

London Asbestos Support Awareness Group (LASAG)

LASAG NEWSLETTER

FOR ANYONE AFFECTED BY MESOTHELIOMA OR OTHER ASBESTOS RELATED DISEASES

**LASAG
NEWS**

Patricia Diss
living with mesothelioma

AMD
Action Mesothelioma Day

**Mesothelioma
Research Day**

WELL-BEING
Nutritional Supplements

Fundraising



**London
Asbestos Support
Awareness Group**

Registered Charity No. 1174543

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www.LASAG.org.uk

Patricia Diss

Talks about living with mesothelioma

It took me 6 months to say it, spell it, and accept that this was no doubt caused by exposure to Asbestos.

How has it been this first year? The more I try to describe how it has affected me both physically and mentally the more I cannot explain.

Perhaps the best way for me to do so, is compare it to being put through the wringer, what I like to call 'The Washing Machine Syndrome'.

The Program setting: Diagnosed with Mesothelioma in September 2018 following a referral to St Thomas' Hospital for fluid on the lung. Lung was drained of 3 litres and a

drain inserted which remained for nearly 4 months. Ultra sounds, CT scan, and biopsies confirmed Mesothelioma. Referred to Guy's lung cancer unit were a course of chemotherapy Carboplatin and Pemetrexed was prescribed. At the time it seemed a very long and frustrating process to reach the chemotherapy date. No matter how kind, helpful the medical team were and knowing how much effort and care was being given I still felt isolated and things were not moving quickly enough.

Chemo cycles: Much helpful advice, information and support was given, which I was able to apply for the first cycle of chemo. After the first 5 days all seemed well. However, it all went downhill after cycle 2. Physically I became weaker, struggled to find food that was acceptable without aggravating the nausea. Completely rejected meat and spicy, garlic type foods – even my Sunday lunch! However, I did have an appetite, of sorts, and just ate whatever I fancied at that time which was usually cream cheese, dark ryvita, apples, plain rice and as much warm water with lemon slice that I could take. Probably not a helpful tip but basically whatever works for you. Always trying to combat the dreaded constipation. I did not lose a substantial amount of weight. The pain which radiated around the whole lung area back and front was bad and barely controlled by various morphine based medication. This medication combined with nausea prevention tablets worsened the constipation. Various laxatives only aggravated the nausea. The number of trips to Guy's was daunting but manageable with my husband's support. Breathlessness obviously slows any trip.

Draining: One very positive occurrence was the removal of the Pleurex chest drain in December 2018 just before Christmas. Although the drain presented difficult, painful removal it was such a

step forward. It pointed in the right direction that treatment was working.

The spin: For me the mental side of all of this was the most difficult to cope with and I have no answers or tips to cope with it. For me I suppose I just sank into it just trying to cope with each day in different ways. It was a turmoil of the obvious feelings of and thoughts going round and round full of "nots": not able to bear to look at my family's hurt faces, not being able to cope with the grandchildren, not taking care of the house properly, not sleeping well, not coping with friends generosity and kindness, not controlling the depression and tears, not coping with the heading palliative care. Just not getting over the shock and mourning my former self.

Click, unlock: Wow after 5 cycles and a CT scan which showed no further cancer growth I was advised that there was no need for 6th cycle. I began to detox. Every day made a difference, gradually getting a healthy balanced diet back, lots of water, exercise pushing myself and coping with the breathlessness. In February I felt physically able to attend my first meeting of the Mesothelioma Group run by Rachael Thomas, Specialist Nurse at Guy's. After overcoming my initial nervousness I cannot explain just how my whole attitude changed. Having attended quite a few meetings now I have gained far more information about the disease, how to cope with it, and realise just how amazing the support is that I receive, with hindsight, my initial feelings of frustration and isolation were completely unfounded. To hear so many inspiring stories from fellow mesoites is inspirational. It seems with this disease there is no one size fits all. Our care is tailor made for our particular presentation and symptoms. How good is that!

Ironing: I am approaching my first anniversary and have ironed out a lot of my initial fears and concerns. I am now fully aware of the support I have had and still having from Guys Lung team and the various agency who work to help us all. Appreciating the wonderful friends I have who have been with me in mind, never ceasing to send messages, popping in and physically supplying crates of food. My fantastic family where love is so much it hurts. I am a lucky person in an unlucky situation.

So, I am ready to face year two being both positive and realistic but determined I won't be hung out to dry just yet.

Patricia attends the London Support Group

LASAG NEWS



LASAG has been working with the BBC to air a feature about mesothelioma for over a year now, and we were delighted when we got the call to say it was on. David White, a member of the Sevenoaks Support Group agreed to share his story as part of the feature. Mavis and Ray Nye were invited to share their presentation with the Support Group where the filming continued, and Lou Gilham, local CNS at Tunbridge Wells Hospital and Mesothelioma UK representative for South East shared statistics on mesothelioma in Kent and the UK.

Sevenoaks Support Group has a new home - we are now meeting in the Bat & Ball Room, at the newly refurbished Bat & Ball station.



David who was diagnosed nearly three years ago had always wanted to fly in a spitfire. He was encouraged by his partner Maria to do just that. He loved it and certainly looked the part.

Mesothelioma UK are hosting their 14th annual Patient and Carer Day in Blackpool on Friday 4th October. There will be an opportunity to meet others with similar experiences and learn about the latest mesothelioma research, treatment and care. Tickets are free for patients and carers. Please ask your Support Worker for more details.

AM D Action Mesothelioma Day



Canterbury: This year, LASAG hosted our first Action Mesothelioma Day event in Canterbury on 6th July. Alison and Marika went to great lengths to make sure the day was a special one for our guests who enjoyed the cream tea while browsing the stalls and chatting to friends, family and others affected by mesothelioma. We had a fantastic turnout with over 80 guests, volunteers and staff in attendance and thanks to the generosity of everyone who attended, we raised over £1000 from the event. Thanks must also go to the individuals, law firms, local businesses and local supermarkets who contributed to the various stalls.



London: Rachel Thomas from Guy's worked with LASAG to put on a beautiful remembrance service at Guys Chapel on the 12th July. It was another special day to remember those past and present who have been affected by mesothelioma. The service was hosted by Reverend Mia Hilborn, and included poem readings, a candle-lighting ceremony, and a message of hope from Mavis Nye. After the service, guests were invited to enjoy tea and coffee in the courtyard.



Local PC Chapman and PCSO Smeed attended our **Dagenham Support Group** to talk about personal and home safety with some helpful tips such as:

- Double check that doors are fully locked
- Protect your contactless payment cards
- Keep valuables out of sight - in homes and cars
- Be wary of telephone scams - don't reveal personal or financial information on a cold call
- Store car keys in a secure location in your home



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. I sweat a lot at night, is this normal and what can I do about it?

A. Mesothelioma can cause some people to sweat a lot at night. This can be distressing, especially if you wake at night with damp bed clothes and bedding. Let your doctor know if this happens to you as they may be able to give you medicines to help.

You may also find the following tips helpful:

- Try avoiding drinks that contain caffeine before you go to bed or in the night.
- Keep the room temperature cool or use a fan.
- Avoid using duvets or blankets that make you too hot.
- Lie on a towel so that you avoid getting your bedding damp.
- Use cotton sheets and bed clothes, and have some spare so that you can change them in the night if you need to.

Q. I seem to have lost my appetite, why is this and what can I do?

A. Treatments can sometimes cause problems with eating and digestion. If your appetite is poor, try having smaller, more frequent meals. You can also add high-protein powders to your normal food. Or you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can be prescribed by your GP.

If you have lost your appetite, medicines such as steroids may help improve it. You can also ask to be referred to a dietitian at your hospital. They can advise you which foods are best for you and also whether any food supplements would help you. If you're at home, your GP can arrange this for you.

Q. What complementary therapies are there to help me?

A. Some people find that complementary therapies, such as acupuncture, massage, aromatherapy and relaxation techniques, can help them feel better and reduce symptoms. Many hospitals and hospices offer these therapies.

If you'd like to try a complementary therapy, check with your cancer specialist or GP before using it. This is important because some complementary therapies should be avoided during, and for a short time after, cancer treatments.

The Harmony Therapy Trust have attended recent support groups and are able to provide different types of complementary and supportive therapy to medically referred NHS patients totally free of charge. Speak to your Support Worker for more details.

Your Panel of Experts include:

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

Mesothelioma Research Day

Yvonne is a LASAG Support Worker and runs a Support Group in Dagenham



I attended the Mesothelioma Research Day organised by the British Lung Foundation which brought together over 100 professionals from medical, legal, research and support fields. Speakers presented current research, planned projects as well as their vision for the future of treatments and care for mesothelioma patients.

Improving Patient Care: We heard how patients with mesothelioma symptoms can be cared for, what tests should be undertaken & the best way to deliver a diagnosis of mesothelioma. With consideration after having full information to make their own decision about the care an individual would want to receive. Another presentation discussed new ways to deliver drugs for treatment directly targeting the tumour cells.

In order to reduce the feelings of isolation experts are developing a mobile app that allows patients to record daily symptoms & provides direct contact with clinicians who can monitor & advise on managing these symptoms.

Learning to Understand Mesothelioma Better:

Presentations included laboratory work with cells/tissue aiming to identify best models & effectiveness before going forward to full clinical trials, as well as research looking at how we could attempt to prevent mesothelioma developing in those exposed to asbestos - including the use of zinc as one of the supplements.

Clinical Trials Update: Several well known clinicians & researchers including Professor Dean Fennell & Mr David Waller presented an update on clinical trials. Prof Fennell said at this time we still have nothing better than current standard treatment of carboplatin / premetrexed since 2003. However immunotherapy studies are ongoing & showing positive results but still await the full outcomes later this year /early next year.

I was impressed with how much work is being done to advance care and research in mesothelioma. It was a great opportunity to gain more understanding of the complexities & challenges facing the researchers in developing good, safe & accessible trials that will get reliable & honest results. For me the speaker that struck a chord was Simon Clark - He told us about his experience of getting a diagnosis of mesothelioma after being exposed to asbestos when he worked as an electrical engineer. He talked about the loneliness of this despite a caring family around. He said how he had benefitted from the advice & support of a patient support group. He has remained positive in his outlook & hopeful for the future. Overall that I would reiterate the message of the day is of Hope for all those diagnosed with mesothelioma & for the future for those exposed.

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

Nutritional Supplements

There are many nutritional supplements available, which can add extra energy or protein (or both) to your diet. You can add them to your everyday foods, or they can be an addition to your normal diet. Sometimes they can be used to replace meals. The types of nutritional supplements available include:

- milk-based supplements
- juice-tasting supplements
- soups
- powdered drinks
- ready-made puddings
- concentrated liquids.

They come in many different flavours. If you have a dairy (lactose) intolerance, ask your GP, specialist nurse or dietitian to prescribe dairy-free food supplements. If you are diabetic, it is important to get advice from your GP, specialist nurse or dietitian before using nutritional supplements.

Powdered drinks

Some powdered drink supplements can be used to replace a meal. You can mix them with fortified milk or water. Some can be prescribed by your doctor. You can buy some products from your chemist and some supermarkets.

Milk-based supplements

These are available on prescription in a variety of flavours, including sweet, savoury and neutral. The supplements usually need to be used within 24 hours. If you can only manage small amounts at a time, you can pour some into a glass and keep the rest in the fridge. We have ideas on how to include these in your everyday diet above.

Juice-tasting supplements

These ready-made, flavoured supplements are available on prescription.

High-energy and juice-tasting supplements have a

high sugar content. If you are diabetic, talk to your dietitian before using them. These drinks may not be suitable if you have a sore mouth or throat, as they may sting.

It is a good idea to clean your teeth or use a mouthwash after any sugary snacks and make sure you have your teeth regularly checked by a dentist. Your GP, nurse or dietitian can give you more advice about this.

Fat-based liquids

You can take these supplements separately in small doses, or you can add them to some foods. Your doctor or dietitian will give you advice on how and when you should use this type of supplement.

Energy and protein powders

Unflavoured powders are also available on prescription from your GP or dietitian. These are almost tasteless, so you can add them to:

- drinks
- soups
- sauces
- gravies
- casseroles
- flan fillings
- milk puddings
- instant desserts.

Your GP or dietitian can explain how much powder to use in different meals or drinks.



The Sevenoaks Support Group recently held a fortified foods taster session.

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.



Last year Marika and her husband Simon walked the entire length of the Pigrims Way to raise funds for LASAG. This year, they have upped the stakes by taking to the air on a zip wire 500 feet up across the Penrhyn Quarry in North Wales. Marika said "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! We hope to raise valuable funds for this amazing charity that provides support in so many ways for the patients and families who are affected by Mesothelioma and other asbestos related diseases."



A special thank you to Lyn Cornelius, and the Lower Hardres and Nackington Gardening Society, who have generously committed to raising funds for LASAG from their 3 gardening shows. Thanks also to Canterbury Support Group members Terry and Marion Talbot who helped make this possible. LASAG had a stand at the Summer Show to raise awareness and highlight our work to attendees, and will be receiving the generous donation at the Autumn Show in October



Volunteer Gilly Hughes-Jones

We are extremely proud of our volunteers who serve and support at LASAG. Gilly is the welcoming face of our Canterbury Support Group, and helped raise over £400 by selling raffle tickets at the Canterbury Action Mesothelioma Day.

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): <input type="checkbox"/> Post <input type="checkbox"/> Email <input type="checkbox"/> Phone <input type="checkbox"/> 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