feel and sleep better.

Distract yourself

Taking up new hobbies or rediscovering old ones can be a huge help in regaining self-worth and purpose. It can also help to have something enjoyable to look forward to, whether it is taking a trip somewhere new or simply having tea and cake with an old friend.

Rediscover old passions – I often play my records very loudly which makes me very happy!

Summary

Many AL amyloidosis patients and their carers experience depression and anxiety. It is important to keep in touch with how you are feeling and to take action if you find you are feeling down more often than not.

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Exercising with AL amyloidosis

BY ALICE BARON
Patient Information Officer, Myeloma UK

Exercise is part of many people’s daily life, whether as a hobby, a pastime with family and friends or at a competitive level. Every patient is different, but exercise in some form is encouraged for everyone. Exercise can reduce fatigue, boost energy levels, build muscle strength and help to reduce feelings of anxiety and depression. Regardless of your exercise history or fitness level, you can find an exercise routine to suit you.

What types of exercises are safe to do?
Aerobic exercises like walking, swimming, cycling or using a cross trainer are safe for AL amyloidosis patients. If you have not exercised much before, start off gently and build up your exercise routine over time. Try starting with 10 minute sessions and build up by 10 minutes at a time over a number of weeks, with the aim of exercising for 40 mins three times a week.

It is important to listen to your body and exercise within your limits to avoid exhaustion. Remember that you may be limited in what you can do depending on your individual organ involvement. If you have not exercised much in the past, speak to your doctor before you begin exercising. They may refer you to a physiotherapist who can tailor an exercise programme to your needs and ability.

The key point to remember when exercising is not to overdo it and only do as much as you feel capable of doing. Stop exercising and consult your doctor if you experience any of the following symptoms:
• Shortness of breath
• Dizziness or nausea
• A sharp pain in a specific area, particularly the chest
• Becoming increasingly fatigued or weak

Remember to include a warm up at the start and cool down at the end of your sessions to help you avoid muscle strains.

What types of exercises should I avoid?
AL amyloidosis patients sometimes have weakened bones so contact sports and more adventurous sports should be avoided in case of injury.

If you have a weakened immune system, such as after high-dose therapy and stem cell transplantation, minimise the risk of infection by avoiding busy gyms, public swimming pools and saunas.

Practical tips for exercising with AL amyloidosis
• Wear comfortable and suitable clothing
• Have a clear and clutter-free workout area
• Build up gradually
• Pace yourself and listen to your body

Summary
Gentle exercise is encouraged for patients to increase general wellbeing and reduce some symptoms such as fatigue. You should gradually build up your fitness level by doing aerobic exercises like walking, cycling or swimming, taking care not overexert yourself. Speak to your doctor if you would like to be referred to a physiotherapist for tailored advice.

Cardiac amyloidosis patients in particular should take care not to overexert themselves when exercising:
• You should stay below 80% of your maximum heart rate (which is worked out using your height, weight and age)
• You can wear a heart rate monitor while you exercise to help you exercise at a suitable intensity. These are available in a wrist watch form, with or without a chest strap
• If you have not exercised much before, your heart rate will increase rapidly and to a higher level than if you have been regularly exercising for some time, so remember to start off gently and build up your routine gradually
• If you are on beta blockers your heart rate won’t go very high even when you exercise so be aware of any symptoms such as shortness of breath, dizziness or chest pain and stop if any of these occur
Susan Hunt lives in Birmingham with her 15 year old son, Joshua, and works for West Midlands Police. Here she shares her experience of having lymphoma and AL amyloidosis.

July 2012: a summer I will never forget. I started to feel unwell with tiredness and fatigue and noticed my neck had swollen. I visited my local walk-in medical centre - the nurse put it down to swollen glands, and said to come back if it was still the same in a couple of weeks. Two weeks passed and my neck was still swollen, so I went back. The nurse took some blood tests and I began what would be a long journey.

I received a call two days after the blood tests asking me to attend Heartlands Hospital; I knew something wasn’t right, so I took my sister Karen (’my rock’) with me. The consultant told me straight away that I had Waldenstrom’s Macroglobulinemia Lymphoma, a rare type of non-Hodgkin lymphoma. In September 2012 I had a bone marrow biopsy and the results showed that I also had AL amyloidosis; also a rare condition. I remember thinking “I don’t do things by half”.

It was soon after this that I started to feel very breathless, and everything became an effort. Tests showed that I had amyloid deposits in my spleen, kidneys, lungs, and heart. The cardiac involvement was what I worried about the most.

I am a single parent and Joshua was 11 years old at the time of my diagnosis. I decided to tell him the truth on a need to know basis, so that he was aware of why I may not be feeling well. I also advised his school in case there were any issues.

Everything became a blur after that; my first appointment at the National Amyloidosis Centre (NAC) was over two days in November 2012. I attended with Karen - an adventure, but not one we wanted to be a part of.

On arrival at the NAC a lovely nurse called me for the first of many tests, an ECG and echocardiogram. I remember my first words to her, "I’m going to die aren’t I?"; “Not at all” was her reply. She explained that many of the patients had been attending the NAC for many years, and it was not always doom and gloom. Was I relieved? Not quite.

On the second day, after many more tests, we saw a consultant who explained everything to me about lambda, and kappa levels, something every amyloidosis patient soon becomes familiar with. He said I had a lot of fluid gathering around my lungs, which would account for my breathlessness and fatigue, and it would need to be treated. Between November 2012 and October 2013 I had several procedures aimed at decreasing the levels of fluid on my lungs, including talc insertions (filling the pleural cavity with a talc-like substance), insertion of a chest drain and keyhole surgery.

I was also advised to have daily injections of Clexane® to prevent my blood from clotting. Joshua was so keen to get involved that he was taught how to administer these, and gave me the injections into my stomach every day. I was so proud of him handling this in such a grown up manner. At a time that his world should have come crashing down, he was so positive and supportive.

In December 2012 I began treatment for my lymphoma with R-CVP (rituximab, cyclophosphamide, vincristine, prednisolone). Unfortunately I only partially responded to four cycles of this. In April 2013 I started a new course of treatment called FCR (fludarabine, cyclophosphamide, rituximab), and consideration would be given to a high-dose therapy and stem cell transplant (HDT-SCT) from a donor if a good response was achieved. After completing three cycles of FCR it was difficult...
to decide whether there was a good response or not. There was evidence of a partial response due to a reduction in my light chain levels. However, the swollen glands in the neck and fluid on my lungs persisted.

My consultant at this point decided to biopsy the lumps on my neck. It was found that the lumps were in fact amyloid deposits rather than enlarged lymph nodes relating to my lymphoma. This complicated the clinical picture so treatment was stopped and further direction was sought from the NAC.

It was decided to continue with HDT-SCT but using my own stem cells rather than a donor’s was recommended as this carried less risk.

In May 2014, the time for HDT-SCT arrived. I was admitted to hospital in a room that would become my home for about a month. I received the high-dose therapy which made me feel so sick. This was the first time I felt really ill. The isolation was awful; people only came into the room when necessary. I had a TV but you can only watch so much Jeremy Kyle. It was awful only seeing my son for an hour each day.

I had managed to keep my hair until now but one morning whilst in isolation tufts of it started to come out. The nurse suggested shaving it because it would all come out at some point. I don’t think I was too upset about this to be honest, I took it better than I thought. At first I was aware of my hair loss and had a wig. However, I only wore it once and decided to ‘go bald’. In a way I was proud to have no hair. I didn’t want them to feel awkward.

I am currently in remission from my lymphoma, and indications are that amyloid production has also reduced. I have started to suffer from breathlessness again, and recent scans show that fluid is around my right lung again, but no treatment is needed just yet.

I returned to work as soon as I could as I was keen to get things ‘back to normal’. I visited my colleagues prior to starting back so they could get used to seeing me with no hair. I didn’t want them to feel awkward.

I look at life in a different way now. Nothing bothers me, and I rarely stress about anything. Life is far too short and should be lived to the full. None of us know what is around the corner. I feel a strange sense of calm in my life these days, when I always used to be stressed. My son is my world and so are my family, all of them are so very special to me and have helped me more than they can imagine. Where would I have been without any one of them and ‘my rock’, Karen?

People ask me how I cope. I tell them it’s all about getting up in the mornings, doing the things you usually do. It would be easy to close the curtains, shut yourself off from the world, and condemn yourself to a death sentence. That was not for me. I soon learned to have a positive mind or at least I made sure I always looked on the bright side; I was alive. I had an 11 year old son who needed me. There was no way I was going anywhere if I had my way about it.

Faith, hope, positivity and cure - onwards and upwards!
YOUR SUPPORT REALLY MATTERS

“Myeloma UK does great work in supporting AL amyloidosis patients and promoting awareness of this incurable disease.”

Pat Pinchin, PATIENT, POOLE

Everything we achieve for AL amyloidosis patients is thanks to people like you who donate and fundraise to support our work.

To donate or set up a direct debit today visit www.myeloma.org.uk/donate, or to discuss leaving a legacy in your will contact Claire Durham on 0131 557 3332 or email claire.durham@myeloma.org.uk

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