

DERBYSHIRE ASBESTOS SUPPORT TEAM (DAST)



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Welcome to the August/September Newsletter

Action Mesothelioma Day 2016

Background

As you are no doubt aware Action Mesothelioma Day was designated by the British Lung Foundation in 2006. Since then the date has changed from February to the first Friday in July, in the hope of better weather.

At DAST we believe the day is important to raise awareness about mesothelioma and the dangers of exposure to asbestos. It also enables families to come together and share their experiences whilst receiving information and advice from professionals.

2016

Our event this year took place in Derby at the Quad. We hadn't held the event in Derby for a number of years and it was great to be back. Joanne gave a short overview of Action Mesothelioma Day before introducing Dr John Hadfield, who is a Respiratory Consultant at Chesterfield Royal Hospital. His speech was well received, as it was informative, practical, down to earth and gave an understanding of the diagnosis and treatment of mesothelioma and he was happy to answer questions.



Dr Hadfield

Next to speak was Colin Smith who is 68 years old and has been diagnosed with mesothelioma. He is now a Surveyor and Company Director but began his working life as a joiner. Colin has spent a lifetime in technical services across the UK, Government, military, food and rail industry along with more recently health sector experience and service provision as a Company Director over the last 16 years.



Colin Smith

Colin not only shared his own story of living with mesothelioma but also talked about how, as a joiner, he came into contact with asbestos. We received great feedback about Colin's speech.

We decided to try something a little different and asked David Lees to speak. David is an ordained Taoist Master and an experienced Mindfulness and Qigong meditation teacher, traditional Chinese medicine practitioner, counsellor and coach. He talked about self compassion, acceptance and mindfulness.



Living in the moment is something we can all learn from.

David finished with a simple mindfulness technique.

David Lees

“Forget-Me-Not”



Simon Ball

Before moving outside to conclude our day of reflection, Simon Ball sang (acappella) the “Forget-Me-Not” song.

The song was originally written as a poem by DAST volunteer Audrey Carlin, and tells the life story of a joiner who is diagnosed with mesothelioma. A very fitting tribute for our Action Mesothelioma Day. We then moved outside into the Market Square where our Bereavement Support Worker, Jo Reeve, gave a short reflection speech whilst bubbles bearing messages from families and supportive organisations were placed on the tree. At this point Simon sang the Forget-me-Not song again drawing attention to passers-by who stopped to listen to the words.

Ongoing Awareness

The day was filmed by Jack Todhunter who has used footage to make a fantastic video of the song to continue to raise awareness about mesothelioma and the dangers of asbestos. You can view the video on our [website](http://www.asbestosupport.co.uk) www.asbestosupport.co.uk - go to What's happening? News – the Latest News box will appear on the right hand side of the screen and then choose Action Mesothelioma Day. Alternatively, both our facebook pages DAST (Derbyshire Asbestos Support Team) and DAST Bereavement Support have the video on it. It can also be viewed on YouTube <https://www.youtube.com/watch?v=8m-BixLHYQ>

For anyone who doesn't have access to the internet but would like to see the video please contact DAST and we can send it to you on disc.

Sponsorship

We also raised £1,540.00 at the event which was forwarded to the organisations as requested by people sponsoring the donations. This included DAST, Mesothelioma UK, The June Hancock Mesothelioma Research Fund, Mick Knighton Mesothelioma Research Fund and a small amount to the Chesterfield appeal for the Macmillan Advice Centre.

Thank you to everyone who sponsored a bubble.

Thank You



A BIG Thank You to all our speakers on the day. Also to Mrs Dudden (above) who worked hard handing out leaflets about Action Mesothelioma Day to the general public.

Mesothelioma, Fascination & Curse by Colin Smith

How wonderful and how fascinating the subject of Mesothelioma is but what a curse to have your life blighted by this complex terminal disease. So – how grateful to DAST I was to be



invited to speak at the recent Derby Conference in which the background and my own situation was used.

So who am I? – I am the fairly unremarkable Colin Smith –

a 68 year old former joiner, surveyor and company director.

In respect of my working life – this spanned 1964 to the present in which those early years saw me exposed to Asbestos Insulating Board (AIB) and the deadly asbestos fibres it contained. At that time, there was no worker awareness of the deadly nature of asbestos exposure or its devastating effects on health and life and as a result no personal protection or control measures were available.

Like so many words, we use 'devastating' and 'deadly' so frequently, that they lose their meaning – to put this into context, there was in excess of 3000 asbestos related deaths in 2013 with 2538 being attributed to Mesothelioma. It is now confidently reported that the mesothelioma deaths for 2016 will exceed 3000 which is expected to

increase year on year until 2020 and possibly beyond.

Regardless, Mesothelioma research has, as far as I can ascertain, received very low governmental clinical research funding, although things appear to be improving. There also appears to have been a somewhat half-hearted effort to control the asbestos risk related to the large amounts of asbestos that remain within buildings and facilities which pre-date November 1999.

Essentially, the government has elected for a management of asbestos strategy, where the 3000 or more materials known to contain asbestos are subject to owner (The Duty Holder) inspection, location and condition, recording and control (i.e. repair, remove, monitor). However, the fact remains that these materials remain and wait to entrap and expose the unwary or those with a cavalier attitude. In all of this, my personal experience indicates compliance is at best patchy, with poor quality, non-compliant work, not being unusual.



So it is my personal opinion that the faith put in a management control system is misplaced in which personal observation suggests that exposure will continue to rise well beyond 2020 with ill health and death following after the forecast latency period of 30 to 50 years.

In my own case, my exposure occurred 50 or more years ago and was not brought to light until after a perceived gym injury which after self-treatment by over the counter analgesics and osteopathic visits, was finally diagnosed as Malignant Epithelial Mesothelioma in December 2015, but how lucky I was to be directed by my GP to Newark Hospital, which has a mesothelioma history profile based on the engineering history of the town and heavy use of asbestos. From there I was rapidly but professionally processed by my consultant, Dr Hodgson and others in the team, resulting in a failed needle biopsy and final open thoracic biopsy which confirmed the diagnosis. My specific request to be referred to Leicester University Hospital and enter trials was acted on immediately and I was accepted onto the Hope Clinical Trials Unit under the management of the Lead Clinician, Professor Dean Fennell.

From the start, my wife and I decided that the right course for us was one of optimism, openness and a positive outlook, all of which, whilst not changing the prognosis, has enabled us to face the future together with good mental strength.

The future – well who knows – many new treatments are emerging from genome research and talk abounds of wonder drugs based on immunotherapy. This news is often conveyed, in addition to newspaper coverage, by my consultant Professor Fennell, whose world renowned reputation goes before him. Regardless it is his realistic yet infectious optimism, which is so valuable, such that each consultation is like receiving a bolt or massive charge of energy.

So in summary, it is clear that all this cost and suffering and potentially future cost and suffering could have and can be avoided. It is equally clear in my mind that the government's reliance on asbestos management is misplaced and their woefully inadequate funding of Mesothelioma research, new drug therapies and post code access should be ended as a matter of urgency and adequate funding for research and treatment provided. Mesothelioma is the poor relation, with vast sums being spent on road safety against the 1713 road traffic deaths in 2013 compared to the mesothelioma deaths of 2538. With a forecast of decreased road traffic deaths for 2016 and increased mesothelioma deaths of 3000+ or beyond is it time to redirect some of that money to mesothelioma research and treatment?

Well these are my views and background explanation in which I would like to pay tribute to my wife for all her dedication and care, my lead clinician Professor Fennell and his team at Leicester University Hospitals Hope Clinical Trials Unit for their on-going treatment and support and finally those at DAST – who support those suffering from this dreadful disease.

THANK YOU ALL

Dates for your Diary and forthcoming events

- **11th October 2016 – Coffee Morning for Mesothelioma and Lung Cancer patients and Carers. 10.30am – 12.30pm at The Corn Exchange, Broad Street, Stamford, PE9 1PX**

- **11th October 2016 – Afternoon Tea for families bereaved by asbestos related diseases. 1.00pm – 3.00pm at The Corn Exchange, Broad Street, Stamford, PE9 1PX**

Getting to the Corn Exchange Theatre

There is a pay and display car park about 5 minutes away from the theatre called North Street – North Street PE9 1EG. There is also parking opposite the Theatre but it is only for 1 hour and is competitive, but may be ideal for a drop off point if someone is coming with you. The Theatre is also within 5/10 minutes' walk of the bus station and about a 15/20 minute walk away from the train station or a short taxi-ride. Tea, coffee and scones will be served

- **Mesothelioma in the Midlands Monday 17th October 2016 from 11.00am – 3.40pm (Registration from 10.30am) at the Spot, Wilmot Street West, Derby, DE1 2JW.**

Speakers will include Liz Darlison, Mesothelioma UK Nurse Consultant and Director of Services, Dr Kate Hill (Researcher), Luciano Mutti, Medical Oncologist and Chair of Cancer Research at Salford University and Sheree Hall, Macmillan Lead Cancer Nurse at Chesterfield Royal Hospital as well as comments and observations from patients and carers. The conference will end with the "Forget Me Not" song.

- **9th November 2016 – Reflection and Celebration of Life at Lincoln Cathedral from 6.30pm to approx. 8.30pm.**

The poignant scrolling of the names of loved ones will be projected onto the West Wall of the Cathedral (starting at 6.30pm so you may wish to arrive a little earlier). Viewing from the Cloisters will ensure you are protected from the winter weather. This will be followed by speeches, music and a period of reflection to be held in the warmth of the Chapter House. Refreshments of soup and bread roll, tea/coffee will be served afterwards. (Approx. 7.30pm)

- **DAST AGM Friday 2nd December 2016 at the Spot, Wilmot Street West, Derby, DE1 2JW.**
AGM from 10.00am – 10.30am followed by:
- **DAST Social from 11.00am – 1.00pm followed by Hot Buffet Lunch.**
- **13th December 2016 – Coffee Morning for Mesothelioma and Lung Cancer patients to be held in Nottingham – venue to be confirmed**
- **13th December 2016 – Afternoon Tea for families bereaved by asbestos related diseases to be held in Nottingham – venue to be confirmed**

Festival of Trees

DAST will again be joining in with the Festival of Trees at the Crooked Spire in Chesterfield. Last year there were over 100 Christmas trees from charities and other organisations. Not only do they look beautiful but it is also a way of promoting DAST in the local community. The messages sent for

Action Mesothelioma Day will be displayed at this event. We have plenty more bubbles (now baubles), so if you would like to send a message to asbestos victims at Christmas or to remember loved ones, please send it to Joanne either by post to the address on the top of the newsletter or email to joanne.gordon@asbestossupport.co.uk (no sponsorship is required - just send your messages.



New Grant to Encourage Exercise

We have been awarded a grant by the Sir John Eastwood Foundation to buy some equipment that encourages mesothelioma sufferers to try different ways of easing their symptoms. The Macmillan website recommends gentle exercise such as short strolls to help alleviate breathing difficulties, along with the use of a fan and a massager to release tension. It might also help to keep a record of activities and their effect on your wellbeing.

So, with the Foundation's grant, we are in the process of purchasing some DAST branded pedometers, fans, massagers and notebooks. We are also going to purchase a small number of personal air purifiers to try and find out if these have a positive effect on breathing. These will be given out to a small group of mesothelioma sufferers

whom we will ask to use them and to give us feedback on their usefulness. If we receive positive feedback, then we will seek funding to purchase more. The pedometers, fans, notebooks and massagers will be out on display at events later in the year, where people can help themselves and give them a try.

Train Safe, Work Safe, Keep Safe



UKATA, who are a huge supporter of DAST, are promoting the campaign, Train Safe, Work Safe, Stay Safe. UKATA's training company members have been taking part in the campaign over the last 2 years during September and October by offering free Asbestos Awareness Training to organisations. Last year, members of UKATA involved in the campaign offered over 3,500 hours of free asbestos training, in an attempt to further raise the profile of the importance of the correct handling of asbestos. Now back again for 2016, UKATA's General Manager, Craig Evans, says the campaign is crucial for all tradespeople.

"Train Safe, Work Safe, Keep Safe is a campaign we've put a lot of backing into since its inception two years ago," said Craig. "Given the dangers asbestos presents us all with, the campaign is extremely useful and informative for anyone in the trade industry."

Your Legacy, DAST's Future

It is both sad and heart lifting when DAST is sent notification of a legacy. We recently learned that we had been left 10% of the estate of Mr H, and a fixed sum from Mr P. Of course we were sad to hear of their passing. Because we visit people whom we help in their homes and meet them at our events, it is a sombre moment to discover that someone's own personal battle with asbestos is over.

But this is tempered with the knowledge that they have entrusted DAST with part of their estate. It is an honour to find that a person really believed in the work that we do, and knew that by supporting us, we will give real help to others – and keep on pushing for greater awareness of asbestos and Mesothelioma. It is a ray of sunshine hitting the office.

These two legacies come at a time when we are seeking donations towards several events. There is Mesothelioma in the Midlands and the DAST Social but we are also planning the event at Lincoln Cathedral this November, where we will project the names of those affected by mesothelioma, as we did in Derby some years back.

We are proposing to use Mr H and Mr P's legacies towards our Lincoln event. It feels appropriate to put the money to good use within their home county, where we will be warning others of the deadly effects of asbestos exposure. As a small, tightly run charity, we can ensure that any legacy is spent in this way and doesn't just disappear into general running costs like it might with some of the big national charities.

If you would like to know more, we have legacy information sheets. You can download these from our website

– or we can post/email them out on request.

We are still seeking sponsorship from local companies or trade union branches for the event in Lincoln – if you know of an organisation that would like to be associated with this Mesothelioma memorial, please urge them to get in touch with us.

Recycle for DAST

We have now started collecting foreign currency in addition to stamps, HP ink cartridges and mobile phones – all of which can be turned into cash for DAST. So if you have any leftover cash from your holidays, please bring the coins and notes along to one of our events. The recycling company will also accept old British money.

All of the above can be posted to us too...except for mobile phones – Royal Mail no longer accept them in their system. Any handsets need to be handed directly to us.

Raffle Prizes

Another way of recycling for DAST is to donate unwanted gifts. We will be having an event at The Spot in Derby at the beginning of December and we will be running a raffle – anything that you have no use for, but might make a great prize for someone else would be very welcome.

Last year we managed to secure a few prizes from local companies, but we can't keep returning to the same businesses each year...if you know of a shop or business that would like to donate a prize in return for publicity, please put them in touch with us.

New Leaflet

Because of changes to Gift Aid, we have had to prepare a new donation leaflet. This is available to download as a pdf from our website or a copy can be posted out to you on request.

You can make an online donation through The Big Give or Virgin Money Giving websites.

Asbestos in Schools Launch and Exhibition

As you are no doubt aware any building built before 2000 may contain asbestos, this includes our schools. It was for this reason that DAST have developed an interactive model to highlight where asbestos could be found in schools. This model has been downloaded onto memory sticks and we have been distributing them to schools via the NASUWT and NUT.

We are formally launching our project on **21st October 2016 at The New Art Exchange at 39 - 41 Gregory Boulevard, Nottingham NG7 6BE at 10.00am.** Light refreshments will be served.



This will be followed by an exhibition of DAST's awareness projects which include interactive programmes on asbestos in the home, asbestos in schools as well as information about our asbestos heritage and vintage items which may still contain asbestos. **The Exhibition will be open from 1pm – 4.00pm on Friday 21st October and 10.00am – 4.30pm on Monday 24th October 2016.** We are looking for volunteers to give out leaflets and encourage the general public to view the exhibition.