

London Asbestos Support Awareness Group (LASAG)

LASAG NEWSLETTER

FOR ANYONE AFFECTED BY MESOTHELIOMA OR OTHER ASBESTOS RELATED DISEASES

LASAG NEWS

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London
Asbestos Support
Awareness Group

Registered Charity No. 1174543

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www.LASAG.org.uk



David Atkins'

Motorcycle Adventures

My adventure began last March 2018 – I call it an adventure because boy has it been a roller coaster of a ride. When I was diagnosed with Mesothelioma last March it was a real shock as at the age of 74 I have been lucky enough never to have any serious illnesses. So having people fussing over me is not for me.

Before this problem arose, I was planning to go on a motorbike tour in India with my daughter and son in-law. so when I phoned my daughter to let her know about the diagnosis – I said bad news I have cancer – good news they are getting me ready to go to India!. This was my plan to get myself fit for India and the cancer was just a hurdle to get over.

I had my operation in Guys Hospital in September and my daughter wanted me to focus on getting well so designed a chart on the wall – called footsteps to India – i got a step closer to India every time i achieved goal in hospital – like walking the length of the ward – climbing the stairs. Many of my friends told me I was mad at my age and with my illness.... but nothing was going to stop me.

December came and I flew to Dehli with a group of bikers – 14 of us in total – we spent 3 days sightseeing and we saw the magnificent Taj Mahal. Then the excitement began – we flew to Siliguri (North East India) and took tut tuts to the hotel where our motorcycle where lined up ready and waiting. The first day had us riding up and up – up winding twisting roads to Darjeeling – this is a place I had always wanted to go to – I had watched many documentaries on the Darjeeling steam railway - I had made it and never thought I would – it was such an emotional feeling. Then i was surprised when they said we were going to ride on the steam train – a dream come true.

We rode for 10 days though the Himalayas rough roads, smooth roads and even up to 10,000 feet . I had to keep stopping and thinking this is real and I am really in India. So many of stories to tell including getting lost at the top of a mountain, riding in 1940s land rovers, eating lots of different curries. It was a trip of a lifetime.

I returned home after an amazing trip and then a few weeks later my son in law said – 'Dave do you fancy a motorcycle tour in Columbia?'. It's a place I had never even thought about going to but I thought why not?

Unfortunately in February this year, after a scan I got the news that the cancer was growing and I would need chemo, not the news that I wanted but I thought it is what it is - as long as it does not interfere with my trip. I had noticed that riding in India I had lost my upper body strength so I got a personal trainer to help me twice a week to build up my stamina. I also emailed my consultant and asked them to plan my chemo around my trip to Columbia and my other two holidays I had planned in my 1930's vintage car.

In May, I had my chemo session and then a week later i was flying to Bogata. This time there were 8 of us on tour. We rode through a desert – boy was it hot and then smooth winding roads and then a day of off roading. We had to get the bikes onto a canoe and cross a fast river, then ten minutes later, over a very narrow bridge then riding through a river. The trip was amazing with a visit to a coffee plantation, up a volcano to feed the humming birds. I was tired every night but i was determined to ride every day. – what great memories we made.

I have had a boring September – with a few unplanned stays in hospital but we are talking about riding skidoos in Finland in February – so watch this space.

David Atkins Age 75 and a bit!!

Since this was written, David has sadly passed away. He was an inspiration to everyone he met and as you can see from the article, never let his illness get in the way of anything he wanted to achieve. His family ensured he had the send off he deserved and would have loved, arriving in style at the church in a motorbike and sidecar with a family entourage of vintage cars awaited by a church full of friends and family to celebrate the life of a truly remarkable man.



LASAG NEWS



Congratulations to Marika Townsend, her husband Simon and friends for completing their **Zipwire challenge** and raising over £2000 for LASAG. Before the challenge, Marika said "Last year we walked the entire length of the Pigrims Way, but we have upped the stakes this year to raise funds for LASAG by taking to the air on a zip wire 500 feet up across the Penrhyn Quarry in North Wales. I am terrified of heights so am relying on Simon to push me off, hopefully with my harness on!! In addition we are doing this on Friday 13th September, Lucky for some!" You can still show your support by visiting www.justgiving.com/fundraising/flyinghigh2019

Please join us in welcoming **Denise Hodges** to the team. Denise joins LASAG after 7 years as a Lung Cancer CNS at Medway, and brings a wealth of experience in in supporting sufferers of asbestos related diseases.



In October, Alison attended the **Lower Hardres and Nackington Gardening Society** show to collect the £600 raised from the sale of plants. Thanks to the late Terry Talbot who nominated LASAG as the society's chosen charity of the year.



Last year, we had the **Rock Choir** perform at our Christmas Support Group in Canterbury, and we were delighted that they agreed to perform again this year with some great renditions of a variety of songs including Mandy, We Will Rock You, I'm Still Standing, and a Christmas mash-up of The First Noel and Silent Night (which you can watch on our Facebook page). Many thanks to Alison, who is a member of the Rock Choir for organising the event, and thank you to everyone who wore their festive jumpers. Merry Christmas!

Christmas In Canterbury



We are delighted to announce that LASAG will be launching a **new Support Group** which will be hosted at **Maggies at The Royal Marsden** from February 2020. Currently The Royal Marsden sees over 100 new mesothelioma patients per year, and we are pleased to be able to support more people in the surrounding areas.

Jim Harris, a member of the Canterbury Support Group has kindly agreed to let us use his watercolour painting of a cornflower for our new design of Thank You cards.





ASK the Experts

In each issue, we have an expert panel answer your questions - anything covering nutrition, treatment, exercise, travel insurance, sleep, research, trials, carer advice, diagnosis, support, benefits, compensation... If you have a question you would like us to answer, please send it to asktheexperts@lasag.org.uk and we will get back to you as well as include the response in the next issue.

Q. What is Industrial Injuries Disablement Benefit?

A. Industrial Injuries Disablement Benefit is for people whose illness was caused by their work. This includes people who have cancer because they were exposed to asbestos. You cannot claim it if you were exposed to asbestos outside of work or while self-employed. This benefit is paid regularly. The amount paid depends on how much your illness affects you. There are also lump sum payments you may be entitled to. These are:

- The Pneumoconiosis etc. (Workers' Compensation) Act 1979 – for people who have been awarded Industrial Injuries Disablement Benefit.
- Diffuse mesothelioma payments (2008 scheme) – for people not entitled to Industrial Injuries Disablement Benefit.
- Diffuse Mesothelioma Payment Scheme (DMPS) – for people exposed to asbestos at work, but who can't trace their employer, or employer's liability insurer.

If you came into contact with asbestos while in the armed forces you can claim with the Veterans Advisory & Pensions Committee.

Q. Why do I feel so tired and have a lack of energy?

A. Feeling tired and lacking in energy are common symptoms in all cancers. Sometimes fatigue is related to the effort of breathing. Cancer-related fatigue sometimes improves with attention to nutrition as many patients experience loss of appetite. In some cases a trial of steroids is appropriate. Learning to slow down and pace activities and making life easier by the use of

aids and appliances in the home or practical adjustments such as bringing a bed downstairs may help to conserve some energy.

Q. How can I reduce constipation?

A. Medication, poor food and fluid intake and lack of physical activity can result in constipation. Preventive measures such as attempting to drink extra fluids may help but when medication such as strong painkillers are being taken it is almost inevitable that constipation will occur and therefore essential to avoid this by the regular use of laxatives. A large variety of preparations are available and doctors and nurses can advise on the most appropriate medication.

Your Panel of Experts include:

- **Professors**
- **Surgeons**
- **Oncologists**
- **Respiratory Physicians**
- **Cancer Nurses**
- **Pathologists**
- **Solicitors**
- **Benefits Advisors**

Approximately 300 nursing delegates met for the 20th anniversary of the Lung Cancer Forum for Nursing (now rebranded as Lung Cancer Nursing UK).

*Our newest member of the team, **Denise Hodges** attended the conference where quite a few innovative projects and plans for the future were discussed. Denise has provided an update below:*

Detecting germline BAP1 mutations

One interesting session discussed germline testing for predisposition to mesothelioma, which looks at whether mesothelioma is sporadic or an inherited cancer risk. The session looked at genetic mutations, i.e. cancer causing genes which are hereditary, versus sporadic mutations, which are developed during a person's lifetime. The BAP1 gene was first identified in 1998 and is related to mesothelioma. This gene helps to regulate cell growth, division and cell death – repairing damaged DNA. If one mutated copy of the BAP1 gene is inherited it affects every cell. This impaired function can give rise to cancer syndrome – including mesothelioma or tumour predisposition syndrome. It is not very widely known but testing for BAP1 is funded centrally. Around 5 percent of mesothelioma patients have BAP1 in their tumour. Often these are younger patients. Unfortunately there are not really any effective screening modalities for mesothelioma and there are limited treatment options, but this needs to be challenged. This germline testing could be an opportunity for early detection or prevention in the future.

LASAG collaboration with Mesothelioma UK on regional data audit

Louise Gilham, the UK Mesothelioma Lead Nurse for Kent and Medway undertook a local and regional audit of clinical classification coding including a review of the asbestos exposure by occupation. As well as Lung CNSs providing this data, LASAG collaborated with Louise in order to ensure the data was accurate. Unfortunately Louise discovered inaccuracies in the National Cancer Data Set which meant that only fifty six per cent of patients information was recorded accurately. This was due to incorrect codes being used for mesothelioma patients. All trust multidisciplinary team coordinators were asked to review the codes being used and the data was amended. The National Cancer Registration and Analysis Service contacted Louise to discuss the findings. The codes are now entered in “real time” to ensure correct coding in the future.

Armed Forces Project

Around one hundred veterans a year are diagnosed with mesothelioma. The Armed Forces Project, which specifically looks at veterans' issues and includes a package of support and care tailored to meet the needs of the armed forces and veterans. A Mesothelioma UK CNS will attend various armed forces events such as breakfast clubs to offer advice and support.

MORE Study (Mesothelioma Outcomes Research and Experience)

Between January and August 2019, a selection of patients were invited to describe their experience of investigations, treatment and care. 31 patients across Kent were recruited through clinics, support groups, and over the telephone. The survey will inform health care providers about what is being done well, what could be improved and where there are variations in treatment and care.

Clinical Trial App

A clinical trial app will be released early in the new year. The app will be easy to use, and provide up-to-date trial information, making it easier for patients to discuss options with their oncologists when they meet.

Care Passport

The trial of a “care passport” for mesothelioma patients is currently underway. The idea is that patients take the passport to all their appointments where it can be updated with their planned care and treatment, as discussed and agreed with the health care professionals. Patients can easily keep track and make sense of what is happening. There is space in the passport for useful contacts, medical data and their care plan.



WELL-BEING

Advice for Carers

Getting Extra Support

If you are a carer for someone with mesothelioma, you may help with their everyday needs, such as:

- cooking meals
- helping around the house
- helping them with washing and bathing.

While you may be very happy to do this, there may come a time when you might need some extra support. Let your Support Worker, GP or nurse know if you do. There are different health and social care professionals who can help.

Looking after yourself

Caring for someone you love can be physically and emotionally difficult. If you have been looking after them for some time, you may start to feel tired. It is important to look after yourself too. Getting the help you need can help your relationship with the person you are caring for. If it would help, it may be possible to get a short-term payment from a compensation claim, to help pay for some care.

Talking about cancer

As a relative or friend, you may find it hard to talk about the disease or share your feelings. You might think it is best to pretend everything is fine and carry on as normal. You might not want to worry the person with mesothelioma, or you might feel you are letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person you are caring for feeling isolated. You can help by listening carefully to what they want to say. It may be best not to rush into talking about the disease. Usually, it is enough just to listen and let the person talk when they are ready.

Inquest after someone dies

There may come a time when treatments are no longer working for your relative or friend and you have to prepare for their death. When someone

dies of mesothelioma, there will need to be an inquest. An inquest is needed because mesothelioma is an occupational disease. When a person with mesothelioma dies, the doctor who signs the death certificate must inform the coroner who will carry out the inquest. The need for an inquest will not usually mean any delay before your relative or friend's funeral can take place as the coroner will issue a temporary death certificate in most cases. This is because a full certificate cannot be issued until after the inquest is completed, which may take a few months.

The coroner will decide if a post mortem is needed to find out whether the death was due to mesothelioma or another cause. In many situations, a post mortem is not needed if there is enough medical evidence to confirm the person had mesothelioma. This evidence may come from samples (biopsies) that were taken when the person was first diagnosed with mesothelioma.

It can be distressing when you have to deal with these issues as well as the possible death of your relative or friend. You may wish to get support from your Support Worker. LASAG has set up friendship groups in Canterbury and Sittingbourne for bereaved family and friends to get together monthly.

Financial Help

Relatives of people who have died from mesothelioma may be able to claim compensation for their relative's pain and suffering, and some financial losses suffered as a result of the illness. This may not be possible if the person who died from mesothelioma had already made a claim which had been settled. It is important to get legal advice from a specialist solicitor on how to make a claim. A LASAG Support Worker can put you in touch with a solicitor if you haven't appointed one.

Fundraising

Everything we do depends on the generous donations of our supporters. 100% of the money we spend each year comes from the people, companies and trusts who decide to support us. Whether it is putting a few pounds in the donation tins, donations in lieu of flowers, making a corporate donation or hosting an event, we are extremely grateful for your support.

In Memory Giving

This year, LASAG has seen an increase in donations honouring the memory of loved ones who have passed away. Giving in memory of someone is a very special way to commemorate their life, and we are so grateful for the donations that have come in. Friends and relatives often wish to mark an occasion as a lasting tribute to someone they wish to remember. To meet this wish you can establish a **Tribute Fund** in their name via our JustGiving page at www.justgiving.com/lasag or get in touch to find out more about ways to honour a loved one.



A special thank you to everyone who has been involved in raising money for LASAG this year. In particular, we'd like to say thank you to Carole and Janet from the Canterbury Support Group for selling cards and knitted garments, Carol and Caron from the Sittinbourne Friendship Group for making and selling decorations, and Sylvia for setting up a stall of knitted goods at the combined Christmas support group. We collected over £150 at the event which will go towards the running of future Support Groups.

LASAG Community Fundraising Committee

In 2020, we will be forming a fundraising committee, and would like to invite anyone who would be interested in helping shape LASAG's community fundraising efforts. Whether it's organising a bake sale, helping at Action Mesothelioma Day, taking part in sponsored events or rallying family and friends to raise awareness and raise money to support anyone affected by mesothelioma and asbestos-related diseases. Please get in touch if you would like to be involved.

I wish to make a donation to LASAG for £_____ by Cheque / Cash / Standing Order

Please make cheques payable to: London Asbestos Support Awareness Group
Post to: Farthings, Bridle Lane, Loudwater Rickmansworth Herts. WD3 4JQ

Bank Transfer/Standing Orders should be made to London Asbestos Support Awareness Group
Bank: Lloyds **Account Number:** 18406368 **Sort Code:** 30-98-90
(Please get in touch if you require a Standing Order mandate)

Credit and Debit Card donations can also be made online: www.justgiving.com/LASAG

Title:	Name:
Address:	
	Postcode:
Email:	Phone:

Please let us know how we can keep in touch with you by ticking the relevant boxes below.

I am happy for LASAG to contact me by (tick all that apply): Post Email Phone SMS

	Boost your donation by 25p for every £1 you donate by ticking the Gift Aid box *	<input type="checkbox"/> I am a UK taxpayer and wish to Gift Aid my donation and any donations I make in the future or have made in the past 4 years.
	*You must pay income tax equal to the tax reclaimed by the charity on the donation. If you pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all donations in that tax year it is your responsibility to pay any difference.	

Support Groups

for anyone affected by mesothelioma and other asbestos related diseases

Join us for coffee, cake and conversation at your nearest support group.

An opportunity to meet others living with the disease

Regular talks on topics including:

- Managing Diet
- Clinical Trials
- Hobbies & Interests
- Benefits available
- Alternative therapies
- Updates on new treatments
- Advice on insurance
- Health and Wellbeing

Our experienced staff together with specialist guest speakers and other professionals will be available to provide information, advice or a listening ear in a safe & private environment.

Canterbury

Second Tuesday (2pm - 4pm)
Ashford Road Community Association
151 Ashford Road,
Thanington Without,
Canterbury, Kent CT1 3XR
Contact: Alison Blake
M: 07585 337230
E: alison@LASAG.org.uk

Sevenoaks

Third Wednesday (2pm - 4pm)
The Luggage Room
Bat & Ball Station,
Bat & Ball Road
Sevenoaks, Kent TN14 5AP
Contact: Marika Townsend
M: 07880 201751
E: marika@LASAG.org.uk

Dagenham

Last Thursday (11am - 1pm)
Toby Carvery Moby Dick,
Whalebone Lane North,
Dagenham, Essex RM6 6QU
Contact: Yvonne Miah
M: 07917 194454
E: yvonne@LASAG.org.uk

Bexley

First Friday (2pm - 4pm)
Baldwyne Park Baptist Church
The Manse, Dartford Road
Bexley, Kent DA5 2AY
Contact: Marika Townsend
M: 07880 201751
E: marika@LASAG.org.uk

London

First Tuesday (11am - 1pm)
Dimpleby Offices, Ground Floor
Guys Cancer Centre.
Great Maze Pond, London SE1 9RT
Contact: Rachel Thomas
T: 0207 188 4758
E: Rachel.C.Thomas@gstt.nhs.uk