Summer Edition 2020

MESOTHELIOMA UK

MESOTHELIOMA MATTERS

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Welcome

Welcome to the summer edition of our Mesothelioma Matters magazine. This is our first edition since the Covid-19 lockdown and we hope that you're all keeping as well as possible in these unprecedented times.

During this period, our UK team of Clinical Nurse Specialists has tried to find new ways of treating and caring for mesothelioma patients, and the charity has also had to adapt with new approaches to service delivery. Despite this, there have been plenty of positive developments going on and we hope that you enjoy reading about them in this latest magazine.

Liz Darlison,
Head of Services,
Mesothelioma UK

Investigating patient experience during pandemic

Mesothelioma UK has surveyed patients about their treatment and care experiences during the coronavirus pandemic. Patients were asked about any impacts on their treatment schedule, hospital appointments and scans, the patient shielding list, contact with healthcare teams, and other areas affected by the pandemic.

The key findings from the 64 responders to the survey include:

- 50% said their treatment had been affected including postponement of chemotherapy and entry onto clinical trials
- 64% said their scans or outpatient appointments had been changed, cancelled or postponed
- 52% automatically received a letter from the NHS advising them that they were on the patient shielding list
- 28% experienced difficulty obtaining shopping, including medicines

Based on the responses, Mesothelioma UK makes the following recommendations:

1. Cancer treatments should be reinstated as soon as it is safely possible and alternatives such as home treatment should be considered to avoid hospital visits for the most vulnerable
2. Telephone or video consultations are acceptable and should be considered after the pandemic
3. Review of the shielding patient list with clearer guidelines
4. Hospital and community prescriptions to be compatible and home delivery service for prescriptions to be considered

Head of Services for Mesothelioma UK, Liz Darlison commented: "Understandably, the COVID-19 pandemic has had a huge impact on healthcare services and we understand that decisions made about cancer patients' treatment and care are made with their safety in mind. Sadly, some patients have said they feel frightened, in limbo and even abandoned. However, Mesothelioma UK wants to reassure patients that they really matter and everything is being done to get their treatment and care back on track.

> "As part of our ongoing and comprehensive support for patients, Mesothelioma UK will do all it can to share the survey findings appropriately with any groups, organisations and healthcare providers, to ensure that the voices of our patients are still heard."

Patient questions about coronavirus

Mesothelioma UK has been running a series of live Q&A sessions on Facebook with our nurses answering some of your most common questions regarding the impact of coronavirus on your care and treatment. The sessions have been very popular. Here are some of your most frequently asked questions and our responses:

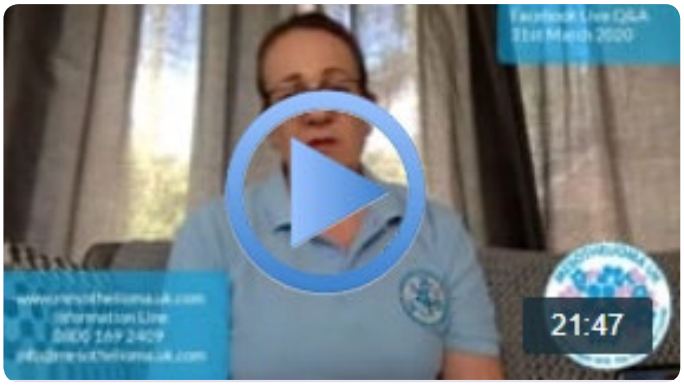
Should I be on the Patient Shielding List?
If you go onto the .gov site, it doesn't explicitly list mesothelioma patients. However, we have asked several experts who have confirmed that yes, mesothelioma patients need to be shielding from any unnecessary contact or exposure.

To get register yourself on the extremely vulnerable list, go to www.gov.uk/coronavirus-extremely-vulnerable and register online.

GP surgeries can also add patients to that list. If you need help or guidance with using the website, please reach out to relatives, friends or professionals who may be able to talk you through the steps.

How might COVID-19 affect my mesothelioma treatment?
Your healthcare team will be doing all they can to minimise the impact to your treatment and care. They will be weighing up the risks versus benefits which will differ for each patient.

If your cancer treatment has been paused, deferred or cancelled, it is because your cancer team have weighed up the risk vs. benefit for you individually.



It is not a capacity issue or a directive from NHS England but a clinical decision for each patient.

It is likely over the coming weeks and months that your healthcare team will be asked to support local efforts. This may mean clinics will be cancelled or alternative consultation methods may need to be used such as video or telephone calling. You may also find it hard to contact your keyworker or nurse. Please ensure that your contact details are up to date in your medical records and perhaps familiarise yourself with video calling options such as Facetime and Skype.

Ensure that any medication you are using regularly is on repeat prescription to avoid unnecessary trips to the GP surgery.

I have had my spleen removed - am I more vulnerable to contracting COVID-19?
Yes, you are more vulnerable and are listed on the Government website to say that you are more vulnerable. Please ensure that you have your emergency pack available to you, which includes an urgent supply of antibiotics.

Will I have access to a Mesothelioma Clinical Nurse Specialist?
Please be reassured that Mesothelioma UK will continue to try and ensure that a Mesothelioma Clinical Nurse Specialist is available through our information line to answer individual questions and concerns.

If you are struggling to contact your local Mesothelioma UK nurse, please call our information line on 0800 169 2409.

Should I attend routine scans?
Currently, routine disease CT scanning is still going ahead. The advice is to go straight to the CT department and leave immediately after, and of course, to remember hand hygiene throughout your visit.

Please get dropped off and picked up so you're not taking anyone else in with you. Some long-term mesothelioma patients who have three-monthly CT scans have made the decision that they will skip this CT scan after their own personal risk assessment. On an individual basis, please feel free to speak to your healthcare team, or speak to one of our specialist nurses on the information line, as in some circumstances it may be acceptable to prolong the interval between your scans or to skip one.

You will now be contacted via telephone to discuss the results of your scan, so please ensure that your phone number is up to date on your records.

What will I need for a telephone consultation?
Try to have the following information to hand and make a note of any questions you wish to ask:

- NHS number
- Diagnosis letter
- Information about what treatment you have had and when
- Date of your last CT scan
- Any medication you are on

All this and more information is on our website at www.mesothelioma.uk.com

Clinical Research Network appoints Liz Darlison as new Clinical Research Lead

Mesothelioma UK's Head of Services, Liz Darlison has been appointed to be Clinical Research Lead for Division 1 (Cancer) for the Clinical Research Network (CRN) East Midlands.

Liz is also a Consultant Nurse at the University Hospitals of Leicester NHS Trust, an Honorary Senior Lecturer at De Montfort University, University of Leicester and the University of Sheffield, and brings this vast experience and expertise from her time working in research in the NHS to help shape the direction of cancer research across the East Midlands.

Commenting on the appointment, Professor David Rowbotham, Clinical Director at CRN East Midlands, said: "We are very pleased to welcome Liz to our clinical leadership team.

"She has a wealth of knowledge and experience from her time working in the NHS, and her passion for delivering research to change lives makes her ideally suited to join our team. We look forward to working with Liz to continue delivering high-quality cancer research across the region."

Liz Darlison added: "I would like to thank the senior management team at the CRN East Midlands for providing me, and nursing, with this opportunity.

> "I am optimistic about the impact that nurses can have on clinical research, particularly equitable access for our patients. I am grateful for the warm welcome I have received and look forward to working with the whole CRN East Midlands team, particularly my Division 1 colleagues."

UK Mesothelioma Alliance to coordinate virtual Action Mesothelioma Day 2020

Action Mesothelioma Day is a significant event in the calendar of many people in the mesothelioma community. Originally started by Mesothelioma UK over 13 years ago as a day of remembrance and commemoration, it has in recent years been powered by asbestos and patient support groups around the country. It became a series of local events, owned by local groups – a testament to the passion of the meso community.

With the COVID-19 pandemic putting a stop to large gatherings and public events, and closing many venues, the 2020 event is going virtual. The UK Mesothelioma Alliance (UKMA), which brings together mesothelioma stakeholders as one voice to raise awareness of mesothelioma through agreed projects, will be helping to co-ordinate and promote Action Mesothelioma Day 2020 with the help of support groups and other organisations.

UKMA is planning a joint virtual event as a national commemoration, with links to local virtual events or activities planned by support and patient groups.

The virtual Action Meso Day 2020 day will take place on Friday 3 July. The theme of the day will very much be focused around 'the patient', as well as the issues and solutions since being diagnosed with mesothelioma.

The UKMA team are currently finalising plans, looking at online options to host the event and working on resources to help raise awareness and make this yet another memorable AMD. Please visit www.ukmesoalliance.org for more information.

Lorraine Creech appointed as new Head of Nursing

Lorraine Creech has been appointed Head of Nursing for Mesothelioma UK. Formerly Clinical Nurse Specialist Team Leader, Lorraine has been promoted to strategic lead for the 26-strong UK nursing team.

Lorraine, who has worked for Mesothelioma UK for almost six years, will work closely with the charity's operational team, trustees and nurses to strategically lead and develop the clinical nurse specialist team.

Commenting on her new role, Lorraine Creech said: "I am delighted to take on the role of Mesothelioma UK's Head of Nursing. To be at the helm of the expert clinical nurse specialist service is such a privilege as we endeavour to support mesothelioma patients, their families and the NHS.

"This is more apparent than ever due to the coronavirus pandemic and witnessing how members of the Mesothelioma UK Clinical Nurse Specialist Team have altered their roles, accommodated new ways of supporting mesothelioma patients and diligently refreshed clinical skills in readiness to support the COVID crisis, has been amazing.

"Going forward, we would like to establish a Mesothelioma Clinical Nurse Specialist post in every Cancer Alliance in England, and increase our footprint in Wales, Scotland and Northern Ireland. The Mesothelioma Clinical Nurse Specialists are our tour de force, of course, ably supported by our dedicated Operational Team."

Head of Services for Mesothelioma UK, Liz Darlison added: "We feel that this new Head of Nursing post is vital, especially in the current health crisis, and we're delighted that Lorraine, with all of her experience and passion, has stepped into this post.

"Our nurses are currently supporting NHS colleagues to care for coronavirus patients as well as mesothelioma patients, but once the situation has improved, Lorraine will be preparing a nursing strategy and furthering our vision for mesothelioma nursing."

From physiotherapist to Meso UK Head of Nursing

We talked to Lorraine Creech, Head of Nursing about her career and the role of clinical nurse specialists...

What made you want to become a nurse and when did you qualify?
After completing my A levels and before commencing training as a physiotherapist, I worked during the summer as a nursing assistant. I was placed on a care of the elderly ward, mainly dealing with patients who had dementia and I loved it. I knew that nursing would be what I wanted to do, so after almost a year of physiotherapy training, I changed to nursing. I qualified in 1979 after my training at the University Hospital of South Manchester.

In which areas/departments/hospitals have you worked?
After qualifying, I worked on a general medical ward specialising in endocrinology, rheumatology and cardiology. It seems bizarre now to have all of these specialities on one ward, but this was when coronary care units were just being devised.

After that, I worked in the community as a district nurse in Central Manchester. This was an excellent grounding experience and there is something about looking after people in their own homes. It is their 'ground' and teaches you about being on their agenda and how to be resourceful.

Following on from this early experience, cancer and palliative care became the area of nursing which most interested me. To further my experience in palliative care, I worked at St Ann's Hospice in South Manchester.

I became a Macmillan Palliative Care Nurse at East Cheshire NHS Trust in 1990 and developed the Macmillan Lung Cancer Nursing Service in 1999. In 2007, I was appointed as the Macmillan Lung Cancer Lead Clinician for the trust. At that time, only two nurses in the UK held that position.

I was also the non-medical prescribing lead for the trust. I was the first nurse to qualify as a non-medical prescriber at the trust.

How did you come to work as a Mesothelioma Clinical Nurse Specialist?
As a Macmillan lung cancer nurse, looking after patients with mesothelioma always intrigued me. You know, it is often patients and their families who spark these interests in pathways to follow for healthcare professionals. Some years before, I had spent some time with Mavis Robinson who was based at Cookridge Hospital in Leeds and had developed a Mesothelioma Advice Service. I had also worked with Liz Darlison as a committee member for the National Lung Cancer Forum for Nurses (now known as Lung Cancer Nursing UK). Liz launched the Mesothelioma UK National Resource Centre in 2004, which was to become the Mesothelioma UK Charitable Trust in 2009.

Liz devised a team of nurses who were able to represent the area in which they worked. I became one of these nurses and we were known as MNAT (Mesothelioma Nurse Action Team). I represented Greater Manchester and Cheshire. Professor Mick Peake had also worked with Liz on setting up Mesothelioma UK and, with others, had developed a Mesothelioma Framework in 2006 which recommended that each cancer network should have a lead clinician and a lead nurse for mesothelioma.

I became the lead nurse for Greater Manchester and Cheshire. These roles were additions to our day jobs.

In 2013/14, funds were available for Mesothelioma UK to increase the number of Mesothelioma Clinical Nurse Specialists. With a number of key clinicians, we were able to complete an expression of interest and I was able to set up the Mesothelioma UK Nursing Service at Wythenshawe Hospital in South Manchester, which is the thoracic oncology unit for Greater Manchester and Cheshire.

Can you explain the importance of clinical nurse specialists? What specific contribution do they make to patients and the wider medical team?
The Clinical Nurse Specialists make a tremendous contribution to patients and the wider medical team. The Mesothelioma Clinical Nurse Specialists demonstrate advanced nursing practice, are clinical experts, and a professional resource for patients, carers and the multi-disciplinary team.

The CNS ensures the delivery of high quality, clinically effective care, advocacy and prioritises the needs of the patient. The CNS is alongside the patient as they navigate the pathway from diagnosis, treatment, throughout clinical trials and to end of life care. The CNS also carries out a brokering service of 'opening doors' for communication, support and signposting. All of these are vital to the physical and psychological wellbeing of the patient.

It is essential for the Mesothelioma CNS to be a team player and to have the determination to make changes and develop services. They play a vital role in the multi-disciplinary team and I also think it is important to have the courage to always do your best and be an advocate for the patient.

How has mesothelioma treatment and care developed since you started working in the field?
The treatment for mesothelioma is changing all the time. Not only do we have the standard chemotherapy, we also have many clinical trials that have been undertaken, are in process or are awaiting outcome reports. These have included different drug combinations, immunotherapy and other targeted therapies.

Some of the trials are also looking at the different modalities of treatment. For example, the MARS2 trial is examining the benefit of the surgical operation extrapleural decortication, combined with chemotherapy versus chemotherapy alone.

There can be no doubt that clinical trials and patient-related research are the way forward in improving the treatment and care for people with mesothelioma.

The treatment and care of patients with peritoneal mesothelioma is also improving and the National Peritoneal Multi-disciplinary Meeting has had an impact on this.

Why has the new Head of Nursing role been created?
As Mesothelioma UK develops, it is important to continually evaluate our structure. The Head of Nursing role has been created to enable a reporting mechanism and be accountable to the Chief Operating Officer/Head of Services. The role is responsible for the professional nurse leadership of Mesothelioma UK. The Head of Nursing will develop service strategies, ensure delivery of targets and foster a positive partnership across the Clinical Nurse Specialists of Mesothelioma UK, the Mesothelioma UK Operational Team and external agencies/NHS organisations.

What are your priorities and longer-term aims in your new role?
To be at the helm of the expert clinical nurse specialist service is such a privilege as we continue to support mesothelioma patients, their families and the NHS. Going forward, we would like to establish a mesothelioma clinical nurse specialist post in every Cancer Alliance in England and increase our footprint in Wales, Scotland and Northern Ireland.

There are 21 Cancer Alliances in England and increasing the number of nurses within the alliances and devolved nations is our aim. Amongst other projects, I will be working on a plan of action to achieve this goal.

Other priorities are to lead nursing staff in developing appropriate changes to practice in keeping with the service level agreement between their host trusts and Mesothelioma UK, and to promote a common vision and ownership of Mesothelioma UK's values.

How will your role support the Mesothelioma UK nurses team?
Alongside the Mesothelioma UK CNS Team Leaders, my role is to support the Mesothelioma UK nurses to drive up standards and equitable access to world-class treatment, trials and care. We have very strong links and communication channels allowing us to do this. Mesothelioma UK and I will continue to look where best to place new posts and where the infrastructure, support and expertise that they require can be provided. The nursing team is continually reviewed via an official arrangement at the review of the Mesothelioma UK/employing trust service level agreement which takes place every two years.

I will also continue to be integral in the planning and delivery of the Mesothelioma UK Clinical Nurse Specialist Professional Forum which takes place three times per year. I will endeavour to be a conduit for delivering information to the nurses and I believe this to be key to our success as a team.

What challenges do you see ahead for Mesothelioma Clinical Nurse Specialists, both during and beyond the pandemic?
The COVID-19 pandemic is obviously a very challenging time for everyone. I am immensely proud to be a nurse and witness how the NHS and other care authorities have responded. Some of the nurses have been redeployed to utilise their skills in different areas such as ITU, palliative care and within the ward environments as ward nursing staff.

All of the Mesothelioma UK nurses have changed their practices as we try to reduce the footfall of patients at hospital to promote safety, especially when the patients are vulnerable and on the shielding list.

A large amount of support has had to be delivered via telephone consultations and video links. We know this cannot replace the face-to-face contact which offers so much reassurance. However, we are endeavouring to make sure that patients and relatives feel informed, supported and reassessed to deal with any queries and concerns. Many treatments and follow up regimes have been changed, and it is very important that patients and carers are informed of the reasons for these changes. It is also very important that patients continue to report new, or a change in symptoms to enable the mesothelioma nurses to assist with these.

Beyond the COVID-19 pandemic there will be tremendous challenges as services have a period of stabilisation and treatments that have been altered recommence. Obviously, our first concern will be for our patients but in addition, I think that our nurses will need support, particularly psychologically. I feel sure that as a team, we will be able to address this because we are very supportive of each other.

As a charity, we may have funding problems going forward which could impact the development of new roles. Our income has been affected as crucial events and fundraising activities have been cancelled in the interest of safety and public health. Despite this, Mesothelioma UK staff, trustees and nurses are committed to continuing our work with patients, carers, families, support groups, fundraisers, our new legal panel and other healthcare professionals to grow the work of the charity and improve treatment and care for patients.

A new path to justice

By Brendan J. Tully, a Partner at New York-based Phillips Paolicelli LLP, representing veterans, workers and families who have been hurt by dangerous asbestos products and other dangerous chemicals.

For generations British citizens have been exposed to asbestos from products manufactured by American companies. However, they have customarily been unable to access American courts to seek redress for these exposures. Not anymore. A series of recent legal wins has made it possible for some British asbestos victims to bring cases in American courts. Global commerce necessitates a global approach to litigation, which has enabled British mesothelioma victims to recover millions of dollars and achieve justice for their families.

Historically, United Kingdom asbestos litigation focuses on employer and public liability. American asbestos litigation developed differently; focusing on the manufacturers of asbestos containing products. American companies sold asbestos containing/ contaminated products around the world, invariably exposing British workers and consumers to asbestos at home and abroad, causing mesothelioma in the UK. British mesothelioma victims' exposure was not limited to British products; their access to obtain monetary recoveries from those responsible should not be limited either.

Two types of cases have resulted in favourable outcomes for British mesothelioma victims in the United States; Royal Navy veterans/British seamen who travelled to the US and people who used American asbestos-contaminated talcum powder products. Although challenging, these cases can be very successful and can provide life changing recoveries that can support victims' families and pay for new medical treatments not covered by the NHS.

British law limits Royal Navy veterans' recovery for asbestos-related disease to a limited governmental benefit. However, the Royal Navy regularly docked in America and many ships were equipped with American asbestos products. Accordingly, Royal Navy and British seamen frequently have strong U.S. product liability cases against American companies.

For example, we represented a Welsh ship engineer who worked on various passenger and cargo ships that visited the United States, where he worked on American asbestos containing equipment such as pumps, valves, boilers, engines and turbines. We filed the case in the United States and recovered over $4 million for him and his family. In another case, we represented a former British Merchant sailor. He was exposed to asbestos from working in the engine rooms of British ships as they travelled abroad and in the United States. We filed suit in an American court against American asbestos product manufacturers and obtained over $3 million for our client and his family. These two cases are not alone. In these cases and many others, American law allows British veterans/workers to sue American companies in American courts.

We also represent British citizens exposed to asbestos contaminated talcum powder manufactured in the United States. These citizens have no legal recourse in the UK because there is no employer or premises owner to hold responsible. However, an American case against American talcum powder manufacturers may be viable.

In a recent decision, Pyle v. Pfizer, Inc., the New York Appellate Division upheld the rights of an English wife and her husband, to proceed with a legal action in New York against a New York manufacturer. Mrs. Pyle lived in England and Wales and never came to the United States. However, she used an American -made talcum powder (Coty) for decades and developed mesothelioma. The court rejected Pfizer's arguments to send the case to England, where it could not have been brought, and granted the Pyle family their day in court, in New York.

American companies that sold dangerous products in the UK for decades have, until now, escaped responsibility. That appears to be changing now that these brave British mesothelioma sufferers and their families are standing up and demanding justice; opening a new path to justice.

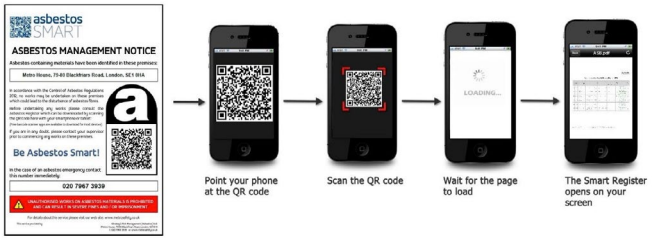
New partnership with UKNAR to highlight asbestos exposure

Mesothelioma UK has announced a new partnership with UKNAR (UK National Asbestos Register) to support fundraising, whilst highlighting the danger of disease resulting from exposure to asbestos.

UKNAR is a new social enterprise which helps dutyholders to manage asbestos simply and safely, while better informing and educating those at risk. UKNAR operates via its Asbestos SMART system, which allows 24/7 access to the UK National Asbestos Register. The UK National Asbestos Register aims to identify all known asbestos threats in UK buildings and can be immediately accessed via a mobile phone or tablet, by simply scanning a unique site-specific QR code.

UKNAR will donate five per cent of its license fees to Mesothelioma UK, as well as raising awareness of the charity's aims in support of key beneficiaries.

Andrew Paten, UKNAR Co-Founder said: "We are thrilled to be joining forces with Mesothelioma UK. UKNAR exists to make information visible, in order to save lives, by protecting people from unnecessary and potentially deadly exposure to asbestos fibres. Two million UK workplaces, schools, hospitals and homes still contain asbestos. Despite improved legislation, there continues to be thousands of accidental disturbances and exposures to asbestos every year.



"With our joint dedication to asbestos awareness and prevention, we are truly excited to offer practical support to the Mesothelioma UK cause."

Liz Darlison, Head of Services at Mesothelioma UK commented: "We are delighted that UKNAR is keen to fundraise for Mesothelioma UK through the introduction of Asbestos SMART.

"Having become very familiar with the Register, I am amazed how practical, incredibly easy and affordable the Asbestos SMART system is. It's a wonder that we haven't had something like this before in the UK, a national register to protect people against the dangers of asbestos, and sincerely, putting aside the potential income generation for the charity, preventing exposure to asbestos is something that everyone at Mesothelioma UK is delighted to support."

Andy Brown, UKNAR Co-Founder, added: "Our main focus this summer is getting the UKNAR message out to UK schools, sadly an alarmingly high-risk sector. Our pilot programme with UK schools is due to launch in the next few weeks and we are looking to onboard 50 schools initially to take part in our Asbestos SMART trials."

If you know a local school that might be interested in taking part in UKNAR's Asbestos SMART school pilot programme, please contact Stuart Towers, UKNAR Head of Research & Sales at stuart.towers@uknar.org or visit https://uknar.org/schools-and-education for more information.

PATIENT STORIES

A patient's experience of coronavirus

David Long is 69 and lives in Southampton. In July 2018, he was diagnosed with mesothelioma. He recently tested positive for coronavirus and wanted to share his experience…

Following his mesothelioma diagnosis, David took part in a clinical trial which went well for around 10 months until David experienced a severe reaction to it and had to come off it. David then tried privately -funded immunotherapy in November 2019 which worked to stabilise the cancer but not reduce it. In January 2020, David tried a different type of chemotherapy but again, had to stop due to a bad reaction to it.

David was on no treatment, just pain relief when in mid-March, he began to feel unwell with high blood pressure and a cough. He went to hospital and was tested for coronavirus but was told it was negative. Three days later he still felt unwell and went back to hospital. This time, the coronavirus test came back positive.

David and his wife Jo were shocked and frightened by this news. His consultant had already warned them that if David was to get coronavirus, it would be very serious for him and so they had already been self-isolating for a number of weeks. Understandably, David admits that he panicked a little and thought 'This is it, this could be the end.'

David was sent home and told to isolate – even from each other – within the home. This wasn't easy and the couple had to have separate bedrooms and one ate meals in the conservatory while the other ate in the lounge.

During this time David wasn't feeling too unwell. He had a cough, some breathlessness and had very low energy levels but wasn't in any pain – from the virus or from mesothelioma.

David was able to call his Mesothelioma UK Clinical Nurse Specialist, Helen Wilkes, at any time if he had any questions or concerns. As part of his medical team, Helen was made aware that David had coronavirus and called to check on him three times per week.

David says the support from Helen was fantastic and that she has been there for him from the beginning, always available to answer questions and very helpful.

After three weeks of isolating from each other, David called the NHS 111 helpline and described how he was feeling. He was advised that the virus had passed and that they didn't have to distance themselves from each other anymore – but to continue isolating as everyone else is.

For now, David's mesothelioma treatment is on hold. He is feeling quite well, just some breathlessness remains. He will have a telephone appointment with his consultant.

David's advice to mesothelioma patients who are worried about coronavirus is to follow the shielding advice and isolate as much as possible. He also wants to remind people that even if you do contract coronavirus, it doesn't necessarily mean that you will end up in intensive care or even in hospital. David has made it through coronavirus and is determined to keep fighting against his mesothelioma too.

Living Well With Mesothelioma

By Gordon Fee

Gordon talks about how exercise and a positive mental attitude has helped him to live well with mesothelioma...

During the spring and summer of 2018, I became increasingly breathless. I found jogging difficult and cycling up steep hills impossible. By August, I felt nauseous, and started to lose weight. On 3 September 2018, a visit to my GP and a subsequent X-ray found my right lung was full of fluid. I was immediately admitted to my local hospital, a CT scan confirming my mesothelioma diagnosis. I received the devastating prognosis of my cancer being terminal and given one year to live. Despite lung drainage and a procedure known as pleurodesis, my pleural effusion could not be controlled. Eventually, I was fitted with a permanent chest drain (IPC).

I was fortunate that my mesothelioma was confined to my right lung, with the CT scan revealing that I was at an early stage of the cancer progression. Despite my condition, I was determined to continue being physically active and exercising. I could no longer attend my twice weekly gym sessions but I walked or cycled every day and continued my home exercises.

Despite being 79 years old, my oncologist recommended that I go on the MARS 2 trial. Following an interview and tests, I was accepted on the trial. The medics running the trial were brutally honest about the possible side-effects and outcomes. Having already been informed about the aggressive nature of the cancer, I realised that I had nothing to lose by signing up to the trial. Also, altruistically, if it didn't work for me it may benefit some poor beggar following me.

Before commencing the trial, I was determined to get as fit as possible. Breathlessness made cardio-vascular training (exercise to increase my heart rate) such as running and cycling difficult so I increased my anaerobic exercises. This was helpful as it enabled me to maintain muscle bulk and strengthen bones. Also, it helped maintain stamina which would be essential when undergoing the trial treatments.

The MARS 2 trial began with two cycles of chemotherapy. Although I was warned about side effects of chemo drugs, I did not realise how severe they could be. The first cycle hospitalised me but despite this, I was allowed to exercise by walking along the corridor. Fortunately, I was able to manage the second cycle with a reduced dose. My exercise programme was adapted to light stretching each morning and walking. As the initial side-effects of the chemo wore off, I was able to increase my daily exercise.

Following the initial two cycles of chemotherapy, I was randomised by a computer to go down the surgical arm of the trial. I had been informed in graphic detail what pleurectomy/decortication entailed. It is a radical, aggressive surgery involving removal of the pleural lung lining and all visible tumour masses around the lung. The aim of this lung-sparing surgery is to debulk the visible cancer.

My surgeon warned me that after the surgery I would feel as if a bus had hit me. The Mesothelioma UK nurse also warned that the surgery would be no 'walk in the park'. They were not wrong! Post-surgery recovery was not easy. However, the staff and physios who cared for me were fantastic. I felt I had VIP treatment. My surgeon and ward staff encouraged me to get back on my feet. I was soon able to walk along the corridor, albeit encumbered by carrying lung drains. Before my hospital discharge, I was able to use a portable chair cycle. My ordeal was certainly challenging but I was determined to get fit and well again.

Once home, I worked on my fitness schedule which included chest exercises and walking. At first, I could not walk up my flight of 13 steps without stopping. Gradually, I built up the strength to climb without resting. This was not easy and it took a long time before I could improve my fitness levels. Ten weeks post-surgery, as part of the MARS 2 trial, I had to endure four more cycles of chemo. I struggled with the side-effects of the chemo as well as recovering from the surgery. Some days I was physically exhausted and could hardly get out of bed.

A speaker at the 2018 Mesothelioma UK Patient and Carer Day talked about coping with cancer treatments. She recommended meditation to help one relax and warned about the problem of 'Boom or Bust'. I realised that I was a 'Boom or Bust' guy. When my energy improved it was 'Boom', I went mad doing my exercises. Unfortunately, the next day I was 'Bust'. I was physically wiped out. I had to learn to pace myself, to think positively and enjoy each day as it came.

Fortunately, the surgery had debulked the cancer and I no longer had problems with fluid on my lung. Sadly however, despite six cycles of chemotherapy on the trial, the cancer had progressed. Further chemo Vinorelbine was commenced but was discontinued due to serious side effects.

I am now receiving palliative care. My local hospice has been fantastic. They provided a 12-week course with advice on how to live well with terminal illness. One important piece of advice was to think positively, relax and try to stay active.

Another invaluable source of support in keeping me positive is our local mesothelioma support group, MESSY, which meets approximately every month. Our forums have been informative and encouraging. They give many of the meso suffers and their partners an opportunity to socialise and encourage each other.

York Against Cancer runs a gym session with a personal trainer who assists cancer patients in improving their fitness. It has given me the confidence to return to the gym. Despite an impaired lung, I can gentle jog on a treadmill, use a rowing machine and do strength training. With the aid of a Fitbit I can monitor my cardio-vascular activities such as walking and cycling. In learning to adapt, purchasing an Ebike has encouraged me to continue my cycling.

Lastly, my Christian faith has been an essential part of my life. Believing in the power of prayer is a fundamental aspect of my being. A 16th century prayer puts it this way, "I thank God for my creation, preservation and all the blessings of this life…"

Welcoming Tracy Petrie to Meso UK

Mesothelioma UK's latest Clinical Nurse Specialist was appointed in April 2020. Tracy Petrie is based at Aberdeen Royal Infirmary, covering the NHS Grampian, Orkney and Shetland regions.

Tracy will be focused on caring for patients with lung cancer and mesothelioma at every part of their treatment journey, helping to make their journey as smooth as possible. She will also be working with Asbestos Action agencies in Scotland and with third sector organisations.

Prior to joining Mesothelioma UK, Tracy has been caring for patients with mesothelioma within her lung cancer clinical nurse specialist role for the last six years. Previously she worked in palliative care for seven years and has also been a Senior Charge Nurse elsewhere within NHS Grampian.

Tracy says: "The opportunity to become part of Mesothelioma UK's network of Clinical Nurse Specialists means that we will get ready access to information on the latest clinical studies, find out more easily about what other nurses and regions are doing to enhance best practice, and know where the north east of Scotland fits in to the wider UK picture for treatment and care.

"Since the national MDT was set up in Scotland, it's now more beneficial for patients to access research trials not just in Aberdeen, but wherever they are in Scotland."

LEGAL PANEL

Eight major UK law firms selected to support Mesothelioma UK

Mesothelioma UK has launched its first Legal Panel. The panel includes eight UK law firms which will support and raise awareness of the charity, as well as offering independent legal support to mesothelioma patients and their families.

The eight UK law firms represented on the Mesothelioma UK Legal Panel are:

fieldfisher

HUGH | JAMES

royds withy king
lawyers ahead of the curve

NOVUM LAW
NOVUMLAW.COM

IM irwinmitchell

Leigh Day

THOMPSONS SOLICITORS
STANDING UP FOR YOU

Slater Gordon
Lawyers

The Legal Panel covers a two-year period and the selected law firms will also support Mesothelioma UK fundraising events and campaigns, promote donations through legacies, share information for research and support other companies' claims work.

Head of Services for Mesothelioma UK, Liz Darlison commented: "We're delighted to be able to announce our Legal Panel supporters for the next two years. All eight law firms were selected following an open and comprehensive application process.

> "We're confident that they'll bring significant legal expertise to help us to promote the work of the charity and to increase our support for mesothelioma patients, their families and carers throughout the UK."

COVID-19, mesothelioma and you

By Helen Childs, head of a specialist team of asbestos-related claims lawyers at Royds Withy King Solicitors...

We are all living in unprecedented times. So much of the world is in lockdown in an effort to limit the spread of COVID-19. It's a particularly difficult and worrying time for any individuals and families affected by mesothelioma, or those who are unwell and as yet undiagnosed.

So many of our amazing specialist mesothelioma nurses remain diverted to the NHS front line, with several working in Intensive Care or on the wards treating COVID positive patients, and much of the normal running of the NHS has been put on hold to allow it to cope as well as possible. The normal cancer referral pathways - including for mesothelioma - have been disrupted because of delay in seeking advice due to a natural reluctance to see GPs for fear of infection, and the typical early symptoms of mesothelioma – including shortness or breath and a persistent cough - being so easily confused with the onset of -19. The NHS is very keen to encourage anyone with worrying new symptoms not to delay in seeking medical advice.

Those already diagnosed with mesothelioma are facing delays to the start of their treatment regimes and ongoing treatment, and many clinical trials being paused. Access to palliative care is more difficult, and those in hospital and hospices can be left feeling very isolated as visitor numbers are considerably restricted or banned. Even access to supermarket delivery slots has been difficult. The worry and uncertainty this new situation causes is considerable.

In an effort to help, charities like Meso UK and support groups have embraced and championed online services to try and relieve the isolation and answer practical questions posed by those affected. It would be nice to think that this online support could continue even when face to face meetings and support are possible again, as they enable charities and support groups to reach out to so many more families, including people unable to travel for support. The NHS has also been able to innovate and offer online consultations and remote Multi Disciplinary Team meetings – offering the possibility of help for patients without the difficulty of travelling to hospital, and the inefficiencies and inevitable delays caused by medics travelling to face to face MDTs to discuss diagnosis and any treatment options.

For those in hospital and hospices, the increased use of technology to keep in touch with families (I even saw a treatment chart on Twitter today with 'FaceTime with family' prescribed twice a day) is something to be embraced as an addition to care and treatment in the future.

Despite the anguish caused by a delay in any treatment being commenced, hopefully what will turn out to be a relatively short delay shouldn't adversely affect the outcome of that treatment for most.

The human spirit and willingness to find the silver lining in every cloud is humbling to hear. For example, one of my clients, who underwent an Extra Pleural Pneumonectomy in the autumn before commencing chemotherapy, was finding the chemotherapy so gruelling that she was really worried she would be unable to complete the course. Despite the worry caused by her treatment being paused, she is hoping that the additional recovery from her op and the first couple of cycles each week will put her in a much better state to embark on the remaining chemotherapy, and hopefully then immunotherapy as well.

There are several things about the current situation that are genuinely uplifting and will hopefully bode well for the future. The upsurge of goodwill for the NHS, the way it has been able to cut through layers of bureaucracy and become a much more cohesive whole, hopefully makes it more difficult for any government to fail to fund and support it better.

The uncertainty charities face over their income streams will hopefully be balanced to some extent by what feels like a real increase in community engagement and fundraising efforts – witness the recent 2.6 challenge. It's so important that we all continue to pull together and help in any way we can those charities and organisations that support families with mesothelioma at the moment.

For those pursuing compensation claims, your law firm is hopefully geared up to work from home to continue to support you and your family at this difficult time. The insurers dealing with your claim for the defendants seem, in the most part, to be less well prepared and less able to adapt than the claimants law firms.

The Judges and administrative staff in the High Court based in London that hear most asbestos claims have always been very accessible and responsive - and most hearings up to the trials themselves (which are incredibly rare) have historically been held by telephone for many years, so much of the court is still able to function well. Trials and hearings to assess the compensation payable are now being held remotely too.

Hopefully this means that for many when something approaching normal life begins to return, your lawyer will have been able to use the fact many defendant insurers are less well able to function to gain tactical advantages in your claim, and to issue and progress court proceedings and make sure that procedurally they are able to ensure that you can access bespoke and/or private medical treatment as soon as it's appropriate to do so.

Obviously nothing can compensate you or your loved one for their illness. However the principle of compensation is supposed to put you in the same position you would have been if you had not been unwell. We are, as a law firm, currently seeking enhanced compensation particularly for our clients who are self isolating because of their mesothelioma diagnosis and all the additional expenses that flow from these difficult times.

Just like we are being encouraged not to delay in seeking medical advice, early legal advice can be really important.

Mesothelioma UK has recently launched a panel of eight legal firms who specialise in claims for mesothelioma, and who have all signed up to a charter to ensure high standards of advice and care. It can be really difficult for anyone recently given bad news about their diagnosis to know where to turn to for legal advice, and hopefully the newly launched Meso UK legal panel will really help you and your family navigate through what is often a confusing route to specialist legal advice.

The DMPS – in need of reform

By Ian Bailey, Partner at the London office of national asbestos law firm, Irwin Mitchell

Writing this in the midst of the coronavirus pandemic, it feels like the lockdown status will never end. Most of us will have friends and family working within the NHS who are selflessly supporting sick people and devoting all of their energies to caring for those most in need and helping to steer the country to a much better place.

It seems hard therefore to focus on an injustice for mesothelioma patients which existed before the current medical emergency and will continue as we emerge from the crisis. However, this injustice must now be addressed urgently to support the needs of mesothelioma patients in the future.

Introduced in July 2012, the Diffuse Mesothelioma Payment Scheme (DMPS) was designed to provide one off lump sum awards for victims of mesothelioma comparable to civil awards. The Scheme, which was brought in to force by later legislation in 2014, helped to fill an appalling vacuum which had existed for many years, whereby individuals who had been the victims of negligent exposure to asbestos dust by dissolved employers and had gone on to develop mesothelioma, were unable to obtain compensation if insurance cover (the old policy document) for the dissolved employer could not be traced.

Often, this was because insurers had - on their own admission - failed to keep comprehensive records or those records had been lost or destroyed. Many of these missing records related to companies insured after 1972 when all employers were legally obliged to hold insurance cover against the risk of employees sustaining personal injury at work pursuant to the Employers' Liability (Compulsory Insurance) Act 1969.

Forcing the insurance industry to right this wrong, the Association of British Insurers (ABI) agreed to the introduction of the Scheme from July 2012 with a levy on insurers each year of a maximum of 3% of employers' liability insurance premiums. This was projected to provide £300m over a period of 10 years.

Those diagnosed before 25 July 2012 were unable to benefit from the Scheme which began to take applications in July 2014. In its report of the financial year to April 2018, the Department for Work & Pensions advised that the average award to sufferers was £145,000. The equivalent sum to April 2019 was £148,000 which has allowed the Scheme administrators to operate with a significant surplus.

These awards now fall some way short of compensation levels through the courts. Additionally, since the introduction of the Scheme, my experience as a specialist asbestos practitioner is that a two-tier system has emerged which the Scheme was designed to remedy. There are those who receive the fixed non-negotiable tariff under the Scheme, and those who are able to trace insurers and are therefore able to access funds for immunotherapy and other treatments not available on the NHS. The difference is therefore whether an historic policy of insurance has been traced by the insurance industry or not.

It has become increasingly apparent that treatments for mesothelioma which are not currently available on the NHS can be effective in controlling disease progression. Though clinical trials at many specialist centres are ongoing, from experience with my own clients, I can say that treatments have been successful in prolonging the lives of some clients and a small number have exceeded all expectations.

The problem is of course that whilst those with viable claims against insurers are able, for example, to claim loss of earnings in addition to the costs of treatment, those whose only remedy is via the DMPS cannot. With treatment costs on occasions exceeding £10,000 every three weeks, an average DMPS payment is likely to provide treatment for less than a year, leaving nothing for the family to compensate for other areas of financial loss.

Many will not be able to benefit from these new and evolving treatments because their disease has progressed too far, the patient declines treatment, opts to participate in a clinical trial or other unrelated conditions make any form of treatment unadvisable. However, for those who were negligently exposed to asbestos by their employers, the determining factor must be whether these treatments are recommended by the treating oncologist.

The Scheme can and must be amended to catch up with medical developments and expectations of patients and their families. In turn, the Scheme administrators can be satisfied that payments need be paid only to patients who receive treatment. It's time for the DMPS to end the two-tier system for victims.

RESEARCH AND STUDIES

New Audit and Research Strategy launched

In 2016, Mesothelioma UK launched a new strategy that explains what it will do to 'Make Mesothelioma Matter'. The charity wants to reach out to more people affected by mesothelioma, improving their experience and outcomes of treatment and care. Recognising that this vision will only be realised through relevant and scientific research, it has developed a new and exciting 'Mesothelioma UK 2020-2023 Audit and Research Strategy'.

The strategy outlines the charity's plan to offer a range of grant opportunities that will fund research and explore patients' experiences of care, through to research on patient treatments and outcomes of care. As part of this, the charity will fund an academic institute to host a new centre for research, called the 'Mesothelioma UK Research Centre'.

New funding streams will support new and existing audit research collaborations with academics, healthcare professionals and the charitable sector. Mesothelioma UK's vision is to use one-third of its income to fund this work. The Scientific Committee will review all funding opportunities and determine where best to spend the money.

To read or download a copy of the new 2020-2023 Audit and Research Strategy, please visit www.mesothelioma.uk.com/researchstrategy

European partnership to accelerate research

Researchers at the University of Glasgow and NHS Greater Glasgow and Clyde are set to benefit from a £5 million European research award to refocus research efforts on mesothelioma.

The award will support the University-led PREDICT-Meso (Pre-malignant drivers combined with target-drug validation in mesothelioma) project, which will establish an international network of researchers across the UK, Spain and Italy.

Together, teams hope to better understand how mesothelioma develops from its early stages and translate this into better treatments for patients.

The programme, which provides five years of funding for international projects, reflects a long-standing link between the UK and Europe working together to drive progress for people affected by cancer. The funding will help scientists across the UK develop new research tools, resources and infrastructure to improve scientists' understanding of cancer, including rare and hard-to-treat cancers, helping to find better ways to treat them.

Kevin Blyth

The project will be led by Kevin Blyth, Honorary Professor at the University's Institute of Cancer Sciences, Consultant Respiratory Physician at the Queen Elizabeth University Hospital and Senior NHS Research Fellow, as part of the Cancer Research UK Accelerator Awards programme.

Queen Elizabeth University Hospital

MAGS project complete

The MAGS (Healthcare Staff Mesothelioma Asbestos Guidance Study) project, funded by Mesothelioma UK and undertaken with the University of Sheffield, has now been completed.

The project examined the experiences of presentation, diagnosis, treatment and care of healthcare staff. Its aim was to gather up-to-date figures on the level of mesothelioma amongst healthcare staff, to look at published research examining their experiences and to interview healthcare staff with mesothelioma (or their partners). This was with a view to developing recommendations for increasing awareness of the risk of mesothelioma to healthcare staff. The project had three stages.

Stage one was a rapid review of the literature. All of the literature found concerned healthcare professionals, mainly doctors or nurses. There was nothing that examined the experiences of others such as porters, cleaners and laundry staff. This is important because anecdotal evidence from legal professionals suggests that such staff make many of the claims for negligent exposure to asbestos against the NHS. The literature itself showed that the doctors and nurses shared many physical and emotional experiences with other mesothelioma patients. In addition, they seemed more likely to be critical of some care provided.

Stage two was a Freedom of Information (FOI) request to NHS Resolution, the Body that deals with legal claims against the NHS. This found that the number of claims made for negligence suggests a much higher rate of asbestos exposure and mesothelioma than is currently reflected in official data. This official data has led to the conclusion that hospital staff are not at greater risk of asbestos exposure than the average person in the population. Our findings raise doubts about this conclusion.

Stage three was a set of interviews with seven current or former healthcare staff diagnosed with mesothelioma and with two partners, nine interviews in all. One interview concerned an administrative worker, the remainder concerned doctors or nurses. As such, we still lack information about non-professional healthcare staff. The interviewees had some experiences they shared with those in the literature review. In addition, there were others, such as a disappointment that the NHS was the source of their likely exposure to asbestos.

The study provides a basis for recommendations. These include the need to maintain FOI requests to NHS Resolution in order to get a more accurate picture of the extent of mesothelioma amongst healthcare staff than currently shown in official data. We suggest also that awareness of asbestos risk should be added to the mandatory training for new members of NHS staff.

The full report will soon be available on the Mesothelioma UK website.

MORE results finalised

Mesothelioma UK is finalising the responses to its second large scale survey - Mesothelioma Outcomes Research and Experience (MORE) - seeking to comprehensively capture patients' experiences.

Responses from 503 patients from across the UK were included in the final analysis across a range of areas including Occupation and Exposure, Appointment and Admissions, Managing Symptoms, and Communication and Support.

The survey highlights confidence and satisfaction across many areas but it has also revealed a number of interesting findings that Mesothelioma UK hopes to address over the coming months and years. The charity will share and disseminate findings to improve services, resources or any aspect of mesothelioma experience, treatment or care.

The final results will be published on the Mesothelioma UK website and shared via our social media channels soon.

New paper explores 'exceptional case' of immunotherapy treatment

A new medical paper, focused on how immunotherapy can treat mesothelioma, has been released. The paper, entitled 'Molecular and immunological features of a prolonged exceptional responder with malignant pleural mesothelioma treated initially and rechallenged with pembrolizumab' examined the case of mesothelioma patient and Meso Warrior, Mavis Nye.

Anna Minchom

Dr Anna Minchom, Consultant Medical Oncologist at the Drug Development Unit at the Royal Marsden Hospital and The Institute of Cancer Research, was one of the lead authors of the paper. Anna said: "There's lots of interest in immunotherapy treatments for mesothelioma. However, immunotherapy doesn't work for everybody so it's vital that we try to unpick why some patients respond well and others, not at all.

Mavis Nye

"Mavis responded really well and was an exceptional case. We looked at the biology of why Mavis responded, focusing on changes in immune cells and DNA changes in the cancer throughout her treatment. Though the information from the paper does not suggest specific new treatments, it furthers our knowledge of how mesothelioma patients respond to immunotherapy and I hope this will help in the fight to develop new, much needed, drug treatments for mesothelioma."

Mavis Nye added: "We are only at the start of treatments as 11 years ago, there was only chemotherapy, but in 2014, I was lucky to attend the Royal Marsden and to be given the chance to enter the MK3475 MSD Trial. After the harsh treatment of four years of chemotherapy, it was such a relief to find immunotherapy was so gentle with me. I didn't have many side-effects so the two-year trial was pleasant, even.

"My treatment has been on hold because of the coronavirus and I have been in lockdown for three months, so I was shocked when my scan showed progression to my spine. Although 17 per cent growth is still counted as stable and slow, I feared being told no more treatment but that wasn't so. The Royal Marsden had me back early so that I could carry on with the HyPer trial*.

"If this does fail, maybe the results will help in choosing other drug treatments for me in the future. It's not often a patient is able to read the results but to have the added bonus of a DNA report, I'm very privileged. I would like to see every Meso Warrior have a DNA report done at diagnosis to match them up to a drug but that's the new future. I'm only surviving due to research, which is so important."

You can read a copy of the paper at www.ncbi.nlm.nih.gov/pmc/articles/PMC7069263

* HyPeR is a multi-centre Phase 1 Dose Escalation Study of Guadecitabine (SGI-110), a Second Generation Hypo-Methylating Agent in Combination with Pembrolizumab (MK3475) in Patients with Refractory Solid Tumours.

CLINICAL TRIALS

Encouraging results from clinical trial

In April 2020, pharmaceutical company, Bristol Myers Squibb announced positive topline results from its latest drug trial. Checkmate -743, a pivotal Phase 3 trial met the primary endpoint of improved overall survival.

The trial evaluated the use of Opdivo® (nivolumab) in combination with Yervoy® (ipilimumab) compared to chemotherapy in patients with previously untreated malignant pleural mesothelioma.

Based on a pre-specified interim analysis conducted by the independent Data Monitoring Committee, Opdivo® in combination with Yervoy® resulted in a statistically significant and clinically meaningful improvement in patients' overall survival compared to chemotherapy (pemetrexed and cisplatin or carboplatin).

Sabine Maier, M.D., development lead, thoracic cancers, Bristol Myers Squibb said: "Malignant pleural mesothelioma is a devastating disease that has seen limited treatment advances over the past decade.

"These topline results from the CheckMate -743 trial demonstrate the potential of Opdivo® plus Yervoy® in previously untreated patients with malignant pleural mesothelioma, and is another example of the established efficacy and safety of the dual immunotherapy combination seen in multiple tumour types.

"We would like to thank the patients who participated in this trial, as well as the investigators and site personnel for their perseverance during the conduct of this study and in delivering this important result for patients in the midst of the COVID-19 pandemic. We look forward to working with investigators to present the results at a future medical meeting, and to discussing them with health authorities."

These interim results are the most positive mesothelioma drug trial results there have been in around 16 years. Mesothelioma UK looks forward to following the progress of the trial and its results.

Checkmate -743 – a patient's experience

Michael Conway, 68, took part in the Checkmate -743 trial and told us about his experience...

Michael was diagnosed with bi-phasic pleural mesothelioma in 2017. He was a builder and suffered an accident at work when a door fell on him. He carried on working but a couple of weeks later was still in pain and visited his GP. An x-ray revealed not only broken ribs but also fluid and a shadow on his lungs.

Michael was referred for a PET CT scan and a lung biopsy. These confirmed a diagnosis of mesothelioma. The news turned Michael and his wife, Denise's world upside down. Michael remembers just staying at home for weeks not knowing what to do or who to turn to. In his 65 years, Michael had never been ill and to be told he had an inoperable, terminal disease was devastating.

It was suggested that they try to speak to a mesothelioma specialist and, when they did, Michael and Denise discovered that there was an immunotherapy trial for which he might be eligible. The trial was Checkmate -743.

For the first time since the diagnosis, Michael felt positive and began the trial in August 2017. Michael was given both drugs – nivolumab and ipilimumab – and apart from some mild side effects (tiredness, itchy hands, reduced sense of taste and darker hair!), he tolerated the treatments with no problems and at some points even thought that he must be on a placebo.

Within a few months, Michael's tumours had shrunk from 21mm and 29mm down to 5mm. The couple were overjoyed and amazed at the results.

In December 2017, Michael began to experience more serious side effects which resulted in hepatitis. He had to stop the trial and was put on steroids. However, his sense of taste returned and he felt well.

Since then, Michael has been having regular checks and there has been no growth in the tumours. He has not needed any further treatment for mesothelioma.

Michael urges anyone diagnosed with mesothelioma to seek the advice of a specialist. He feels that being told that there was something that could be done brought him from a very dark place to a place of hope and positivity. The trial completely transformed his outlook on life, and he found himself talking to other patients, reassuring them that there is hope and encouraging them to be positive.

Michael changed from thinking 'Why me?' to feeling lucky that he had 65 years of good health. He says that taking part in the trial is the most positive thing he has done in his whole life and it meant that he didn't feel alone anymore – something he feels is vital to getting through a mesothelioma diagnosis.

As for his healthcare team, Michael couldn't praise them enough. He is forever grateful to the whole team and tells them this at every opportunity. They reply that they are just doing their jobs but, to Michael and Denise, it is so much more than this. They feel that the doctors and nurses really do care and they want others to know that there are people who will help and support them through the whole journey.

Michael wouldn't hesitate to encourage anyone to take part in a clinical trial. One of the reasons he joined Checkmate -743 was because he felt that even if it didn't work for him, he was confident that eventually the research would help others and lead to better treatment and outcomes for mesothelioma patients.

ARMED FORCES

Mesothelioma UK signs Armed Forces Covenant

Mesothelioma UK has signed the Armed Forces Covenant to demonstrate the charity's long-term commitment to the military community in the UK, as part of its 'Supporting our Armed Forces' project.

The Armed Forces Covenant is 'a promise by the nation ensuring that those who serve or who have served in the armed forces, and their families, are treated fairly'. By signing the Covenant, Mesothelioma UK is formally committing to uphold the key principles and recognise the value that the Armed Forces community brings to the country.

As part of the Covenant, Mesothelioma UK commits to training all clinical and benefits advice team members in Armed Forces communication, refer all Armed Forces patients to specialist benefits advisors, and undertake research to better understand the incidence and impact of mesothelioma among the Armed Forces community.

Mesothelioma UK's national 'Supporting our Armed Forces' project offers specialist information, an advice and support service for armed forces veterans and serving personnel affected by mesothelioma.

John Wilson OBE DL, Director of Employer Engagement at East Midlands Reserve Forces Cadets Association, commented: "We are delighted to have such an important charity as Mesothelioma UK on board with the Armed Forces Covenant. They are already providing direct support to members of the Armed Forces affected by asbestos cancer, but they have also made clear by their actions and policies that they intend to support our wider Armed Forces community, and we are very grateful for their support."

Head of Services for Mesothelioma UK, Liz Darlison, commented: "Our Supporting our Armed Forces project has gone from strength to strength and we're delighted, through signing the covenant, to formally commit long term to supporting the Armed Forces community."

Colonel (Retired) Ian Crowe added: "Today, I was pleased to witness the signing of the Armed Forces Covenant by Mesothelioma UK. It gives me the opportunity to thank the charity for all its doing in support of the Armed Forces Community and Veterans in particular who contract this terrible disease."

VE Day 75 Year Anniversary - commemorating our heroes

On Friday 8 May 2020, celebrations were in full swing throughout the UK as people celebrated the 75th anniversary of VE Day. For us, it has been great to see communities coming together during these challenging times, and to see individuals and families make the day special by decorating homes and gardens, and cooking up special treats.

Brian Wallis, Mesothelioma UK Ambassador reported back on VE Day celebrations by sharing efforts from the East of England region, from Cambridge to Wisbech and Bury St Edmunds to Southend.

Brian Wallis, Mesothelioma UK Ambassador with veteran Cpl. Fred Dunce, Essex Regt. (Guest of Honour, aged 94)

Cambridge – VE Day table display

Brian Wallis, Mesothelioma UK Ambassador made an upside down pineapple cake

Military Mesothelioma Research Project update

As part of the Military Mesothelioma (MiMES) research project at the University of Sheffield, Virginia Sherborne is working towards a PhD. She has recently completed a review of the research literature about the psychological effects of mesothelioma on patients and their carers, and the review has now been submitted for publication in a peer-reviewed journal.

Virginia's next step is to carry out an interview-based study. This study will explore the psychological effects of mesothelioma from the perspective of carers of UK military veterans with the illness.

From July 2020, Virginia will be aiming to interview people remotely who are the main informal and unpaid supporter of a veteran with mesothelioma. This could include spouses, partners, relatives or close friends. More information about the study and how to participate will be available on the Mesothelioma UK website soon.

FUNDRAISING

The Fundraising section of Mesothelioma Matters is where we usually highlight some of the fantastic and inspiring events, campaigns and activities held by our generous meso community to raise valuable funds for the charity.

COVID-19 has meant that all of our physical events have been cancelled, along with those planned by our amazing supporters and donors. We've tried to adapt to this challenging environment and have created all sorts of virtual fundraising events.

However, we still really need your support, now more than ever, as we face uncertain times financially.

If you can, please donate or come up with new ways to fundraise for Mesothelioma UK. You can find more details at www.mesothelioma.uk.com/getting-involved. Your support is so important at this difficult time and we thank you all for all that you do to help.

The Mesothelioma UK Fundraising team

Dorothy's artwork raises funds

The Dorothy Aromando Art Fund sells products such as prints and cards from Dorothy's artwork collection, with proceeds going to Mesothelioma UK. It was set up by Dorothy's daughter, Susannah Aromando, after receiving support from the charity during her mother's illness. Dorothy sadly died of mesothelioma in 2015 and so far, the initiative has raised around £4,000 for the charity through sales of Dorothy's wonderful creations.

Susannah wanted to thank Clinical Nurse Specialist, Sam for her support.

Dorothy's work can be seen at www.dorothyaromandoartfund.com

Leigh Day staff get fit in Feb!

During February, staff from Leigh Day Solicitors accepted Mesothelioma UK's challenge to get fit and supported their 'Fitness February 4 Meso' event.

A number of teams of budding athletes were formed from across the business and they ran, cycled, rowed, danced and lunged their way through the month in aid of Mesothelioma UK. The event was a brilliant success and Leigh Day raised over £1,000.

Effortless fundraising with Amazon

Mesothelioma UK, led by Liz Darlison and her team, gave my brother Mike wonderful support and hope when he was diagnosed with this dreadful disease. His life and quality of life were extended significantly from his original prognosis by the care and respect he received from everyone in Mr Waller and Professor Fennell's teams at Leicester.

Mike got to enjoy more trips abroad – where he liked to wander with no particular aim in sight, nights in a 5 star hotel drinking gin and tonic with lime (which I introduced him to when he couldn't cope with his normal beer), getting back to his juggling and of course, watching his beloved football club – Everton - yet again not win a major trophy.

Charities such as Mesothelioma UK need a regular flow of funding and you may not know about one way of doing this, which you might like to help with.

Now that so many of us are in lockdown we are probably making more use of delivery services such as Amazon. Did you know that if you subscribe to Amazon Smile you can nominate a donation to your chosen charity? I nominated Mesothelioma UK. Although they only receive a small amount each time I order, if we all started to subscribe it would soon add up.

This is Mike, juggling underneath the Eiffel Tower

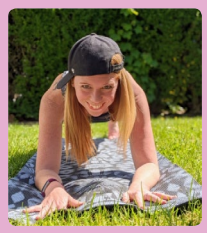
All you do is go to www.amazonsmile.co.uk. Choose your charity from the drop-down menu and order your goods as normal. It costs you nothing more and the charity gets the benefit. Think how this will grow when we all put our Christmas orders in!

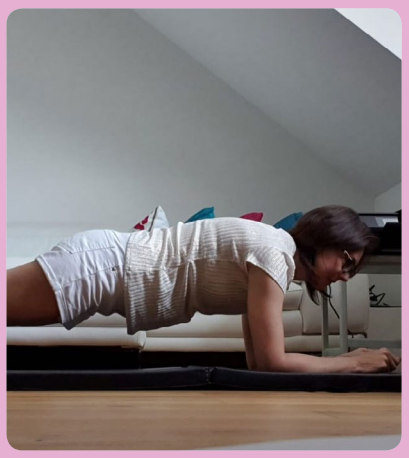
At times, when looking after Mike, my family and I felt completely helpless, so we are aware of how many of you must feel today. This is only a small way of staying positive, helping the team at Mesothelioma UK find better outcomes and supporting us all. One day they will find a cure.

Chris Emmett

Hugh James team take on 2.6 Challenge

On Sunday 26 April, Natalia Rushworth -White, Angharad Jones and Mary Mulhall from Hugh James took part in the 2.6 challenge by holding a plank for 2.6 minutes. Including Gift Aid, they raised an amazing £112.50!





Jenny takes on the Bath half marathon

Our amazing daughter-in-law, Jenny Buckle, from Southwick near Trowbridge in Wiltshire completed the Bath half marathon on Sunday 15 March 2020 in aid of Mesothelioma UK.

Her official finish time was 2 hours 28 minutes and 13 seconds! Her target was to raise £1,000 which she achieved and surpassed by collecting a wonderful £1,080.07! There was much anxiety as to whether the run would be able to take place due to the coronavirus issue. On the big day, the rain came down heavily - but it didn't dampen her spirits and just made her more determined.

My husband, John Buckle, was diagnosed with pleural mesothelioma in May 2016 and he is in complete admiration of Jenny for all the hours of training in the dark, whilst working full time and looking after her husband and two children.

I'm so proud of her for this achievement and I thank her from the bottom of my heart.

Mike's virtual birthday fundraiser

Mike Wilkes started a JustGiving page in celebration of his birthday and asked his friends and family to donate to Mesothelioma UK. Mike's daughter, Helen, is a Clinical Nurse Specialist for Mesothelioma UK. In support of his daughter and all of the team at Mesothelioma UK, Mike raised an incredible £1,000 including Gift Aid.

Helen's sewing marathon

Royds Withy King solicitor and one of Meso UK's very own trustees, Helen Childs took part in the 2.6 Challenge by purchasing 26 metres of fabric and sewing scrubs and scrub bags for the NHS to raise money for Mesothelioma UK and HASAG Asbestos Disease Support.

Helen completed her fantastic challenge and said: "I sewed for three solid days and have produced five sets of remarkably professional looking scrubs which are winging their way to a local hospital tomorrow. Thanks to my amazing sponsors for their generous support, and to HASAG and Meso UK, the charities who will benefit. I am also so pleased to report sewing is like riding a bike, you don't forget, and that I now remember how I love it!!!"

Including Gift Aid, Helen raised a fantastic £192.50 for the two charities.

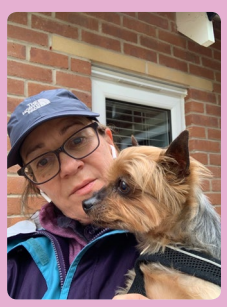
Team Meso Social Distancing DISTANCE Challenge: 5,000 km in 5 weeks!

To help our team spirit and to encourage fitness and activity during these weeks of confinement, the whole Meso UK team, operational staff, trustees, communications team and nurses, pledged to walk or run 5,000 kilometres across five weeks in March and April 2020.

During their allowed, once-daily exercise or on treadmills at home, team members recorded their walk or run, logged it and added it to the activity tracker.

Tracey Calvert, our Finance Manager, racked up the most kilometres with a whopping 520.83km!

Thank you for all your support and donations. We smashed our 5,000km in 5 weeks challenge and raised an amazing total of £7,170. Thank you all so much for your support, particularly to the South West Asbestos Support Group (SWASAG) for a huge donation of £5k.



Mesothelioma UK quiz night

A whopping £3,740.38 was raised for Mesothelioma UK in September by the dedicated London asbestos team at Irwin Mitchell Solicitors. The annual quiz night hosted by the London team is a brilliant celebration of the incredible work that Mesothelioma UK does to support victims and their families facing mesothelioma.

Touching speeches were made by former Irwin Mitchell clients on the night, reinforcing to everyone just how vitally important the work of Mesothelioma UK is to patients and families affected by mesothelioma.

Professor Jeremy Steele, a leading oncologist from Bart's Hospital gave an overview of the expansion plans for Mesothelioma UK to provide more support for patients across the UK.

The quiz night was a sell-out evening, with over 80 guests on the night and the competition for the top prize was very strong. All guests generously purchased raffle tickets, drinks and also made donations on the night, helping to achieve such an amazing figure of £3,740.38 for Mesothelioma UK.

Staff at Thompsons Solicitors bake up a storm in support of Mesothelioma UK

To mark VE Day, staff at Thompsons Solicitors took part in a virtual bake off to support 'Muffins for Meso UK'.

Traditionally, the annual fundraiser is used as a time for staff to get together and sell cakes to raise funds for Mesothelioma UK. However, with the current lockdown restrictions in place, teams instead took part from the comfort of their homes.

Thompsons, part of the newly appointed Mesothelioma UK legal panel of asbestos specialist solicitors, enrolled help from family and friends to create a variety of muffins, cakes, buns and scones as part of VE Day celebrations.

As part of the bake-off challenge, Thompsons' staff also donated to Mesothelioma UK to show their support for the charity, helping the charity to continue offering advice and support to sufferers and families affected by mesothelioma.

Helen Tomlin, one of Thompsons' specialist asbestos solicitors, said: "Despite the unique challenges posed by COVID-19, raising awareness and funds for charities such as Mesothelioma UK remains as – if not more – important than ever.

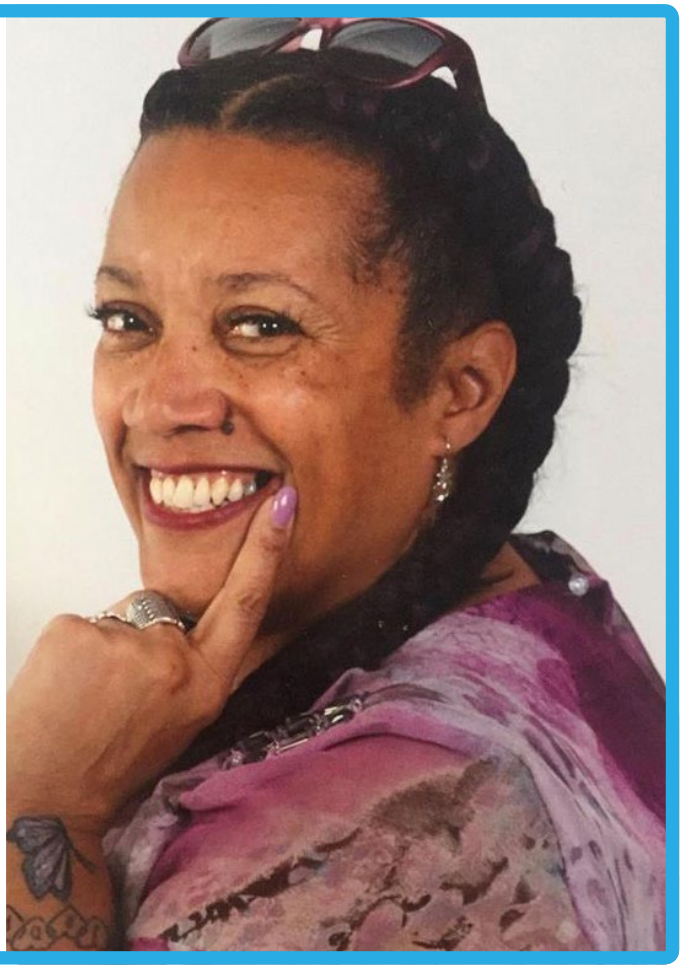
"The 'virtual' bake off also gave our teams a chance to do something creative with their families, which helps to keep spirits high in these testing times."

Raising awareness about mesothelioma is more important than ever – and the Thompsons asbestos team was delighted to support the Mesothelioma UK event once again.

In memory of Beverley Alleyne

Robyn Alleyne created a Just Giving page in memory of her mum, Beverley Alleyne, who sadly passed away from mesothelioma in July 2019.

Beverley, since her 50th birthday, had held a party each year and asked people to donate to Mesothelioma UK so Robyn and her siblings continued the tradition this year and held a party asking for family and friends to donate to Mesothelioma UK in her memory. In total, including donations collected from Beverley's funeral, they raised an incredible £1,075.00.



Much fun with muffins for Novum Law staff

Novum Law were thrilled to take part in this year's Muffins for Meso in May event. Due to the current working from home restrictions, we each made our muffins, shared our recipes and photos, and then had a Zoom call to show off our baking attempts.

We were lucky enough to be joined by Liz Darlison MBE who was able to judge our competition and gave out first prize to Steph Gerdes, who cleverly made the inside of her muffins rainbow patterned in the spirit of thanking our NHS and key workers. It was a great virtual event, all at Novum Law enjoyed taking part and managed to raise £240 for Mesothelioma UK.

Mesothelioma UK exists to provide services for the treatment and care of mesothelioma patients across the UK. Any sponsorship, grants or donations made to the charity support this activity.

Mesothelioma UK would like to thank all of our wonderful donors.
If you would like to find out more about becoming a corporate donor, please contact us on **0800 169 2409** or email **info@mesothelioma.uk.com**

Please donate to Mesothelioma UK if you can.

Events Calendar

Weekly Facebook Q&A with Meso UK Clinical Nurse Specialists plus other healthcare providers
Tuesdays from 10.45am
www.facebook.com/therealmesouk

Action Mesothelioma Day (virtual event)
3 July 2020
www.mesothelioma.uk.com/events/action-mesothelioma-day

Patient and Carer Day (virtual event)
2 October 2020
www.mesothelioma.uk.com/events/meso-uk-patient-carer-day-2020

Please send details of any local events to meso@sandstarcomms.com so that they can be added to the Meso UK website.

Many thanks to our Mesothelioma UK Legal Panel supporters

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