

Welcome

With the covid situation easing somewhat we should soon be able to resume our dedicated home visit service to sufferers of asbestos related cancer. This is an important part of the charity's offering to victims of asbestos disease. When we have such a wide geographical area to operate in (from the north of Scotland down the east coast to the borders) it can be challenging expecting sufferers to attend regular meetings. We can always link each person, should they wish to discuss their own experience, with a fellow sufferer, however having your own dedicated support person on call with a vast experience in dealing with many sufferers going through the same challenges as you is invaluable.

It's sometimes easy, when we are talking about numbers such as 2,500 mesothelioma victims each year to forget about the rest of the family members who are also going through such a difficult time. Wives, sons, daughters and grandchildren are hugely affected by the results of a loved one being diagnosed with a debilitating asbestos condition. Often due to the length of time it takes for an asbestos disease to manifest itself the sufferers, themselves of a certain age, may be a carer for their

wife or husband adding greatly to the stress of coping with their own condition and looking after their long time partner. We understand the challenges you are facing and we are here for you.

We often get a person who has been diagnosed with an asbestos condition feeling a bit wary of taking on a civil case especially when the word 'solicitor' is mentioned. I would like to reassure anyone who feels this way that the process is relatively simple for you and the legal advisors that the charity may suggest all have a very empathetic manner and understand your reservations. Although the benefits we help you to obtain are fine, proper justice by means of a civil case against a negligent employer who allowed your health to be damaged through no fault of your own is something we would always encourage.

Thanks and best wishes to you all.



John Fearn, Manager

Mesothelioma Support Group

The Scottish Mesothelioma Network Patient and Carer Virtual Support Group is an on-line meeting for people with mesothelioma and their loved ones or carers. The group provides an opportunity to share information on issues relating to mesothelioma including symptoms, treatments and practical advice.

This Scottish wide group is supported by a mesothelioma Nurse Specialist and a Maggie's Cancer Support Specialist.

To book a place or to find out more call **01463 706306** or email **highlands@maggiescentres.org**



AsbestosACTION

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SUMMER 2021



LEGAL UPDATE

Recovering immunotherapy costs for client diagnosed with mesothelioma

When an individual suffers an injury and decides to pursue a claim for compensation, they primarily think about recovering compensation for the injury itself. That holds true for those suffering from asbestos related diseases - they rightly expect the courts to award them compensation for the injury that they have suffered.

What is less well known is that compensation for the injury ("solatium" to use its latin name) is only one 'head of claim' that individuals diagnosed with asbestos related diseases can claim for. In addition to that, they can look to recover compensation for loss of past and future earnings or the value of assistance provided by family members.

However, it is now possible to include another 'head of claim' for certain individuals diagnosed with mesothelioma: immunotherapy costs.

Immunotherapy as a treatment for mesothelioma

Immunotherapy is a new class of drugs which aim to switch on the immune system (which has been turned off by the cancer), to fight off the cancer.

There are numerous ongoing clinical trials which are investigating the benefits of immunotherapy as a treatment for mesothelioma. The aim of

the treatment is to extend and improve the quality of life for those living with mesothelioma. The trials of these drugs, which include Pembrolizumab and Nivolumab, have so far shown quite promising results.

Unfortunately, these treatments are not yet licenced for use within the NHS. They are, however, available for use under the Government "Early Access to Medicines Scheme" but must be paid for privately. The cost of such treatments (often running into hundreds of thousands of pounds) is out of reach of the vast majority of individuals.

In the context of a civil claim for compensation, it may be possible to include the cost of private immunotherapy treatment as a 'head of claim'.

Where someone's life has been shortened as a result of another's negligence (as is the case with mesothelioma), the courts view is that it is entirely reasonable for that individual to have all medical treatment available to them. If that treatment is not available on the NHS, then the negligent party should pay for it.

The Industrial Disease team at Digby Brown has been at the forefront of recovering the cost of immunotherapy treatment for clients diagnosed with mesothelioma. Whether or not this treatment is in a particular

client's interest is entirely down to the medical profession. It is not appropriate for everyone. When it is recommended, we require to enter into carefully worded agreements with defenders, which protect our client's position. There is often uncertainty around the number of treatment cycles that an individual will undergo and when the treatment may be undertaken. Payment may need to be met after the case has 'settled'.

All those diagnosed with mesothelioma deserve cutting edge and promising medical treatment, such as immunotherapy. Until such treatment is available on the NHS, pursuing a claim against the party responsible for their condition is the only way for most people to access such treatments.

Asbestos Action plays a crucial role in signposting individuals to specialists solicitors who are able to fully investigate this treatment option.



*Euan Love, Partner
Digby Brown*

Asbestos Action funds two Mesothelioma UK clinical nurse specialists



Picture – Susan Smyth (CNS), Nancy Rattray (Board Member and retired clinical nurse now assisting the Maggie's Centre, Dundee) and John Fearn (General Manager Asbestos Action)

National charity Mesothelioma UK is delighted that Asbestos Action will be funding two clinical nurse specialist (CNS) posts in Scotland. Specialist mesothelioma nurse Susan Smyth is based in Dundee and her post will be funded for two years. Tracy Petrie is based in Aberdeen and her post will be funded for one year.

Mesothelioma is a cancer related to exposure to asbestos and predominantly affects the lining of the lungs. The UK has the highest incidence of the disease in the world with around 2,700 people diagnosed each year. Around 200 cases of mesothelioma are diagnosed each year in Scotland.

Mesothelioma UK is a national resource centre dedicated to providing specialist mesothelioma information, support and improved care and treatment for all UK mesothelioma patients, their carers and health care professionals. The charity integrates into NHS front line services to ensure specialist

mesothelioma nursing is available at the point of need. This is achieved through a growing network of specialist mesothelioma nurses, regionally based in NHS hospitals but funded by Mesothelioma UK and/or collaborations with supporters such as Asbestos Action.

Carolyn MacRae, Mesothelioma UK Team Leader for Scotland, said: *"We're so grateful to Asbestos Action for its generous offer to fund these two posts. Having specialist mesothelioma nurses is vital to improving the treatment and care of patients and their families.*

"Tracy and Susan work in regions where the incidence of mesothelioma is high so their specialist knowledge and expertise is hugely important to both patients and the medical teams at their NHS trusts. Mesothelioma UK is delighted to collaborate with charities such as Asbestos Action to support patients in the region.

"Susan and Tracy will focus on caring for patients with mesothelioma at every part of their treatment journey, helping to make their journey as smooth as possible."

Susan and Tracy will be part of the Scottish Mesothelioma Network, a collaboration between Mesothelioma UK, Macmillan Cancer Support and NHS Scotland.

The Scottish Mesothelioma Network comprises of a team of specialist clinicians across Scotland collaborate to:

- Share best practice
- Provide high quality clinical care
- Provide information and support to all patients, wherever they live in the country
- Ensure all patients have equitable access to potentially life-changing clinical trials

CNSs play a fundamental role in the aims of the Network to speed up diagnosis and treatment of patients wherever they live and help to ensure that optimal care is delivered as close to home as possible.



www.mesothelioma.uk.com

What are Pleural Plaques

We are often asked a lot of questions about pleural plaques from sufferers who have been diagnosed with this condition. Family members also express a concern about the severity of pleural plaques.

This sometimes arises when a sufferer hears the word 'untreatable' and then has a slight mental panic and misses the next reassuring part of the conversation. So, let's have a look at this condition.

Pleural plaques are caused by exposure to asbestos at some time in the past. This may be occupational exposure for example in plumbers, electricians, construction workers, gas fitters or joiners. DIY may be another area of contamination.

Pleural plaques are areas of scar tissue on the pleura. The pleura is a two-layered membrane surrounding the lungs and lining the inside of the rib cage. In virtually all instances of pleural plaques there are no symptoms and you can live with them without having any long term problems with your health.

If you have pleural plaques it does not mean that you will go on to get a more serious disease or have a more serious disease at the moment.

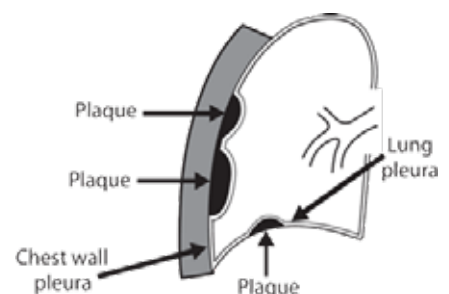
While exposure to asbestos does carry a risk of developing a serious lung disease such as asbestosis, mesothelioma or lung cancer, scientific evidence shows that having a pleural plaque does not increase that risk. Pleural plaques are not the same as asbestosis and they are not a pre-malignant form of cancer.

If you have been exposed to asbestos, but have no symptoms, such as breathlessness then there is no need to have any treatment. If you develop a cough which persists for a long time (more than three weeks) or you cough up blood, it is important to see your doctor straight away. Although these are not symptoms of pleural plaques they may mean that you have a different more serious illness. Pleural plaques are not life threatening and no-one dies from them. There is no need for an operation to treat pleural plaques.

If you have pleural plaques and smoke then it is advisable to seek help to quit. By stopping you will reduce your chances of developing a smoke related disease such as COPD (chronic obstructive pulmonary disease) or lung cancer.

Hopefully if you have been diagnosed with pleural plaques you will find the above re-assuring. However, it is very important that (in Scotland) you seek legal advice, as sufferers of pleural plaques may pursue a civil claim against a previous negligent employer. There is a time limit on when a claim can be raised so we always encourage sufferers to take immediate action.

We asked Fraser Simpson, Partner at Digby Brown Solicitors, who said: *"It is unconscionable that anyone diagnosed with a serious asbestos-related illness should be denied justice because their medical records reveal a previous diagnosis of a condition which their doctor may have told them not to worry about. It is therefore crucial that anyone diagnosed with an asbestos condition, no matter how benign, seeks legal advice as soon as they are told about the diagnosis."*



Gendered Experience of Mesothelioma Study (GEMS)

Produced by Mesothelioma UK and the University of Sheffield, the Gendered Experience of Mesothelioma Study (GEMS) was carried out after consultation with health and legal professionals indicating that women may have a different experience to men in terms of awareness of the disease, diagnosis, access to treatment and compensation and legal processes. Key findings included:

- High risk occupations for men differed from high-risk occupations for women
- Women of all ages and younger men lacked awareness of the dangers of asbestos exposure
- Gender differences existed in the experiences of explanations and support provided at the time of diagnosis
- Men and women had different ways of communicating with professionals along the mesothelioma pathway
- Familial and social expectations of men and women influenced their willingness to pursue civil compensation.

A full copy of the GEMS report, detailing the findings and recommendations, is now available at www.mesothelioma.uk.com/new-report-on-gender-differences-in-the-experience-of-asbestos-related-cancer

HOW TO REDUCE STRESS AND ANXIETY



If you or someone close to you has had a diagnosis of cancer, you have experienced a serious stressful life event. Stress can be positive helping us to feel more resilient when we need to. Over longer periods, however, it can be an exhausting extra burden at an already difficult time. Stress is your body's way of responding to challenging circumstances. If you are stressed you may experience your emotions much more intensely than usual. You may feel tearful, irritable, have feelings that you can't cope or you may feel detached and numb.

Stress can also trigger physical symptoms including headaches, irritable bowel symptoms and rashes. You may not be able to eat or sleep feel sick, or get frequent colds as stress can reduce your resistance to infection.

People with cancer and their families report several factors which add to stress. These include worrying about the uncertain future, tiring treatments, frequent hospital visits, physical changes, financial and employment worries, relationship pressures, and not feeling in control. Stress management includes gaining control of your thoughts, emotions, worries and how you deal with problems. It can also involve making changes and taking back control of other areas of your life for example through exercise and a balanced diet.

Some tips for managing stress

- **Prioritise your health:** try to get enough sleep, eat a balanced diet regularly and drink plenty of water.
- **Exercise:** gentle exercise has many benefits during and after treatment.

- **Master time:** prioritise tasks, allow yourself time to take things step by step. Learn to say no and to ask for help when you need it.
- **Relaxation and breathing exercises:** used regularly these can help reduce stress and feeling overwhelmed.

If you have been diagnosed with cancer then it's worthwhile contacting your local Maggies Centre who will be able to offer advice and support on stress and other issues.

www.maggies.org

 **MAGGIE'S**
Everyone's home of cancer care

Scottish Hazards

We are always concerned when we hear of workers who are worried about the possibility of asbestos (or in fact any health and safety issue) being in their workplace, getting no support from management and are afraid to raise the issue in case of possible repercussions. We believe this tends to happen more often in organisations where there is no trade union presence.

In a case like this we advise contacting Scottish Hazards on: **0800 0015022** or email: info@scottishhazards.org

Meet the specialists

Liz Darlson actually has 3 roles. Her main one being CEO of Mesothelioma UK. In addition she practice as a Nurse Consultant at the University Hospitals of Leicester and is also a clinical lead for cancer in the East Midlands Clinical Research Network (CRN).

Liz explains her roles: *“As CEO for Mesothelioma UK I am responsible for the charity’s overall financial position, strategic planning and delivery of services. Of course I have an amazing team working alongside me to achieve this. As a Nurse Consultant I work with the Thoracic Oncology team to provide a comprehensive Mesothelioma service, I particularly focus on disease surveillance in a busy oncology clinic. Finally as Cancer Clinical Lead in the East Midlands CRN my role is to work with the CRN operational team and 13 sub-speciality leads from across all cancers to improve the clinical trial portfolio and recruitment.”*



We asked Liz

Q. What do you like most about your job?

A. Being able to make a difference to people in their hour of need, it is such a privilege.

Q. Biggest work challenge?

A. Juggling everything!!! There is so much more to do, it will never all be done or perfect of course but there are so many things we need to challenge and improve on.

Q. How do you like to relax away from work?

A. With family and our 2 doggies. I love exercise of any kind so walking, cycling, swimming but not to any great level, just casually but regularly. We are a football family and avidly support Leicester City. I also enjoy gardening and I love to holiday and travel but that has been harder this last 18 months.

Q. Your favourite place in Scotland?

A. I simply love Scotland and have holidayed there many times. For my favourite place I would have to say Lanarkshire as I spent many happy times there as a child visiting my grandparents, aunts, uncles and cousins. Can I have 2 though – my second would be Shin Falls near Lairg. My husband and I marvelled at the salmon jumping up the waterfall on our honeymoon many years ago. We returned there this year and enjoyed it all over again.

Q. Favourite film?

A. Hmm, I do love a good film. Shawshank Redemption, Gladiator, Braveheart, The Green Mile are all favourites but I love girlie chick flicks too, Dirty Dancing, Pretty Woman and The Holiday. I also have lovely memories of being a new mum watching Disney films with my growing brood.

Q. Favorite TV programme?

A. I like a good crime series – Line of Duty, Luther but have to confess to losing myself sometimes in Mills and Boon / Little House on the Prairie type series on Netflix too. Currently enjoying Heartland.

Q. Theme song of your life?

A. The Circle of Life by Elton John from the Lion King. It sums up what it’s all about really, some of the lyrics mesmerise me.

Q. Favourite meal?

A. I love food. I like trying different things and anything well prepared and presented. But for a favourite..... anything cooked by my 88 year old Mum – nothing quite like dinner made by mum, even at my age.

How you can help - donations:

How to donate

- Complete the **form below** and send cheque to "Asbestos Action"
- JustGiving - www.justgiving.com
- **Standing order** (contact us for information)

Your details

NAME:

ADDRESS:

POSTCODE:

TELEPHONE:

EMAIL:

Donation amount - I wish to donate (please tick):

£10 £20 £30

OTHER £:

GIFT AID – important (please tick):

Boost your donation by 25p for every £1 you donate

I want to Gift Aid my donation and any donations I make in the future or have in the past four years, to Asbestos Action. I understand that I must pay an equal amount of UK income tax at least equal to the tax that Asbestos Action will claim in my donations in each year (*currently 25p for every £1*).



SIGNATURE:

DATE:



About Asbestos Action

Asbestos Action is a charity that relies almost entirely on donations from appreciative sufferers and their families.

The charity was founded in 2002 by a small group of sufferers to assist those diagnosed with an asbestos-related condition.

We are committed to helping anyone affected by an asbestos-related condition, from supporting sufferers and their families after diagnosis to home visits to help fill in complicated benefits forms.

With a small staff of five the charity punches well above its weight in providing this emotional and practical support.

You're the reason we can keep providing our vital service, so no one has to face asbestos-related disease alone.

Donating can help us to support more sufferers and their families who have been affected through no fault of their own.

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Asbestos-Action-Tayside