

London Asbestos Support Awareness Group (LASAG)

LASAG NEWSLETTER

FOR ANYONE AFFECTED BY MESOTHELIOMA OR OTHER ASBESTOS RELATED DISEASES

**LASAG
NEWS**

Mavis Nye
shares her story

ASK
the Experts

Clinical Trials

WELL-BEING
tips & advice

Fundraising

**Support
Groups**



**London
Asbestos Support
Awareness Group**

Registered Charity No. 1174543

0808 278 2515

www.LASAG.org.uk



Mavis Nye

shares her inspirational story

My journey with Mesothelioma began as so many Patients find with the day

I couldn't breathe. I was rushed to A&E and they had found a bed where they drained 7 litres of fluid. So my lung had collapsed and my diaphragm had bent.

They found Mesothelioma cells when testing the fluid. And I was given 3 months diagnosis. After going to Guys hospital, where I had a pleurodesis, I came home with a drain. The Bi-op that had been carried out at the same time confirmed the Diagnosis.

4 Years of Chemotherapy then followed with shrinkage then regrowth 4 times within those years. I became too toxic and I was told there was no more treatment. I had already made it know I was interested in any trial and Immunotherapy was just being investigated. MSD had this trial at the Royal Marsden and I was referred there on my request as Dean Fennel thought it would suit me. Prof De Bono agreed and I was one of 3 patients to start

MK3475-28. I had complete response only because I had Sepsis right at the end of the 2 year trial I didn't get that result in time so I'm under the heading of ongoing. That was disappointing.

I had 2 years freedom but then last March new growth showed. The old Meso was still in remission though. The new growth was bi-oped and it was found it was full of PDL1 where as I only had 1% before.

I became the first patients in the world to re-challenge the drug. Within 4 infusions it shrunk 14% and then stopped. It is growing again very slowly, not enough to bi-op yet. The Royal Marsden have matched my DNA to a drug that they can use to boost Pembro and maybe kick it in to work again. That is in the future.

In the meantime I do attend LASAG support meetings in Canterbury as I love to talk face to face and keep in touch with others that are suffering with the disease. They have helpful advice and also invite guest speakers as they say its good to talk!

Action Mesothelioma Day 2019

Join us as we remember and recognise those affected by Mesothelioma and other Asbestos related diseases

Canterbury:

Friday 5th July 11am - 3pm
Ashford Road Community Association
151 Ashford Road, Canterbury CT1 3XR
Welcome message from Mavis Nye
followed by Cream Tea

London:

Friday 12th July 10.30am - 2pm
Guy's Chapel, King's College London SE1 1UL
Memorial Candle Lighting Service at 10.30am
followed by refreshments



LASAG NEWS

New Friendship Groups

One of the things we pride ourselves on is keeping in touch with those who have lost a loved one to mesothelioma, and we know how grateful people are when they receive a call 6 months later to make sure they are ok.

What really stood out with everyone is the feeling of loneliness, being on their own after sometimes decades of living with a partner. We thought it would be a good idea to give them the opportunity to meet each other in an informal setting where they could chat to others who have been through a similar experience and not have to explain what mesothelioma is and how it affects someone.

We decided on a date and central venue that would be easier for people travelling from all over Kent and sent out an invitation to see if this would be something they would attend. We had around 16 people replying saying that they were interested with 8 of them able to come on that date. The others said they were unable to come along but definitely wanted to be kept notified of any future events.

On the day, we had 8 people come along and meet for a coffee. They appreciated the get-together so much that they want to meet on a monthly basis. There was a lot of reflection and sometimes sadness but there was equally plenty of laughter. Phone numbers were swapped and friendships started.

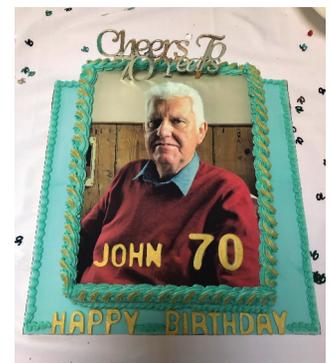
If LASAG have somehow made life a bit happier for those attending, then we have achieved our aim. This is something that we think would work across London and the South East, and we are actively seeking volunteers who could help organise future events.

Please get in touch with Alison or Marika if you would like to know more or get involved.



HAPPY 70th BIRTHDAY JOHN

Trustees were privileged to meet John and Beverley at the Guy's Support Group in April when they visited to understand more about how the Group runs. John's wife, Beverley told us that, when John was diagnosed back in 2015, they never thought he would reach his 70th Birthday. In spite of the prognosis, and with his strength & positivity, John was able to celebrate this fantastic milestone over the Easter weekend. Beverley said that John had a marvelous day joined by friends & family from wide and far for the celebration. They raised £1000 for Mesothelioma victims.



LASAG Appoints an Operations Director: Richard Mullens has been appointed to the post of Operations Director, which will make a significant contribution to the leadership and management of our charity as we embrace the opportunities to grow and to improve wider access to our services over the coming years.

Richard said *"Since joining LASAG in early March, I have had the pleasure of attending three support groups as well as accompanying our Advisors on client visits. I am in awe of the courage, resilience and outlook of the people I have spoken to, and am looking forward to helping LASAG make a positive impact on the lives of those affected by mesothelioma across London and the South East"*.



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. Do Travel Insurance companies cover my condition?

- A. It will make your search easier if you have certain information ready when you start looking for travel insurance. Whether you apply through an online form or on the phone, you may need to answer some difficult or upsetting questions. For example, the provider may ask about the likely outcome of the cancer (the prognosis). The provider may do this so they can decide whether they need to ask you for more medical information. Some providers call this their medical screening process.

Roy Castle Lung Foundation do a very informative booklet on travelling with a lung cancer and has a number of insurance companies listed who will insure our patients to go on holiday.

Q. What do I need to think about when considering my diet?

- A. The most common nutritional problems for mesothelioma cancer patients include consuming too little protein and too few calories, both of which are essential to aid recovery, support immunity and fight fatigue. Begin with a balanced, healthy diet. A balanced mesothelioma diet can help you feel better, maintain weight and energy, fight off infection, manage side effects of cancer treatment and recover more quickly.

Q. I am having problems sleeping. What can I do to get a better night's sleep?

- A. There are many reasons why sleep can be affected when someone has mesothelioma.

Here are some tips for a good night's sleep:

- Limit screen time on tablets and mobile phones prior to bed.
- Try lavender pillow sprays which can help increase relaxation and ease people to sleep.
- Have a pre-bed ritual to mentally prepare for bed such as a milky drink or warm bath before bed.
- Take pain relief if needed 30mins before bedtime to give them time to take action.

Q. How can I improve my prognosis?

- A. The first step you can take towards improving your prognosis is speaking with a mesothelioma specialist. A qualified specialist can draw on their experience in treating mesothelioma and create a treatment plan tailored to your specific diagnosis. If you've been diagnosed with advanced-stage mesothelioma, they can also help you get access to new treatments being developed in clinical trials. In addition to seeking treatment from a specialist, you can improve your prognosis by eating healthy and being active. A healthy body responds better to treatment, which helps support the care you receive from your specialist.?

Your Panel of Experts include:

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

Clinical Trials Update

Rachel Thomas runs a mesothelioma support group at Guy's Hospital and represents the Trust and mesothelioma patients at the All Party Parliamentary Asbestos Sub-Committee.



Trials that are carried out on patients are known as clinical trials, and their aim is to try to find new and better treatments for cancer.

Many drugs and treatments that have been tested in clinical trials are now in common use and without ongoing clinical trials it would not be possible to add to the current knowledge about effective treatments

Clinical trials of new treatments rarely stop when specialists agree that it works. There may be better ways of using it, such as giving it in different doses or combining it with other treatments.

Clinical trials are divided into different stages, called phases. The earliest phase trials look at whether a drug is safe or the side effects it causes. Later phase trials will aim to test whether a new treatment is better than existing treatments. There are 3 main phases of trials: Phases 1 to 3. Some trials will have an earlier stage 0 and there are some phase 4 trials undertaken after drug has been licensed.

Many drugs and treatments that have been tested in clinical trials are now in common use and without ongoing clinical trials it would not be possible to add to the current knowledge about effective treatments.

There are currently only a couple of trials open for recruitment in London:

MARS 2 is open at Guy's and Barts - this trial is looking at whether chemotherapy alone or chemotherapy and surgery is better for people who have mesothelioma of the chest. It is recruiting people who have pleural mesothelioma that is only affecting one side of the chest.

ADI-PEG 20 is open at Barts - this trial is looking at a new drug called ADI-PEG 20 with cisplatin and pemetrexed. It is for people with mesothelioma that started in the lining of the lungs (pleura) and that can't be cured by surgery.

Both these trials have inclusion and exclusion criteria so not all patients will be eligible to enter.

Mesothelioma UK has compiled and continues to regularly update a list of mesothelioma clinical trials in the UK (PDF), as provided by the respective trial co-ordinators or investigators. Search Clinical Trials at mesothelioma.uk.com

To find out more about trials in your area, get in touch with your local CNS on the details below.

Guy's Hospital

Rachel Thomas

Tel: 020 7188 4758

Email: rachel.c.thomas@gstt.nhs.uk

St Bart's Hospital

Joanne Hargrave

Tel: 020 7377 7000

Email: joanne.hargrave@bartshealth.nhs.uk

Maidstone and Tunbridge Wells

Louise Gilham

Tel: 01892 625358

Email: louise.gilham@nhs.net

Kent and Canterbury / QEQM /

William Harvey

Toni Fleming

Tel: 01227 868666

Email: toni.fleming@nhs.net

Lewisham and Greenwich

Nayomi Wickramasinghe

Tel: 020 8836 4111

Email: nwickramasinghe@nhs.net

Darent Valley

Karen Connolly

Tel: 01322 428100

Email: karen.connolly2@nhs.net

WELL-BEING

Helpful tips & advice

The Alexander Technique



Posture and ease in moving.

It was really nice to give a little presentation to the Asbestos Support Awareness Group, everyone was very welcoming and open to try new things, so we had a good laugh looking at simple things like turning your head or sitting and standing.

We learnt together that the Alexander Technique is a way of working on your body, giving it self-sufficiency to move sustainably again; with a new ease, grace and comfort.

Each of us has our own unique way of walking, sitting and moving, and this shifts through time with our changing moods and level of fatigue.

Stress, over-tension, harmful habits and injuries can disrupt the optimal coordination of our whole body in the longer-term.

We need this coordination to function smoothly, and these disruptions introduce changes into our movement so that what once was easy and effortless becomes more difficult and even painful, usually without us noticing. The subtlety of the changes means we may still feel "normal", even if we're not.

Just one or two lessons with a teacher skilled in the use of his or her hands can connect into the nervous system in a way which begins to loosen the underlying misuse, and to result in a dramatic reduction in pain or other symptoms. It is possible to use such lessons as a therapy but the real progress in the technique is when students start to develop the skills to release underlying holding patterns and reactions and then to move actively out of those patterns into openness and expansion. It changes the way we move and the way we look.

In a session usually we look at:

- *Whole-body coordination and balance.*
- *Breathing with ease, coordination and directions.*
- *Awareness of your limbs in relation to the all-important trio, the head, neck and back.*
- *"Body mapping".*
- *Constructive rest: a quick and easy way to "reset" your posture.*
- *Integrating what you have learned into your standing, walking and other everyday activities like sitting at a desk or driving.*

Rossella Buono gave a talk and demonstration of The Alexander Technique at our Canterbury Support Group in April.

Fundraising



We were honoured to be invited to join a group of Freemasons from The Chequered Cloth Lodge No. 5569 in London to be presented with a generous donation of £1242.50.

Belinda Chadwick, a Trustee of LASAG received the cheque on behalf of LASAG from Kim Halifax, the Lodge Charity Steward. Belinda said "The money will go towards funding our support groups and helping more people affected by Asbestos related diseases."

David Ellis, Chairman of LASAG said "We are delighted to have received such a generous donation from the Freemasons to continue our valuable work."

A big thank you to every supporter for their generous contributions in 2019 and an extra special Thank You to all the Volunteers and Nurses who give up their time to help with the running of our Support Groups

Other Fundraising Activity:

- Crocheting Brooches
- Sales of Cornflower Seeds
- Grants & Trust Applications
- Anonymous Donations
- Corporate Gifts
- Collection Boxes
- Sponsored Activities & Events

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. We have included different ways to support us below.



Fundraising



Individual Donations



Corporate Donations



Volunteering

I wish to make a donation to LASAG for £ by Cheque Cash

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

Please make cheques payable to:

London Asbestos Support Awareness Group

And post to:
Farthings, Bridle Lane,
Loudwater
Rickmansworth
Herts. WD3 4JQ

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 Post Email Phone SMS

I no longer wish to keep in touch with LASAG (We will not send you any further communications)

Support Groups

for anyone affected by mesothelioma and other asbestos related diseases

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

Canterbury:

2nd Tuesday of every Month (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:

3rd Wednesday of every Month (2pm - 4pm)
Sevenoaks Community Centre,
Cramptons Road (off Offord Road),
Sevenoaks, Kent TN14 5DN

Contact:

Marika Townsend
M: 07880 201751
E: marika@LASAG.org.uk

Dagenham:

Last Thursday of every Month (11am - 1pm)
Toby Carvery Moby Dick,
Whalebone Lane North,
Dagenham, Essex RM6 6QU

Contact:

Yvonne Miah
M: 07917 194454
E: yvonne@LASAG.org.uk

**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.**



**London
Asbestos Support
Awareness Group**

Registered Charity No. 1174543

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