

DERBYSHIRE ASBESTOS SUPPORT TEAM (DAST)



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Asbestos Awareness Project

As a support group, we feel it is important to raise awareness about the dangers of exposure to asbestos. The UK was the biggest importer of asbestos within the world and it was only in November 1999 that the use of asbestos was banned.

We feel it is our moral duty to continually raise awareness in the hope that we may be able to save the lives of future generations and put an end to the devastation that asbestos has caused to thousands of families.

We believe there is little awareness amongst the general public and those who undertake DIY. With the vast number of DIY programmes on television, it is of vital importance that we alert the general public to the potential dangers they may face by simply carrying out work on their homes.

With this in mind, on 25th February 2015, at the Winding Wheel in Chesterfield, we launched our interactive programme highlighting where asbestos may be found in the home. The interactive programme looked impressive as it was projected onto a large screen half the size of a house.

The project also attracted the support of Chesterfield MP Toby Perkins, and Council Leaders, John Burrows and Anne Western who

endorsed our awareness campaign. Also speaking were representatives of the major trade unions who informed the audience about the practical measures that their unions were taking to let members know of the dangers of exposure to asbestos.

The event also gave the Health and Safety Executive (HSE) an opportunity to speak about their new 'Beware Asbestos' campaign which offers advice and information to trade workers who regularly come into contact with asbestos.

DAST Ambassadors, Angela Sharp and Helen Redfern, who sadly lost loved ones to Mesothelioma, bravely spoke of their personal loss, bringing home to the audience the reality of the dangers of asbestos. A life lost to the disease causes a lasting ripple effect, affecting the lives of loved ones.



Those attending the event included local tradespeople as well as college students undertaking apprenticeships in professions which could bring them into contact with asbestos. Helpful information was available from the exhibitors which supported our aims of raising awareness within the public in the hope of preventing future loss of life.

Asbestos Support Groups' Forum – Charter

Chair of the Asbestos Support Groups' Forum has put together a list of demands for any new Government. These demands relate to improvements in

- Welfare Justice
- Civil compensation justice
- The right to decent medical treatment
- Calling for a properly funded medical research centre
- Improvements and enforcement to prevent future loss of life

We would be grateful if you could please sign the Charter yourself and also ask your MP to sign up to the Charter. Please contact DAST for additional copies – **01246 380415.**

Workers' Memorial Day 2015

DAST was invited to speak at a number of Workers' Memorial Day events around the East Midlands. Workers' Memorial Day is now Internationally recognised to "Remember the Dead" and to "Fight for the Living". DAST was represented at events in Immingham, Grimsby, Cleethorpes, Chesterfield, Leicester and Derby. At these events we were asking Trade Unionists and other participants to sign up to the Forum's Charter.



Leicester event 2015



Signing the Charter at the GMB Workers' Memorial Day event 28th April 2015

DAST Ambassadors

Yvette Oldham, Angela Sharp, Helen Redfern, Margaret and George Bailey and Dave Trigg continue to raise awareness about the dangers of asbestos, raising the profile of the Cinderella cancer – Mesothelioma, as well as fundraising and speaking out at events. Therefore, we have asked them to be Ambassadors for DAST, which they have willingly accepted.

Biography of a Mesowarrior by Mavis Nye

The mesothelioma presence on the web began some time back. It was first set up by Debbie Brewer. It was started to help anyone diagnosed with mesothelioma. At that time it was not widely known. Information and help was so thin on the ground that it was a case of getting by more on hope and ignorance. So the term Mesowarriors was coined.



When I was diagnosed in 2009 I also was ignorant on where to go for help and to whom to turn to. Macmillan nurses were the obvious choice. But it seemed to lack something. So I set to and searched the web. I came across Debbie and in a very short time we became firm friends. I set up a website called onestopmesothelioma.co.uk and a blog page called rayandmave.wordpress.com

Any articles and information that I could find was posted in both of these. It slowly grew and grew. Until now it's reached over 350,000 contacts, views and comments. It is now daily read and followed around the world.

We have regular contacts with friends and sufferers in America, Australia, Canada, India and many other countries, and, of course, here in the UK. It has grown far bigger than I ever anticipated. Unfortunately Debbie stepped over the Rainbow Bridge and Mesothelioma had claimed another victim. But Mesowarriors has continued to grow. We have active mutual support in Australia with The Bernie Banton Foundation. In America with ADAO. We have held award ceremonies here for those in the Asbestos trade and Medical professions. I was awarded the 2012 IATP award for efforts in awareness. Also in the same year a similar award was presented to me by the CEO of ADAO when Linda Reinstien came over to present it to me, all the way from America.

During the past 6 years since my diagnosis, at which time my prognosis was 3 months, I was told there is no cure and no treatment. All I was offered was palliative care. Later I was offered a new treatment called Pleurodesis. The aim of the Pleurodesis is to cause some inflammation between the two layers covering the lung. This inflammation makes the two layers stick together, and a sort of scar obliterates the space between the layers, so preventing further fluid from accumulating.

Eventually I was on a course of Chemotherapy. This was to become one of 4 separate regimes of Chemo. Each regime usually consisted of up to 6 to 8 sessions. I was also included in a drug trial which, after several sessions, proved not to be working so my trial was terminated. The last Chemo regime was for 20 weeks; it consisted of a 10-hour infusion session every 10 days. This became one long bout of infusion and the next 10 days

of sick and bad then slowly next 10 days returning to normal, only to start all over again. At the end of this regime and a scan I was advised that it had not worked and that my tumours were still growing. This was a great disappointment to me. My Oncologist said that she was unable to offer me any further treatment, only palliative care. This for me basically meant that's it now you can go home put your affairs in order.

On the good breaks between Chemo regimes I was invited to become a NHS Patient Representative. This involved sitting on meetings with Doctors and NHS Staff. I enjoyed this; I have now added a new post to my bow. A TSSG and research patient Rep and a Cancer Network patient Rep. Here I've met several influential Doctors, Professors and senior NHS Staff. I've been invited to be interviewed on TV and Radio. I've given talks to these people. I've attended several functions up and down the country. I got involved with Lord Satchi and his Innovation Bill and attended the House of Commons debate with him.

I have several videos on You Tube of these talks all on my webpage.
Onestopmesothelioma.co.uk

At one of these meetings I met Professor Dean Fennell who has been instrumental in the current upturn in my condition. He advised me to get to the Royal Marsden as a new trial taking place could help me. I pursued this and got an interview there, after which I was accepted with 2 other patients to go on the MK3475 Immunotherapy Drug Trial. This started in June of 2014.

Unfortunately at this point in time I am the last one left as the other 2 have

been removed because for them the drug has not worked. But for me, at my last scan a few weeks ago, it showed that I have undergone major shrinkage in all my tumours. The biggest tumour has gone from 73mm to 43mm but the small Anterior Pleural has gone from 32mm to 5mm. Boy!!! what a result. So far for me it's been one hell of an uphill fight. At the moment I am still fighting, apart from all the treatment I have received, for which I am most grateful My one rock of support has been My Husband Ray. Without his love and support I don't think I would have coped. Bless him.

TRIAL UPDATES

If you would like to know more information about trials that are open in the UK and how to approach your health care professionals to discuss what is appropriate for you, please contact Mesothelioma UK on **0800 169 2409**.

Mesothelioma in the Midlands

Thank you to everyone who came along to the Mesothelioma in the Midlands Conference. A big thank you to all our speakers and to those of you who bravely told your story. We will try to put together a more in-depth piece for our next newsletter. However, for those who attended, I hope that you took away the message that you are not alone in your fight and there is help and support available. Much is happening in terms of pioneering treatments into Mesothelioma. Although there is still a wait for the outcomes, progress is being made.

We were also very proud to put together the Conference with Asbestos Support West Midlands and will be thinking about next year when it will be our turn to host the conference.

'Love Notes' – Update
Yvette Oldham
DAST Ambassador

In the last newsletter I mentioned a tribute project, originated by the Health and Safety Executive, but actioned by the 'Kindred' Agency in London. I am now in a position to give you details of the tribute which was launched last month.

An interactive installation was unveiled on 25 March in St Paul's Church (the Actor's Church) in Covent Garden, London. Its creator, Joe Joiner, an award winning artist and graphic designer from East London, poignantly lost his own great grandmother to asbestos-related disease.

The installation contains 50 messages from grieving families. It consists of two glass boxes which represent a pair of lungs, at risk from breathable, asbestos fibres. The messages inside are blown around by air from two plumbing pipes but then settle for 15 seconds. This allows passers-by to read the heartfelt messages written by victims' loved ones - I was delighted to see my own message displayed on the Mail on-line site.



Yvette Oldham, DAST's Ambassador, holding a picture of her husband, Trevor, with Lauren Ross from Greater Manchester Asbestos Victims' Support Group

Trades people can unwittingly put themselves at risk of deadly asbestos-related diseases such as mesothelioma. Several contributors, including myself, (DAST Ambassador), Joanne Gordon (DAST Co-ordinator) and Helen Redfern (DAST Ambassador) travelled to London to attend the launch of the memorial. Contractors from building sites – in their workplace safety equipment - also attended to highlight the dangers tradespeople could be exposing themselves to. The item featured in the media the following day.

People assume that as asbestos was banned in 1999, the risks are no longer a danger. However as Joe Joiner said 'once he started to discuss the artwork with family and friends, more and more instances were becoming apparent. The fact that so many workers are being affected by this fibrous assassin is a real problem and needs to be prevented'.

Adam Hills, HSE Inspector said 'Asbestos is a real danger to tradespeople. On average 20 people a week die from asbestos-related disease. The artwork is testament to the devastating impact this deadly substance has on families and illustrates that it's more important than ever to ensure workers take simple steps that will help to keep them safe'.

The artwork was displayed for 2 days and then, I believe, was being offered to Mesothelioma UK to make use of.

Coffee Morning for Carers & Patients by Yvette Oldham
DAST Ambassador

The above took place in the morning of 27 March and was held at the Doubletree Hotel, Brayford, Lincoln, a very pleasant location.

The event was attended by Sarah Walters, Joanne Gordon, Natalie Woodward along with Liz Darlinson, Consultant Nurse with Meso UK.

Liz updated us all regarding current treatments on offer to sufferers and answered questions from patients and carers. Natalie had private discussions regarding benefits and queries from several attendees and Joanne was available for any other topics people wanted to discuss.

I thought it was a very useful get together, not only for professional advice, but for informal chats with other people in the same position. Tea, coffee and cakes were provided and much appreciated by all.

Afternoon Tea for Bereaved Relatives organised by Sarah Walters by Yvette Oldham – DAST Ambassador

The afternoon session at the same hotel was held for bereaved relatives – like myself. Joanne had asked me if I would tell mine, and my late husband, Trevor's experience of mesothelioma. I wrote a short, concise piece, detailing Trevor's work history, the process and treatments and how the family, Trevor, myself and our son, Nick, felt during the worst 2 years of our lives. Needless to say I had to stop and swallow hard whilst speaking to reach the end – supported by a fellow DAST Ambassador, Angela Sharp. I also

explained that the injustice to workers like Trevor is what drives me on to speak out when I am presented with the opportunity. Joanne, thank you so much for that.

The next speakers were from CRUSE in Lincoln. They explained their roles and ways in which they try to counsel the bereaved. One speaker mentioned that occasionally quite a time passes before someone seeks help from them. However, it appears time is not an issue and they are happy to see people whenever the need arises – useful information I think.

I thought it was helpful to be able to chat with people in a similar situation to myself. Also I think it's a valuable event as asbestos-related disease is still rare, in comparison to other diseases, and I consider it's vital to talk to other people in the same situation, as we can all learn from each other.

Again we enjoyed lovely tea and cakes.

DATES for your DIARY

• **Vintage Afternoon Tea**
19th June 2015 from **1.00pm – 3.00pm** Imperial Rooms, Imperial Road, Matlock, Derbyshire, **DE4 3NL**
Please come and join us for sandwiches, cakes, tea/coffee and entertainment

• **Action Mesothelioma Day**
Friday 3rd July 2015 at Leicester, Cathedral.

Full details will follow soon. If you have any poems of hope and reflection or calling for any action to support the Justice Charter please send them to me (Joanne) at DAST.



- **Patient and Carer Coffee Morning**

11th September 2015

22 Works Road, Hollingwood, Chesterfield, **S43 2PF** from

11am – 1.00pm.

Refreshments will be served. Directions and booking form to be sent out later. This is a lovely venue at the side of Chesterfield Canal. There is ample parking. Our speaker will be Helena Stanley, Mesothelioma UK Nurse Specialist from Sheffield.

- **DAST Meeting**

20th November 2015 at the Spot, Derby 11.00am – 1.00pm.

Speakers to include Jason Addy, back by popular demand from last year.

Fundraising News from Sarah

Thank you to the Ashbourne branch of Waitrose, who handed us a Community Matters cheque for £382. The Buxton branch of this supermarket also supported us last year.

Do you live near a Waitrose? Please consider nominating us as a Community Matters charity at your local branch. If you can help, contact Sarah, who will then send out an information pack for you to take into the customer services desk. All we ask is that if we are successful, you go along and collect the cheque as a

DAST representative and then forward it on to us.

Nottingham City GMB presented Joanne with a cheque for £515. This money was raised at a Valentine's Dance held especially for DAST. Ahhh....thanks everyone...we love you all!



We have also received a generous cheque from the Stanton Benevolent Fund for £500, towards our work in the Derbyshire/Nottinghamshire area.

Joanne along with her husband Simon, Lauren Mellor and Steve Fitzwalter ran the Manchester 10k on Sunday 10th May. It is not too late to sponsor Joanne. If you would like to do so, please send a cheque to the usual address. Thank you to all those who have sponsored her so far – the response has been fantastic. We will send out individual thanks soon along with some pictures proving she stayed the course.

Just a reminder for all you internet shoppers and browsers. The Give As You Live website sends a donation to your chosen charity every time you make a purchase through their pages. This company is run by Everyclick – a

charity donation search engine. Register to support DAST, and each time you search we receive a few pence.

www.giveasyoulive.com
www.everyclick.com

Don't forget to save your used stamps – we can recycle them and raise money for DAST. We are also considering setting up a recycling bank at future coffee mornings where we can collect used stamps, ink cartridges, mobile phones and items that we can sell on eBay.



We will be **Walking a Mile for Mesothelioma** again in September. DAST will hold their walk in Nottingham – you will be welcome to join us there. Or why not think about organising your own walk in your local area? We'll be sending out a flyer with the next newsletter.

Donate to DAST

- To make a regular monthly donation, ask us for a standing order leaflet or download a form from our website www.asbestosupport.co.uk
- Donate online through The Big Give or Virgin Money Giving websites
- Send a cheque made out to DAST
- Save us your used ink cartridges, stamps and mobile phones
- Hold a fundraising event
- Leave a legacy – ask us for more information about leaving us a gift in your Will. Many people also support us through an In Memoriam collection

