

DERBYSHIRE ASBESTOS SUPPORT TEAM (DAST)



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Newsletter Edited by Joanne Gordon August/September 2012

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New Scheme for untraced insurance but 50% of asbestos victims excluded

DAST, as part of the Asbestos Victims Support Groups' Forum, has been campaigning for an Employers' Liability Insurance Bureau (ELIB) for many years. An ELIB would ensure 'just' compensation for anyone diagnosed with an asbestos related disease who could not trace the insurance of the negligent company that exposed them to asbestos. It would have worked similar to the Motor Insurance Bureau. DWP Minister, Lord Freud, promised an answer before the summer recess of 2012. Although delivering his promise, the Forum was disappointed that victims of asbestos related diseases are still to be treated differently from those who have had road accidents.

On 25th July 2012, Lord Freud announced a Tariff Scheme. The scheme is limited to claimants suffering from the asbestos cancer, Mesothelioma. Claimants suffering from Asbestosis, Pleural Thickening and Asbestos-related Lung Cancer, which constitute 50% of all asbestos diseases, are excluded from the scheme.

The scheme took effect for any Mesothelioma sufferer diagnosed from 25th July 2012 excluding all those diagnosed prior to that date - but no payments will be made for approximately two years because primary legislation is required.

The main option in the consultation undertaken by the previous Government, which attracted comments from all sides, was for an insurance fund of last resort, the Employer's Liability Insurance Bureau (ELIB). Not one respondent to the consultation supported the other option for a Tariff Scheme of fixed payments and for limiting payment to Mesothelioma claimants. All of the responses were either for an ELIB (Claimants) or against an ELIB (Insurers). An impact assessment was provided for an ELIB but not for a Tariff Scheme.

Although welcoming this first movement to pay victims of Mesothelioma who cannot trace the insurers of negligent companies, the Asbestos Victims Support Groups' Forum issued a press statement expressing bitter disappointment at the exclusion of 50% of asbestos victims.



Figure 1: Campaigning for an ELIB (outside the ABI offices in London)

Action Mesothelioma Day 2012

Despite the torrential rain on Friday 6th July 2012, over 80 people attended the Action Mesothelioma Day “Reflection and Celebration of Life” at Leicester Cathedral. This year DAST decided to link more closely with Mesothelioma UK and hold a joint Action Mesothelioma Day in Leicester.

The theme for Action Mesothelioma Day, as set by the Asbestos Victims Support Groups' Forum, was to call for a Worldwide Ban on Asbestos.

Calling for a Worldwide Ban on Asbestos

The theme for Action Mesothelioma Day this year could not have been more timely. Only a few days before, on the 29th June, the Quebec Government finally announced that the deferred loan guarantee of \$58 million

to re-open the Jeffrey Asbestos Mine would go ahead to re-commence the mining of chrysotile (white) asbestos.

The Quebec Government's own health authority, the Canadian Medical Association, the Canadian Cancer Society, the Canadian Public Health Association have all called for an end to the use of chrysotile asbestos. Despite this, five million tonnes of asbestos will be exported from the Jeffrey Asbestos Mine to developing countries, and mostly to India, over the next 20 years. There has also been renewed condemnation from the Health Authority in India.

The New Delhi health campaigner

Mohit Gupta has accused Canada of being “hateful” and “racist”, asking whether, “*only light-skinned people [are] entitled to breathe clean air and drink clean water.*”

“Reflection and Celebration of Life”

The day is also about providing hope to those who currently are ill due to Mesothelioma and the families of those who have lost loved ones.

Over one hundred and fifty names of victims of asbestos cancer in Leicester and the East Midlands were projected inside Leicester Cathedral.

Those attending heard speeches from Liz Darlison of Mesothelioma UK, Professor Dean Fennell of University Hospitals Leicester.

The “Reflection and Celebration of Life” was led by Rev Maggie Sharpe, who gave a very moving speech offering support to those who are suffering from the disease as well as bereaved families.



Everyone had been invited to sponsor messages on roses, which were hung on the reflection tree. Maggie picked up on this theme, placing coloured roses into a vase representing the acknowledgement of feeling such as anger, but also offering hope for the future.

The event concluded with a poem read by Joanne Gordon. There should have also been a dove release but due to the bad weather this could not go ahead.



Joanne Gordon, Jill Lemon (Mesothelioma UK) and Lynda Thornton

Action Mesothelioma Day raised £1,406.00 for Mesothelioma UK.

Mesothelioma UK update

Taken from speech by Liz Darlison
Action Mesothelioma Day.

Mesothelioma UK now support the funding of a second Mesothelioma nurse at Papworth Hospital in Cambridge and hope to financially support the appointment of two more Mesothelioma specific nurses in the near future. Agreement for a Welsh post has been reached and discussions for a London post are ongoing. If they have the funds they will appoint two more the following year.

Mesothelioma UK have completed a national survey of patients and their families asking them specifically about their experience. Nearly 650 people responded, the report will be published this month with key recommendations for improving experience.

They have provided or been present at a number of educational events for patients, carers and health care professionals and continue to run Mesothelioma Nurse Action Team that meets twice a year and communicates regularly to ensure everyone is updated. The E-learning for under graduate and post graduate Mesothelioma course has now trained 36 nurses, 6 of whom were international. Mesothelioma UK was delighted to receive a national excellence in oncology award in November recognising the course as the Best Professional Educational initiative in 2011.

Liz concluded her talk by saying that there is still a lot to do both at home and abroad but the Action Mesothelioma Day events around the country were getting the message out. Liz also urged people to tell their story; stories are powerful, and personal stories help to bring about change. DAST would echo this; much of the progress made could not have been achieved without personal experiences.

Take 5 stay Alive

The British Lung Foundation (BLF) have launched 'Take 5 Stay Alive' campaign to raise awareness of the dangers of asbestos in homes.

According to a survey commissioned by the BLF of 2000 Britons, 67% could not confidently identify asbestos in their homes, with lower rates of recognition amongst women (77%). The DIY campaign answers 5 crucial questions that anyone undertaking DIY would need to know about asbestos.

<http://takefivestayalive.com>

Resources

We have a number of resources in the office available free of charge

- Hand held fans to help with breathlessness
- Macmillan Relax and Breathe CDs
- Move it or Lose it DVD.

Exercise and relaxation benefits anyone with breathing difficulties. Please ring DAST on 01246 380415 if you would like any of our resources.

Strawberry Tea



We were approached by Jan Sheppard who



wanted to organise a Strawberry Tea to raise funds for DAST. Therefore, as this year is the 10th Anniversary of the Derbyshire Asbestos Support Team, we thought it was an excellent idea as we could invite the people whom we have helped and supported to enjoy afternoon tea and relax in the beautiful surroundings of the Whitworth Centre in Darley Dale.

Although hard work sourcing vintage china and baking dozens of scones, it was certainly worthwhile. The Strawberry Tea, which was held on 20th July 2012, enabled people to come along, chat with others in a relaxed environment and enjoy themselves. We received a thank you card from a gentleman diagnosed with Mesothelioma who stated that it had been a 'wonderful occasion'. Looks like it may have to be an annual event! The Strawberry Tea along with raffle made a total of **£624.52**, we also received a further £700 in donations brought along on the day.

Thank you to everyone involved with the Strawberry Tea, who helped to make it a great success.



Thank you to those who helped organise the event, to everyone who brought home-made buns, scones and cakes and

helped out on the day. Thank you also for coming along and donating so generously. (Please see Jan's story of the day).

Asbestos incidents in schools could have been prevented by proper training

Recently two serious asbestos incidents in schools have been in the headlines. Both were caused by a failure in asbestos management and both exposed people to asbestos fibres.

HSE stated: "*Sherborne School was found guilty of breaching Regulation 4(8) of the Control of Asbestos Regulations 2006 and Regulation 14 of the Construction (Design and Management) Regulations 2007. The*

school was fined a total of £60,000 and ordered to pay £13,000 in costs... Sherborne School knew about the risks posed by the presence of asbestos in the school buildings, and yet they failed to manage the risk of exposure to asbestos fibres during the refurbishment project. Asbestos insulation boards were removed in an unsafe way, exposing building contractors and a teenage work experience student to asbestos fibres, and leaving them at risk of developing serious and potentially fatal diseases later in life."

In the other case asbestos materials in the cupboards of Bloomfield Collegiate school were damaged by electrical and computer cable installation eleven years ago, and yet the extent of damage and the implications were only realised during an asbestos survey in May this year. HSE Northern Ireland carried out air sampling and a statement issued by the school stated "*the levels revealed in these tests carried out by HSENI were deemed a risk,*" consequently former pupils were contacted and warned of the potential risk to their health. Because of a failure in asbestos management HSENI issued improvement notices.

Both these incidents could have been avoided had people been properly trained. If asbestos is to be managed effectively then governors, headteachers, teachers and support staff have to be trained in asbestos awareness, and more in-depth training has to be given to members of staff responsible for the management of asbestos. DfE is presently working on basic asbestos awareness e-training for schools which will be available in October. It will not be mandatory but the Asbestos in Schools Group argue that it should be because those who are informed and conscientious will undertake the training, whereas the less informed and less conscientious will not. Most local authorities have an expertise in asbestos management, but there are now 1,957 academies and also many other schools have opted out of local authority

control and are managing their own maintenance projects. Their governors, headteachers and building managers carry the responsibility for the safety of the occupants but they often do not have the essential training or expertise. This was highlighted in a series of HSE inspections in schools outside local authority control that found more than half of the eighty schools that carried out their own maintenance and building work had failed to train their staff. Almost a fifth of the 168 schools had enforcement action taken against them for failing to manage their asbestos. A further 110 had "Advice" given to improve their asbestos management. Four of the six academies that were inspected had enforcement action taken for failures in asbestos management.

The problem is exacerbated because many schools are in a poor condition, and inevitably if the fabric of the building is dilapidated then so is the asbestos it contains. The Local Government Association estimated it would cost £15bn to bring the school stock up to a safe and structurally sound condition, but just £2bn has been allocated in the Priority Schools Building Programme. 587 schools in the worst condition applied for funding and just 261 have been successful.

The particular concern in schools is that children are more at risk from asbestos exposure, because they will live longer for mesothelioma to develop. The risk is so great that, in general, insurance companies will not provide asbestos exposure risk insurance for pupils. Local authorities self insure, but the government has confirmed that most academies and free schools cannot obtain insurance cover for their pupils and that the legal and financial liability for any future mesothelioma claims will rest on the governors in the academy trust – which is clearly an unsustainable position.

The Schools Minister has told Parliament that the government will review their asbestos policies for schools once the Committee on Carcinogenicity report later in the year on the “Relative vulnerability of children to asbestos.” It is essential that the review is carried out. Lack of training not only puts staff and pupils at risk, it can also result in legal action being taken. However every school can afford effective training and that will help prevent future financial liabilities and it will also save lives.

Michael Lees
20th July 2012

The Strawberry Tea Story

By Jan Sheppard

Well after almost 12 months of knowing it was going to happen, I can't believe it is today!! Ahhh. It is 4.20am and I have seen this time in the morning for most of the week, thinking about strawberries etc etc. After much planning, meeting up with Joanne and Audrey from DAST, churning out bunting and tablecloths, scouring the charity shops for china and teapots, the day has arrived and still so much to do! 5.45am in my pyjamas after 3 cups of coffee, out in the car to collect flowers from the hedgerow. I see them every day but as it's torrential rain, what a sight I must have looked. I thought at that time of the morning there would only be me around.... hence the pyjamas - wrong! Several cars have passed me doing a double take at what must have looked a funny sight – old woman in pyjamas in the rain picking flowers! If my darling husband Alan was still alive he would have laughed his head off and said **“That's my Girl”**, a saying he



used frequently, and it is for him and all the other victims of working with asbestos, that I am here now. At 6.00am I start to cover the mini chocolate muffins with a coating of chocolate, a chocolate button and strawberry, one for a cake and one for me, one for a cake and one for me Yum! Nice breakfast. Of course the strawberry is one

of my 5 a day. Makes me feel less guilty! More coffee, lots! Then on to the sandwich fillings, the idea being that we make the sandwich fillings prior to arriving at the Whitworth Centre, it was agreed that it would be easier to transport the fillings rather than making up the sandwiches in advance. The sandwich fillings are tuna, onion and sweetcorn – yum, ham and watercress... more yum, yum and egg and cress, which is a good old favourite – yum, yum, yum.

Now onto packing up the china, flower arrangements, cutlery, bunting, tablecloths. Up and down the 21 steps from our front door to the car, in the pouring rain of 2012. Quickly checking the list before I set off (one of many) to be sure that I have got everything with me. Run up another few yards of bunting, but there is no time to alter the frock I have bought to wear. It will have to be too big on the shoulders. I did consider taking some pins to fix it there but forgot! I race around to pack my bag of clothes to change into, I can't shin up a ladder with bunting in a long tea dress!

I then race off to Darley Dale, another panic attack on the way. Have I got enough blu-tack? I whizz into Sainsbury's in Matlock, at the same time flashing my lights at who I thought was Iris (my friend coming to help) only to find out later that it wasn't. I ran around Sainsbury's – chopping boards do we have any? Another teapot (in the reduced aisle) talk about panic buying. Bought some yummy brioche rolls for us all to have with our coffee on arrival at the Whitworth Centre, only 20 minutes late. Not bad for me. **“That's my girl”** Alan would be saying.



Iris is already there, so is Joanne and Audrey. Pinny on, curlers in and off we go to put the bunting up. I spill water from one of the jugs of flowers all over the floor (a health and safety hazard), so the area is cordoned off and David (Joanne's Dad)

mops it up. Sandwich filling commences, tables are set, china put out and flower arrangements are put in their places. We all grab a quick tea/coffee and a brioche roll. Is that really the time? Surely not ... it is. Panic attack!! More troops arrive to help, Lisa from the Macmillan Information Centre in Derby and her Dad. Lisa's Dad Les starts buttering bread in the kitchen "I feel like a surgeon" he says, wielding the carving knife "Crusts on or off" we put it to the vote and come up with a compromise. Lisa helps Audrey and Joanne filling the sandwiches, hundreds of them. Then on to Joanne and Audrey's home made scones, which Joanne and Iris fill with a layer of jam, strawberries, cream and a dusting of icing sugar.



The early birds arrive, my walking friends, they decided to be early as the bus would either get them there early or late. Best to be early. It is lovely to see them, completely forgetting that I am in shorts, pinny and curlers, which makes us all titter!

I am not suggesting panic set in, but crikey, everyone else is in their posh clothes, so I hastily exit to the loo to get changed into my tea dress. Right on the dot of 1.30pm people started to arrive. Quick all



hands on deck, pots of tea, cups of coffee, assorted sandwiches, scones, jam and cream, strawberries and cream, and a table laden with delicious looking assorted cakes, kindly donated by Iris, Lisa, Sandra (Macmillan Development Manager), Emma, Audrey and Joanne (thank you). The live Jazz in the background just beautiful (I love the saxophone) and we are in full swing. There was a lovely atmosphere, people chatting, some knew each other, strangers talking to strangers, passersby, who had seen the poster outside, and last but not least, the widows

and widowers, people who had lost a family member, and loved ones to Mesothelioma, and those suffering from asbestos related illnesses.

But this wasn't a sad occasion; it was a room in The Whitworth Centre, Darley Dale, overlooking the stunning park, full of chatter, laughter, flowers and bunting. And a lovely time was had by all. New friendships were made, many thank you's were said from those enjoying the Strawberry Tea, lovely comments on the pretty china, we had all found in attics, kitchen cupboards and charity shops.

A huge thank you to all who joined us for our tea; all the helpers, Joanne, Audrey, Iris, Lisa and Dad – Les. Along with Sandra from Macmillan Cancer Support and David for their relentless washing up; as well as Natalie and her daughter Olivia



who had brought her friend Hannah along to help too. A huge thank you to all of those people who kindly

donated cakes, scones and raffle prizes. Not forgetting the beautiful DAST "Reflection Rose" cake, made and donated by David Fisher's (Thompsons Solicitors) daughter, Louise. Thank you to Shay for doing the raffle and thank you to anyone else involved who I have not mentioned. And of course thank you to everyone who attended, for supporting DAST and helping to raise money.

MAYBE WE WILL SEE YOU ALL AT THE NEXT ONE

Jan xx

Dates for your diary
Mesothelioma UK Patient and Carer Day Saturday 6th October 2012 in London – see enclosed

Macmillan Coffee Morning 29th October 2012, Derby.

Unfortunately, we can't take part in the Big Coffee Morning on the actual date.

We shall again join forces with the Macmillan Information Centre at the Royal Derby Hospital. The Information Centre has comfortable chairs for you to sit and relax whilst enjoying a cup of tea or coffee and a cake.

Come and join us on Monday 29th October between 10.30am – 1.30pm at the Macmillan Information Centre Level 1, Entrance 24, Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE

The next DAST meeting will take place on Friday 23rd November 2012 at the Spot Centre, Wilmot Street, Derby, DE1 2JW from 11.00am to 1.00pm. Registration with tea and coffee from 10.30am.

Our speakers at the meeting will be

- Barrister Mr Philip Jones – legal update
- Chris Knighton MBE – talking about her work, Mesothelioma research and fundraising for the Mick Knighton Mesothelioma Research Fund and of course achieving an MBE.
- Karen Fenna – Mindfulness

Reminders and booking forms will be sent out at a later date but please put the date in your diary.

What is Mindfulness?

Mindfulness is currently a therapy being promoted by Macmillan Cancer Support.

Mindfulness promotes a way of being that helps us to take better care of ourselves and lead healthier and more fulfilling lives. It also enables us to access inner resources for coping effectively with stress, illness or any difficulties we encounter in our day-to-day experience. Jon Kabat-Zinn describes Mindfulness as “paying attention

in a particular way; on purpose, in the present moment, and non-judgmentally”:

Paying attention:

- “on purpose”: Mindfulness involves a conscious direction of our awareness. We notice the mind wandering, and purposefully bring our attention back to the here and now. Being purposeful is a very important part of mindfulness: staying with our experience means that we actively shape our mind.
- “in the present moment”: Left to itself, the mind wanders through thoughts, meaning we reinforce the emotions attached to them; we cause ourselves suffering. These thoughts are mainly about the past (sometimes leading to rumination) and future (sometimes with anxiety). The present moment seems to be the one we avoid. By using Mindfulness we cultivate “present moment awareness”. When we think about the past or the future we are aware we are doing so. We use an anchor, such as sounds, concentrating on the breath, counting or looking at a pebble and bring ourselves back to it, creating space where contentment can grow.
- “non-judgmentally”: We simply experience what we are experiencing, without labelling it as ‘good’ or ‘bad’.

Fundraising

Thank you to everyone who has sent us donations, we really appreciate your support to continue our vital service to anyone diagnosed with an asbestos related disease.



Thank you to everyone who has bought the beautiful fragrant ‘Reflection Rose’. We hope the reflection rose will

be bought for all occasions when you may wish to reflect on life. Contact DAST on 01246 380415 for more information and an order form.

Thank you to UNITE the Union for funding our newsletter.