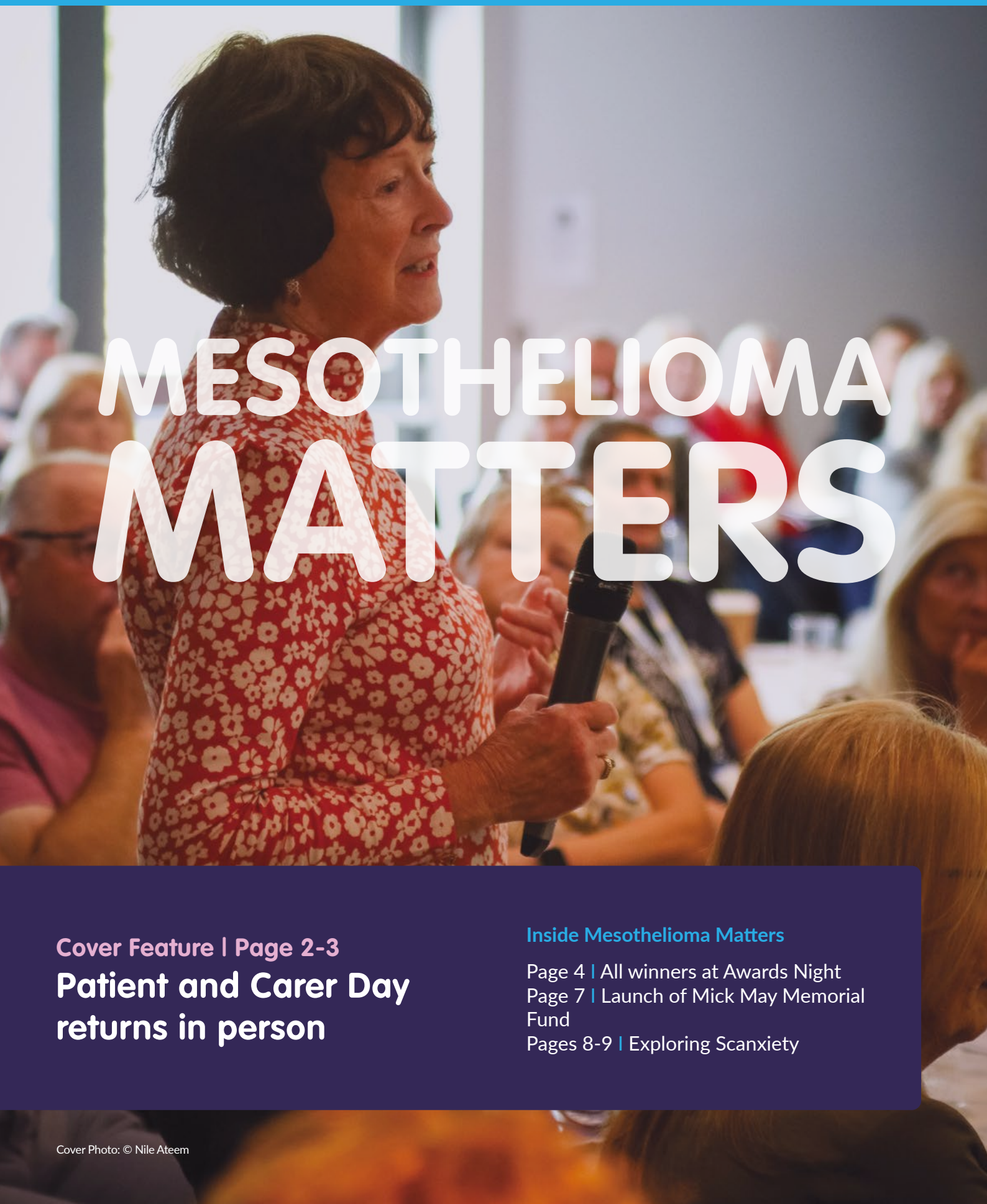
Winter Edition 2022

MESOTHELIOMA UK



MESOTHELIOMA MATTERS

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Patient and Carer Day returns in person

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NEWS

Patient and Carer Day - back in person!

Mesothelioma UK was delighted to host our annual Patient and Carer Day and Awards Night in-person, once again.

The Belfry Nottingham Hotel and Conference Centre was the setting for both events on a sunny autumn day in October.

As the guests began to arrive, it was wonderful to see and hear people enjoying being back in the same room as each other again. There was a real sense of excitement and anticipation to see speakers on stage, rather than on screen!

Mesothelioma UK Clinical Nurse Specialists Anne Moylan and Carolyn MacRae introduced the day and first up was Professor Dean Fennell, Consultant Thoracic Medical Oncologist, who gave an update on the latest clinical trials. Professor Fennell talked about the results of current and past trials, and also plans for new ones.

Up next was Dr Crispin Hiley to talk about radiotherapy and in particular, the innovative proton beam therapy (PBT) – a type of radiotherapy which results in less radiation to healthy tissue. Dr Hiley introduced the new HIT-Meso study that aims to produce high quality evidence for the use of PBT to treat mesothelioma patients.

Continuing the clinical theme, Dr Alastair Greystoke was next to talk about immunotherapy. There has been much talk of immunotherapy as a treatment with positive results lately and Dr Greystoke told us in more detail about how it works.

Mesothelioma UK Clinical Nurse Specialist Samantha Westbrook took to the stage next to talk specifically about peritoneal mesothelioma and how the National Peritoneal Service in Basingstoke supports patients with this type of the disease. She also spoke about the treatments available such as cytoreduction surgery and hyperthermic intraperitoneal chemotherapy.

The patients and carers in the room then had an opportunity to put their questions to the panel of healthcare experts. There was much interest in the new trials, and questions about their suitability and how to get on them were answered by the panel.

Following a short break, guests were then introduced to Dr Sarah Hargreaves and Professor Angela Tod from the Mesothelioma UK Research Centre – Sheffield who talked about their research which focuses on the patient and carer experience and quality of life. Dr Hargreaves also showed the Centre's video on palliative care which received a round of applause.

The interesting topic of accessing non-NHS treatments was then presented by a panel consisting of Partner at Irwin Mitchell solicitors, Ian Toft, Clinical Nurse Specialist at Sciensus, provider of healthcare at home, Andrea Flint, Professor Dean Fennell and patients James Casey and David Waldock. James and David shared their hugely positive experiences of receiving private treatment in their homes and the panel took several questions from the audience about how the service works.

A delicious lunch was served and guests had the opportunity to find out more about Mesothelioma UK's fundraising work, benefits and legal advice services, Armed Forces project and the Health Companion app.

Health and wellbeing were the focus of the afternoon session which began with a talk from the legendary Ron Snaith, or Great North Ron, as he is known. Despite his diagnosis, Ron has completed every Great North Run since 1981. Ron talked about his mesothelioma journey and the support that he's received from Mesothelioma UK and Readley support group. Ron's inspirational story touched many in the audience and he even tried to sign up guests to next year's Great North Run!

Food was the topic for the next guest speaker, dietician, Laura Millar. Laura talked about the issues many patients face in terms of food and diet such as changes in taste, inability to eat certain foods, loss of appetite, etc. She gave some excellent practical advice and received many questions from the guests.

A not-so-common symptom of mesothelioma, but an important one to those who have it, is sweating. Mesothelioma UK Clinical Nurse Specialist, Louise Nelson talked about the causes and practical ways to alleviate it.

Amy Chadwick, Occupational Therapist, spoke next with lots of practical advice on how to cope with everyday tasks at home. She emphasised self-care, physically and mentally, and talked about taking small steps to reach goals and taking the pressure off yourself to achieve everything you could do before.

More practical advice came from Sarah Thomas, Mesothelioma UK Benefits Advisor. Sarah talked about all of the discounts, savings and exemptions available to patients and carers.

Last, but by no means least, we welcomed Helen Bone to the stage. Helen is 39 and was diagnosed with mesothelioma aged 38. Helen shared her inspiring and at times emotional story with the guests and it's safe to say there were both tears and laughter. Helen spoke with honesty, humour and pragmatism, and explained why it's important to her to talk about her journey in her blog, *It Is What It Is* (https://helenbone82.wixsite.com/itiswhatitis), to raise awareness and help others going through a similar experience. Everyone was on their feet at the end of her talk, with a tear in their eye and the utmost respect and admiration for Helen.

Evening of stars at Awards Night

Mesothelioma UK's annual awards event took place on the evening following the Patient and Carer Day. Guests arrived in their finest black and white dress, and enjoyed a meal, drinks and a raffle before the awards were announced.

Many congratulations to our winners who were:

Junior Fundraiser of the Year - Reuben Gaunt
In September 2021, Reuben took part in the 20for20 challenge to raise money for Mesothelioma UK in support of his grandad, Ray. Since then, Reuben and his family have raised over £1,700 for us.

Fundraiser of the Year – Team Horner
The family of Russell Horner, who passed away from peritoneal mesothelioma, took on the Three Peaks twice and team member Robin took on the Leeds Half Marathon. The team has raised over £11,000 in memory of Russell and will continue to support the charity with further fundraising events.

Impact Award – the Rodgers family
The family of the late Tony Rodgers, daughters Laura, Niamh and Helen, and wife Barbara were eager to do what they could to improve support and care for others across Northern Ireland (NI) and we're working with them to achieve this. The family has been an essential catalyst for establishing a team approach to improvements across NI and have raised over £27,000 so far.

Special Contribution – Mavis Nye
Mavis was diagnosed in 2009 and set up the Mavis Nye Foundation in 2017. She works tirelessly to raise awareness and funds to improve treatment and care for other patients. Mavis says she has no intention of slowing down and is continuing her efforts to inform people about mesothelioma through education and campaigns.

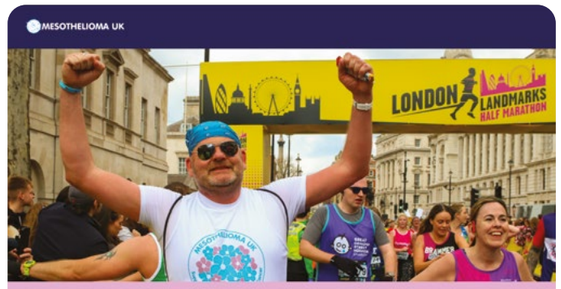
Most Inspirational Award – Sally Collins (posthumously)
This award was given posthumously to Sally Collins and collected by her husband Jasper and sons Rowan and Tom. Sally organised many fundraisers and always had a smile on her face despite facing mesothelioma and breast cancer. Sadly, Sally died in June. She was a true inspiration.

Corporate Sponsor of the Year - JDR Cables Limited
During the past ten years, JDR Cable Systems Ltd. has raised over £146,500 for its selected charities and Mesothelioma UK has benefitted tremendously from its efforts. The company held a charity summer ball this year that raised over £20,000 for Mesothelioma UK and Readley. We are very grateful to JDR Cables for its continued support and fantastic fundraising events.

Thank you to everyone who came and supported the event. We hope you enjoyed it as much as we did.

Launch of new organisational strategy

Mesothelioma UK has launched a new three-year organisational strategy. The new strategy can be downloaded from our website at www.mesothelioma.uk.com/strategy/



Mesothelioma UK Strategy
2022-2025

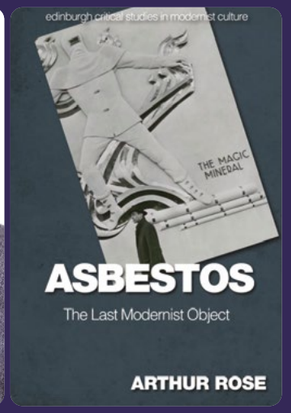
It will run from 2022-2025 and aims to shape the future of the organisation, whilst ensuring that it maintains its focus on supporting people with mesothelioma to live better and longer, and to prevent mesothelioma happening to future generations.

It provides supporters and sponsors with a clear insight into Mesothelioma UK's priorities for the next three years. The strategy also features Mesothelioma UK's vision and lists the key priorities for the Mesothelioma UK team (including the trustees, the operational team and Clinical Nurse Specialists) to work toward.

The strategy is based on five pillars which include improving outcomes and experiences, research, information, awareness, and sustainability. The strategic pillars drive the core business objectives that we aim to achieve and they identify issues that Mesothelioma UK will address. The first pillar for instance, which focuses on improving outcomes and experiences, aims to ensure that patients have equitable access to the best treatment, care, information and support, regardless of where they live. This will lead to better outcomes and experiences for mesothelioma patients and their families.

To achieve this goal, Mesothelioma UK has proposed a series of steps which includes publishing and promoting a good practice guide to mesothelioma, developing mesothelioma multidisciplinary teams and networks, and building its network of clinical nurse specialists. In this way, the new strategy will enable the charity to address different needs over time.

The language of mesothelioma



Arthur Rose is a Senior Research Fellow at the University of Exeter. He has just completed a new book, *Asbestos—The Last Modernist Object*, which looks at the ways that asbestos and asbestos-related diseases are discussed in literature, film and visual culture. Asbestos—The Last Modernist Object is free to download www.edinburghuniversitypress.com/book-asbestos-the-last-modernist-object.html

Arthur talks about his research here...

"Testimonies by people living with mesothelioma and their carers provide important responses to this devastating illness. They help clinicians and researchers come to grips with the lived experience of the disease. They supply lawyers and support groups with crucial information for pursuing compensation and legal redress. They also help efforts to raise awareness and the funds needed to continue vital research and employ specialist nurses. Most importantly, they give some solace to those that also live under the shadow of mesothelioma, from the recently diagnosed to the families left behind.

"And, while people might go to them for anything from practical tips about symptom management to the sense of assurance that others have gone through this before, these stories of experience help to bring people together into a community, reminding them that they are not alone.

"These contributions are valuable in their own right. But I would like to introduce a further role that storytelling, written or spoken, can play in responding to mesothelioma. Useful as these accounts are for others, I think that telling these stories is helpful for the storytellers themselves. By telling stories, we order our experiences. Sometimes this ordering is chronological: it follows the sequence of events as they happened. Other times it is more associative, where events separated by time are brought together because they share some crucial relation. Such ordering is important in bringing together the disparate elements of the mesothelioma experience: an exposure event in the distant past must suddenly be connected to the more recent process of diagnosis, which itself, is often a protracted pathway from noticing a cough to receiving test results. Still, this ordering can feel a bit heartless: how can the richness of an entire life be reduced to a few brief moments?

"In some work I've completed recently, I've been looking at the ways that writers of fiction and nonfiction try to make sense of mesothelioma diagnoses. What I've found is that they usually turn to the language of their everyday life to perform this sense-making. For some, philosophers and scientists, sense is found through talking about metaphysics or biological principles. For others, like teachers or doctors, it is through the language of learning or medicine. Still others, builders or construction workers, find this language in their terms of trade. The point is not that any one language is the right way to make sense of living with mesothelioma, but that everyone has a language that can help make sense of it for them. And, perhaps most importantly, that this sense-making has helped them in some way or another."

Looking forward to Action Mesothelioma Day 2023

Action Mesothelioma Day (Action Meso Day) took place on 1 July 2022 and saw over 100 buildings and landmarks around the country light up blue for the #GoBlueForMeso campaign.

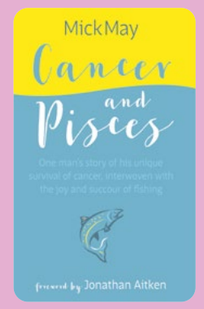
Action Meso Day is an annual event in July to raise awareness of mesothelioma and the dangers of asbestos. The campaign continues in 2023 and will build on the success of 2022 by once again, turning landmarks and buildings blue.

The UK Mesothelioma Alliance (UKMA), organiser of Action Meso Day, is asking people to contact their local building or landmark to see if it can light up blue on 7 July 2023.

More details and template letters/emails explaining about the campaign will be made available on the Action Meso website at www.actionmeso.org

Launch of new Mick May Memorial Fund

Mesothelioma UK is supporting the new Mick May Memorial Fund in honour of the late Mick May, a former City trader who co-founded Blue Sky, a not-for-profit social enterprise dedicated to employing ex-offenders and helping them into long-term work.



In 2013, Mick was diagnosed with mesothelioma. Yet, despite the odds being stacked against him, Mick went on to enjoy a further nine years, which he described as the most productive and happiest of his life, many of which are recalled in his memoir, Cancer and Pisces.

Mick received a series of interventions including a successful operation to remove as much of the lining of his lungs as possible in 2013, then there were three rounds of chemotherapy and he took part in an immunotherapy trial in Lille for 18 months. He was the first mesothelioma patient in the world to receive the cancer drug, vismodegib, to treat a genetic mutation.

Sadly, Mick died on 7 March 2022, aged 63.

If you would like to make a donation to the Mick May Memorial Fund, please go to: www.mesothelioma.uk.com/donate-now/

To fundraise for the Mick May Memorial Fund, please contact us at info@mesothelioma.uk.com and a member of our team will get in touch with you.

Exploring Scanxiety

Mesothelioma UK seeks to understand your experience

We have seen an increase in reports of delays concerning CT scan appointments and results. Faced with an already stressful situation, this can really exacerbate people's anxiety. Whilst the wider pressures faced by the NHS are no doubt a contributing factor, it does not make it any easier to bear. As an organisation, we want to support those affected and advocate on their behalf.

To achieve this, we are monitoring the situation, and collecting personal stories and experiences. Stories are extremely powerful and help us when reaching out to organisations. We will be acting upon the information collected and have a direct channel to the NHS England cancer team to talk about the issues and concerns identified.

We're also linking with Cancer 52, an umbrella organisation for a number of cancer charities. This will help us to understand if patients with other types of cancer are having similar experiences. If so, we can raise concerns through a broader range of groups and channels.

Supporting people in the here and now is also extremely important. We recently held a Facebook Live session where Liz Darlison gave practical advice on coping with feelings of anxiety and how to navigate the appointment system (you can find this under Videos on our Facebook page). For those who may have missed it, we've summarised some of her advice here:

Coping with scanxiety

Scanxiety is a term coined by patients. When something is given a name like that it tells us that it is a very common experience. It is part of the rollercoaster of emotions that are associated with being diagnosed with cancer. But that doesn't mean you have to accept it. There are things that you can do to help.

1. Talk about how you're feeling

Talking to family members and friends is important. But it can feel easier and safer to open up with people outside of your immediate circle. Support groups give you an opportunity to meet with others, in person or virtually, who have been or are going through similar experiences to you. There may also be the opportunity to listen to invited speakers talking about topics such as diet and palliative care. Our website has information about finding your local support group.

You can also contact the Mesothelioma UK support line. Our staff are available to signpost you to further sources of information and support as well as put you in contact with one of our Clinical Nurse Specialists who can offer their mesothelioma expertise. Call 0800 169 2409.

2. Talk to your healthcare team and ask questions

Keep your healthcare team aware of any appointment issues you have. Your oncologist or your nurse may not know you are experiencing delays, so do let them know, either at an appointment, or by phone or email.

Understanding how the appointment system works can also be helpful. It can differ between hospitals, but generally your next routine surveillance scan will be requested on the day that you attend clinic. The CT request form contains a space to enter the patient's next clinic appointment date. Often CT appointments and scan reporting schedules are based on this, so before you leave, ask about your next appointment date.

CT departments and teams prefer at least 7-10 days between your CT scan being performed and the clinic date where you are due to return for results. If you see that your scan hasn't been scheduled, or it has and it's not within this optimal time frame, do check. You can phone the CT appointment number; this should be on any letters you have received. You can also contact your consultant's secretary or your specialist nurse.

Your CT scan often uses an IV contrast to help the radiology team to visualise your lungs more clearly. But to have this, your kidney function needs to be checked every 6-12 months. When you are in clinic, just check to see whether you need a blood test before your next scan appointment. This can prevent any unnecessary hold ups.

3. Dealing with any problems

If you are not being kept sufficiently informed and are experiencing delays, raise this with your healthcare team and ensure that you or someone else lets the relevant department know. If you do this and still don't feel happy with their response, contact your hospitals Patient Advice and Liaison team (PALS). They will be able to look into the situation and will aim to resolve it, or at least find out more information for you.

Don't feel worried about talking to PALS. The number of reports that PALS receives is often used as a way of determining the departments in most need of review and investment. Each hospital will have its own PALS service but you can find out more about the overarching aims of the service at www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/

Opening hours over Christmas and New Year

Mesothelioma UK's head office will be closed from 12.30pm on Friday 23 December and will re-open at 8.30am on Tuesday 3 January 2023.

If you require urgent medical advice during this time, please contact your GP or dial 111 to access NHS medical advice.

We will endeavour to reply to any voicemails received as soon as possible after the office reopens on 3 January.

Mesothelioma Essential Update event

On 1 December, we jointly hosted an event for healthcare professionals with the British Thoracic Oncology Group (BTOG).

The event, a Mesothelioma Essential Update, was a chance for professionals working in the field of mesothelioma to get together to hear from other experts on topics including the genetics and pathology of mesothelioma, surgical and non-surgical treatment options, patient support and achieving excellence in the NHS.

The event was held at the Cavendish Conference Centre in London, and attended by around 150 healthcare professionals including oncologists, surgeons, histopathologists, lung cancer nurses, and respiratory physicians.

The Mesothelioma UK team was out in force with Head of Nursing, Leah Taylor updating attendees on how the charity supports patients; Clinical Nurse Specialist, Jenn Latham talking about a nurse-led Indwelling Pleural Catheter service, and Benefits Advisor, Sarah Thomas explaining how we support patients to access the right benefits.

The day was a huge success and it was great to collaborate with BTOG to educate and support healthcare professionals.

Mesothelioma UK Benefits Advisor, Sarah Thomas

Joining the world asbestos police

"Have you ever had an idea to surprise a few work colleagues but it went bonkers?"

Well, that's how Greg Byrne, Director of RB Asbestos Consultants, put it, when he described the time that he and his colleagues visited the asbestos museum in Rotterdam.

While they were there, they came upon an 'asbestos police badge' from the town of Asbestos in Canada. "I thought I would surprise them (his colleagues) so I got someone to make a few (badges) up from a photo I took. It ended up on LinkedIn and everyone wanted one – because everyone loves a badge, so I placed an order for 50 more and they all went.

"I have been asking people to make a voluntary donation of £5 to Mesothelioma UK, which is the charity my business supports, or the Mavis Nye Foundation."

The badges have been so successful that they have made their way around the world, to the US, Puerto Rico, Turkey and the UK, amongst a host of other countries. People in the US, Australia and Europe who buy the badges are encouraged to make a donation to their local mesothelioma charity.

Greg has run RB Asbestos Consultants for over 30 years now. The firm delivers asbestos compliance services and specialises in the removal of asbestos.

Greg's firm supports these efforts by donating £1 to Mesothelioma UK for every person they train.

In addition, he gives free talks to apprentices and various groups, including universities, to raise awareness of mesothelioma, whilst encouraging everyone who attends these sessions, to make a voluntary donation to Mesothelioma UK or the Mavis Nye Foundation.

Publications

Mesothelioma UK is delighted to include this regular addition to Mesothelioma Matters. In each edition any new publications in the preceding three months, the title, author and journal, will be listed. We hope you find this useful and thank you UHL clinical librarians!

UHL Clinical Librarian Service
"bringing you the evidence"

New scientific research

Systematic Review, Meta-Analysis and Bioinformatic Analysis of Biomarkers for Prognosis of Malignant Pleural Mesothelioma.
Lu Z, Zhang W, Huang K, Zhu M, Gu X, Wei D, Shi M, Chen Y, Wang H.
Diagnostics (Basel). 2022 Sep 12;12(9):2210. doi: 10.3390/diagnostics12092210.

Risk of Mortality from Respiratory Malignant and Non-Malignant Diseases among Talc Miners and Millers: A Systematic Review and Meta-Analysis.
Ciocan C, Godono A, Stefanin S, Boffetta P, Pira E, Clari M.
Toxics. 2022 Oct 5;10(10):589. doi: 10.3390/toxics10100589.

Systematic Review and Meta-Analysis of Pleurectomy/Decortication versus Extrapleural Pneumonectomy in the Treatment of Malignant Pleural Mesothelioma.
Danuzzo F, Maiorca S, Bonitta G, Nosotti M.
J Clin Med. 2022 Sep 22;11(19):5544. doi: 10.3390/jcm11195544.

CAR-T Cell Therapy for Solid Tumors: Are we Still That Far? a Systematic Review of Literature.
Karam A, Mjaess G, Martinez Chanza N, Aoun F, Bou Kheir G, Younes H, Kazzi H, Albisinni S, Roumeguère T.
Cancer Invest. 2022 Sep 20:1-15. doi: 10.1080/07357907.2022.2125004

Proposal for a new local recurrence score in patients with recurrent malignant pleural mesothelioma.
Lauk O, Neuer T, Battilana B, Inci I, Furrer K, Weder W, Hashimoto M, Opitz I.
J Thorac Dis. 2022 Aug;14(8):2835-2844. doi: 10.21037/jtd-21-1628.

Meta-analysis of survival after extrapleural pneumonectomy (EPP) versus pleurectomy/decortication (P/D) for malignant pleural mesothelioma in the context of macroscopic complete resection (MCR).
Magouliotis DE, Zotos PA, Rad AA, Koukousaki D, Vasilaki V, Portesi I, Spiliopoulos K, Athanasiou T.
Updates Surg. 2022 Sep 3. doi: 10.1007/s13304-022-01369-4.

A trial of intra-pleural bacterial immunotherapy in malignant pleural mesothelioma (TILT) - a randomised feasibility study using the trial within a cohort (TwiC) methodology.
Bibby AC, Zahan-Evans N, Keenan E, Comins C, Harvey JE, Day H, Rahman NM, Fallon JE, Gooberman-Hill R, Maskell NA.
Pilot Feasibility Stud. 2022 Sep 3;8(1):196. doi: 10.1186/s40814-022-01156-3.

Feasibility and safety of extended pleurectomy/decortication for malignant pleural mesothelioma. A single group experience.
Falanga F, Rinaldi P, Primiceri C, Bortolotto C, Oneta O, Agustoni F, Morbini P, Saracino L, Eleftheriou D, Sottotetti F, Stella GM.
Thorac Cancer. 2022 Sep 2. doi: 10.1111/1759-7714.14627. Online ahead of print.

Qualitative studies and patient experience

Factors affecting the life expectancy in malignant pleural mesothelioma: Our 10 years of studies and experience.
Cimen F, Agackiran Y, Düzgün S, Aloglu M, Senturk A, Atikcan S.
Medicine (Baltimore). 2022 Sep 30;101(39):e30711. doi: 10.1097/MD.0000000000030711.

Understanding clinical decision-making in mesothelioma care: a mixed methods study.
Henshall C, Dawson P, Rahman N, Ball H, Sundralingam A, Shahidi M, McKeown E, Park J, Walthall H, Davey Z.
BMJ Open Respir Res. 2022 Jul;9(1):e001312. doi: 10.1136/bmjresp-2022-001312.

Impact of Covid-19 on lung cancer and mesothelioma specialist nurses: A survey of experiences and perceptions.
Hargreaves S, Clayton K, Creech L, Darlison L, Ejegi-Memeh S, Fenemore J, Gardiner C, Taylor B, Tod A.Eur J Oncol Nurs. 2022 Oct 2;61:102207. doi: 10.1016/j.ejon.2022.102207. Online ahead of print.

Please contact your own clinical library or view the journals webpages to seek access to the full publications.

CLINICAL TRIALS

Polaris Group has announced positive top line results from Phase 2/3 ATOMIC study.

Polaris Group, a multinational biopharmaceutical company which researches and develops novel biological drugs for cancer and other metabolic diseases, has announced top line efficacy and safety data from the Phase 2/3 ATOMIC Study in patients with malignant pleural mesothelioma to assess ADI-PEG 20 with Pemetrexed and Cisplatin.

Data from Phase 2/3 showed that ADI-PEG 20 can significantly extend the overall survival in patients with malignant pleural mesothelioma. ADI-PEG 20 is the first arginine-degrading therapeutic to show positive top line results in a pivotal trial as a combination therapy for the treatment of malignant pleural mesothelioma.

ADI-PEG 20 is a biologic being developed by Polaris Group to treat cancers. Since arginine is one of the 20 amino acids that are essential for protein synthesis and survival of cells, some cancer cells become dependent upon the external supply of arginine to survive and grow. ADI-PEG 20 is designed to deplete the external supply of arginine, which causes arginine-dependent cancer cells to die while leaving the patient's normal cells unharmed. Multiple cancers have been reported to have a high degree of arginine dependency.

Howard Chen, the Chairman of Polaris Group, said: "The results pave the way towards our working with the regulators to bring this novel biologic to patients with MPM (malignant pleural mesothelioma).

"As this study evaluates a new mechanism of action to treat cancer, having endpoints reach statistical significance is a remarkable finding. We plan to accelerate our pipeline projects and expand to other indications leveraging this unique mechanism of action to starve cancer cells by making use of combination with other chemotherapy and radiation."

Data will be submitted to health authorities globally, including the US Food and Drug Administration and the European Medicines Agency.

Polaris Group's press release on the results from Phase 2/3 of the ATOMIC study, can be viewed at https://polarispharma.com/2022/09/21/20220921001/?lang=en

RESEARCH

Examining the psychological effects of mesothelioma on military veterans from the carer's perspective

Dr Virginia Sherborne from the Mesothelioma UK Research Centre in Sheffield has published the research from her PhD thesis entitled 'The Psychological Effects of Mesothelioma in the UK Military Context From the Carer's Perspective: A Qualitative Study' in the journal of Illness, Crisis & Loss.

The study aims to address previously identified gaps in relation to mesothelioma's psychological effects, particularly from the carer's perspective, along with its effects in different workforce groups.

The study showed that many of the psychological effects experienced by the carers and veteran patients mirror those of the wider mesothelioma population, for example, shock at diagnosis and delay-related anxiety.

The study's participants explicitly talked about how the military culture affected them and their relatives and they reported a reluctance to show weakness, while carers experienced guilt and traumatic stress symptoms. This suggests the concept of military masculinity, where physical endurance and toughness are prioritised over self-care.

More importantly, the study provides greater insights into recognising when traumatic stress affects not only military veteran patients, but their carers too.

The study's data suggested that some participants experienced moral injury, defined in brief as 'a negative self-judgement' with symptoms of shame, depression, survivor guilt, despair and other emotions, which led to them focusing on unresolved anger or blame, negative self-evaluation, and a breakdown in spiritual belief and trust issues.

The study calls for a greater understanding of moral injury and its negative psychological effects, which in turn, can help to develop the support that professionals provide to UK military veterans and their carers, and shed light on potential research to benefit the wider community of people living with mesothelioma.

Dr Sherborne's study is available on the SAGE Journal's website at: https://journals.sagepub.com/doi/full/10.1177/10541373221122964

Mesothelioma UK Research Centre is looking for new volunteers

What is Patient and Public Involvement?
The Mesothelioma UK Research Centre (MURC), based in the Division of Nursing and Midwifery at the University of Sheffield, was established in July 2020. It immediately set up a Patient and Public Involvement (PPI) Panel to support its research activity. The MURC PPI Panel now has approximately 20 members. Patient and Public Involvement (PPI) refers to the involvement of patients, public and lay people in the design, conduct and dissemination of research. PPI is a fundamental component of research.

What has the Mesothelioma UK Research Centre PPI Panel been doing?
Since the PPI Panel was established, it has been central to the research of the Centre. In one 12-month period, the PPI panel contributed to eleven research projects and funding applications. The role of the PPI panel included consultative activities (reviewing funding applications, advising on research questions and methods, advising on dissemination) and collaborative involvement (membership of steering committees, supporting recruitment, developing recommendations). The PPI panel has improved the design and conduct of research in mesothelioma and contributed to a culture which supports active patient involvement in research.

How does the MURC PPI Panel work?
The level and amount of involvement is entirely up to each member. There are meetings every two months that are held online and last 60-90 minutes. Attendance is voluntary so if you don't have time, you don't have to attend. Detailed notes are circulated to everyone to keep people informed. When advice or input is required for a project, all PPI panel members are contacted and volunteers requested. If the time isn't right or the topic isn't of interest, then that's fine. Panel members only become involved if they can and a project fits their interest.

How can you help?
The MURC PPI panel is always looking for new members. If you are interested please do get in touch with us by email at mesotheliomaresearchcentre@sheffield.ac.uk or c.gardiner@sheffield.ac.uk

If you would like more information about our research or the PPI panel, please visit www.sheffield.ac.uk/murc

Share your experiences of pleural mesothelioma

SCAN ME

A market research project is looking to interview people in the UK living with pleural mesothelioma, including carers, to share their experiences. The research is being conducted by Strategic North, an independent market research company, and is sponsored by a pharmaceutical company.

The purpose of the research is to better understand the experiences of those living with this diagnosis, in order to improve the support that is available to them.

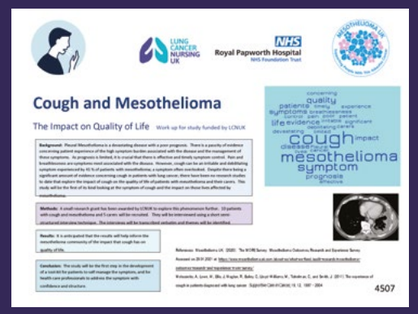
Key information:

- It will be a 60 min online interview with a short pre-task beforehand
- They are interested in understanding the journey you've been on since diagnosis and your experience of support along the way
- It will take place up until March 2023 with flexible slots to fit your schedule

If you are interested in taking part, you can find out by scanning the QR code.

Impact of cough on pleural mesothelioma study now open for recruitment

A new study has been launched which will examine cough and its impact on the quality of life for patients with Pleural Mesothelioma (PM). The research project, headed up by Kate Slaven of Mesothelioma UK, a Lung Cancer Clinical Nurse Specialist based at the Royal Papworth Hospital NHS Foundation Trust, will run for a year and aims to offer greater insights into the experience of cough in patients with PM and the impact it may have on their quality of life, as well as on their carers.



Kate said: “I am thrilled to have been awarded research ethics approval from the University of Sheffield. This will mean that the cough and mesothelioma study can now be started in earnest and is open to recruitment.”

Pleural mesothelioma is a progressive and incurable rare cancer with a poor prognosis. The symptom burden may be significantly distressing and complex. Effective and timely symptom control is crucial given the poor prognosis for patients with PM. Therefore, gaining fast and effective symptom control is paramount.

To lay the groundwork for the study, funded by a research grant from Lung Cancer Nursing UK, members of the local mesothelioma support group who developed a cough were asked a series of questions to determine if ‘cough’ was a subject in need of research. The group members felt that cough is a symptom that is overlooked by healthcare professionals, who tend to focus on breathlessness and pain as a priority. Cough is debilitating and tends to disrupt patients’ quality of life and can lead to embarrassment, exhaustion and fear. In addition, its unpredictable nature causes distress and group members reported that their families feel irritated by the cough. The group reached a consensus that cough is worthy of further exploration.

The study will involve up to 15 people and will be advertised by Lung Cancer Nursing UK (LCNUK) and on the Mesothelioma UK website, its Facebook page and Twitter feed. All Mesothelioma UK nurses will be approached to support the study by identifying PM patients with a cough and their carers who may be interested in taking part.

Kate continued: “I wanted to do the study because I had met several patients in the clinic who were otherwise well except for a troublesome cough and I felt that I had little to offer them. The long-term goal after this initial exploratory study is to establish the most effective ways to manage the symptom and to develop guidelines for cough management for people with PM.”

If people have cough and are interested in participating in the study, please contact the Mesothelioma UK support line on freephone 0800 169 2409 (Mon to Fri 08:30 to 16:30).

Upcoming study: Rethinking continuity in primary care for people with mesothelioma

This project is being undertaken for Dr Emilie Couchman’s PhD. It is funded by Mesothelioma UK and sponsored by the University of Sheffield.

The aim of this study is to understand the experiences of patients with mesothelioma, their close persons and their primary care healthcare professionals. Specifically, we wish to understand the effort it takes patients and their close persons to achieve their desired level of continuity with their GP and other primary care healthcare professionals.

Do you have a diagnosis of mesothelioma? Would you like to take part in this research study? Please email Dr Emilie Couchman at emcouchman1@sheffield.ac.uk with your contact details and she will be in touch.

APPOINTMENTS

Helen joins the Mesothelioma UK nursing team

The Mesothelioma UK nursing team has recently been strengthened by the appointment of Helen Wallace who will be working for the Northumbria Healthcare NHS Foundation Trust. Helen will be based at Wansbeck hospital but will cover all four of the Trust’s hospitals.

Helen has been a lung cancer nurse since 2020 and previously worked on a busy oncology unit. In her new role, Helen will work alongside Mesothelioma UK colleagues Leah Taylor, Head of Nursing, and Joanne Anderson, Clinical Nurse Specialist, to offer support and advice to patients and families and share her expertise with other healthcare professionals.

Commenting on her new role Helen said: “I’ve always been very interested in mesothelioma and I’m honoured to have this opportunity. I am keen to raise awareness of this rare and complex cancer and hope that no one diagnosed ever feels alone.”

Head of Nursing for Mesothelioma UK, Leah Taylor added: “I am delighted that this opportunity has arisen within Northumbria Healthcare NHS Foundation Trust. Helen brings a wealth of knowledge and experience to the role and I look forward to working alongside her to support those affected by mesothelioma within Northumbria and across the North East.”

LEGAL PANEL

The rise of mesothelioma in women

By Simon Rosser, Solicitor and asbestos disease specialist, Simpson Millar, Cardiff office

Simon Rosser

The number of women being diagnosed with mesothelioma is on the rise.

Every year the Health and Safety Executive (HSE) publishes statistics on mesothelioma deaths in Great Britain. These figures show that there has been an increase in the number of women affected by this horrific illness over the long term – with 459 female deaths in 2020, a rise of 7 per cent compared to 2019, and significantly higher than the average of 416 deaths per annum over the last decade; an upward trend we have also seen within the cases we manage on behalf of our clients.

Sadly, the HSE's report goes on to predict that there will continue to be 400-500 female deaths per year throughout the 2020s. Whilst, historically, mesothelioma has typically affected men exposed to asbestos while working in heavy industry, in the case of women it is often more difficult to determine from where the disease was contracted. This is because fewer women worked in such occupations, which can prove challenging when investigating a claim.

We are now seeing more female mesothelioma victims who worked in the tertiary sector - from teachers and school staff, through to nurses and hospital workers - whose exposure is likely to be as a result of the disturbance of the asbestos in the buildings in which they worked.

Worryingly, according to The Asbestos Crisis 2015 paper, it is estimated that at least half a million commercial properties, and around 75 per cent of all schools, still contain asbestos. This includes hospitals, schools, care homes and other local authority buildings, and remains a real cause for concern for those who work, live and spend time in properties which currently expose them to a risk of terminal illness.

Ms M's story

I have recently represented a nurse who was exposed to asbestos whilst working at a hospital in the early 1970s.

Ms M found that she was starting to feel breathless while walking up and down the stairs. Following a visit to her GP, an x-ray and biopsy, it was revealed that she was suffering with mesothelioma. Shortly after her diagnosis her health deteriorated, and she was forced to give up the job she loved and rely on support from friends. In May 2018, she reached out to me to investigate her claim.

I was able to track her exposure to her time working as a student nurse in Ipswich in the 1970s. She and colleagues would often take a shortcut down a maintenance boiler room corridor between the main hospital buildings to get back to the nurses' quarters. This had very low ceilings and thick lagged pipes directly overhead and was in a bad state of repair. This minute or so walk a few times per day over a year or two was enough to expose her to small amounts of asbestos fibres.

Expert occupational hygienist evidence was required to consider the levels of exposure. Despite this being a case of low-level exposure, I was able to settle her claim for £145,000.

Tragically, such cases relating to low level exposure amongst women are becoming more frequent. We are disappointed by the Government and HSE's response to the April 2022 Work and Pensions Report, which appears to sweep over the suite of reforms recommended, and we continue to support the proposals for a National Asbestos Database and the co-ordinated efforts to remove asbestos from at risk buildings.

Digby Brown LLP helps Clydebank Asbestos Group with landmark book

By Fraser Simpson, Partner at Digby Brown LLP

Clydebank is seen by many as being at the epicentre of our post-industrial asbestos legacy, due to the shipbuilding and heavy industry history of the upper-Clyde. For 30 years, Clydebank Asbestos Group has been at the forefront of campaigning for and supporting victims of asbestos-related disease, providing much needed, local, holistic support for many hundreds of families.

To help mark its anniversary, Digby Brown worked with the charity to develop a book, *Asbestos and Clydebank* which is hoped will help raise awareness to improve health and social investment to protect current and future generations.

The 44-page book serves as an easy-read guide on the history of asbestos and heavy industry, suited for all ages and backgrounds. It brings together poignant, first-hand accounts of people affected by asbestos disease, campaigners and supporters, to highlight the devasting impact of asbestos on the community and beyond, and the important role asbestos support charities like Clydebank Asbestos Group have to play.

Contributors range from retired tradesmen who continue to live under the shadow of increased risk of disease due to past occupational asbestos exposure, to current mesothelioma sufferers like Clydebank local Laura Evans, who at 32, is one of the youngest mesothelioma patients in Scotland, and whose words humble us with their strength and dignity,

"It sounds morbid but the reality is, when I die, I want to know my story is there so that more people will take notice."

It is thought *Asbestos and Clydebank* is the first publication of its kind to gather first-hand accounts of people affected by asbestos disease. Professor Andrew Waterson, an occupational health and safety expert, speaks in the book about the importance of hearing from real people, "It's the lost voices that need to be captured."

For Digby Brown, the vision for the book was commendable because it rightly – and finally – places the spotlight on real people and their communities which gives them the recognition they deserve, so we were passionate in providing support to turn this vision into a reality. The company believes *Asbestos and Clydebank* is not just interesting and informative reading material – it is a vital social document that we hope will be a catalyst for positive action to improve the future.

The book is not currently available for public sale, but copies can be requested by contacting the charity on 0141 951 1008 or by emailing rachel@clydebankasbestos.org

There is no charge for the book, but voluntary donations can be made by visiting the charity's Just Giving page at www.justgiving.com/clydebank-asbestos

FUNDRAISING

The Power of Your Pledge – our new legacy booklet

Gifts in wills are a vital source of income for charities to help them continue their work.

Mesothelioma UK's vision is a future free of mesothelioma. Our mission is to support people with mesothelioma to live better, live longer and prevent mesothelioma happening to future generations.

Every gift that we receive is helping us to pursue this mission. We are able to plan ahead to help fund research projects and specialist nurses where they are most needed, and be the patient's voice when talking to the Government and campaigning for change.

Leaving a gift in your will is not complicated. In fact, it's quite easy, especially as we provide a professional free will writing service with all of the guidance that you need. Information on how you can access a free will is in our new legacy booklet.

Click on the QR code and request your copy.

SCAN ME

Every gift, no matter the size, is greatly appreciated and very humbling. It emphasises to us the deep desire of our supporters to see us succeed in our mission. The commitment and generosity of our supporters motivates us to pledge to you that your gift will be used wisely.

We strive to ensure administration and running costs are sensible so that the funds you give can go where they have the biggest impact.

It's your legacy and your right to decide.

The power of your pledge is amazing and can change lives!

If you want to know more, please contact us on 0800 169 2409.

Jill Lemon
Mesothelioma UK Senior Fundraiser, Legacy & Challenges Officer

Share your story

Not everyone knows about the dangers of asbestos and mesothelioma – you can help to change that.

Sharing a video of your story can make a difference, helping those who have been diagnosed with mesothelioma, as well as families and carers.

So, whatever it is you want to talk about, be it your treatment journey or sources of support, we'd like to hear about it.

To find out how to share your story with us contact fundraising@mesothelioma.uk.com or visit our website at www.mesothelioma.uk.com/share-your-story/

Christmas Shop

As the festive season approaches, we would like to remind our supporters that we have a variety of Christmas cards available to purchase on our website, as well as a Mesothelioma UK bauble, which can be personalised with a loved one's name for just £1 extra. These can be found at www.mesothelioma.uk.com/christmas-cards/

Christmas Carol Off 2022

It's that time of the year again! Following last year's successful Christmas Carol Off, the ever-popular singathon showcasing the talent and vocal stylings of our colleagues, is back again this Christmas.

Categories this year include:

- Best Vocal Harmony (for all budding singers)
- Best Performance & Musicality (for those who play an instrument[s] including spoons, kazoo and recorders - anything goes!)
- Best Entertainment & Presence (if you can't sing or play an instrument, then you can just dress up and perform)

You'll be able to watch the array of festive talent as all video entries will be uploaded to the Mesothelioma UK website where they will be featured until 14 December.

Watch the videos at www.mesothelioma.uk.com/christmas-carol-off

A panel of independent judges will vote on the three winning teams and winners will be announced during our Christmas Facebook Quiz on 15 December. The winning entries will then be uploaded to the Mesothelioma UK website on 17 December where they will be featured until 31 December 2022. Each winning team will be presented with a certificate signed by our CEO, Liz Darlison.

Bridget Collier from Field Fisher - Dragons Back Race

On 10 September, Bridget Collier raced into Cardiff, taking second place in the world's toughest mountain race - the Dragon's Back Race.

Starting from Conway Castle, the race takes place over six days, 242 miles/389 kms over countless mountains. There is little rest in between the long days with only rivers and streams for washing and any sleep you can grab in shared tents. The route meanders over the Carneddau, Glyders, Snowdonia, Moelwyns, Rhinogs, the Elan Valley, the Brecon Beacons and onwards to Cardiff.

At the start, I was intimidated, standing one of nearly 300 competitors although only about 10 per cent women. It was 5.30am and dark, a Welsh male voice choir struck up just to really heighten the high emotion, and then I was off running along the castle walls and into the mountains. I knew the terrain, but had no idea how I would cope with such a demanding course.

The first day is feared by many as it takes in the airy and exposed scramble along the knife-edged Crib Goch. Fortunately, this is within my main training ground and I enjoy that sort of terrain, crossing it with cramp kicking in was interesting though. I finished before torrential rain set in and settled into camp life, trying to eat and re-hydrate, and study the map for the next day.

Day two was a different matter with the challenging pathless Rhinogs and bad weather due to come in early afternoon. I took some good navigational lines descending the craggy scramble and just cleared the worst of it before the torrential rain started. Hood up and onward. I spent some of the day with Victoria who was in 3rd place, I was 1st lady vet 50 and importantly, able to run into camp some 36 miles later.

The first two days are toughest and a third had already dropped out or been timed out. With a traverse of Cadair Idris before breakfast, heading into the Cambrian mountains of mid Wales and 44.4 miles.

This was a different day and challenging as the longest so far. Cadair was shrouded in cloud, but later we got some fine views as well as more rain. I passed through Machynlleth, the first town on the route still running well and I noticed I was creeping up the positions. I'd left Victoria behind earlier and I knew others were struggling with injury.

Day four passes through the remote Elan Valley. On my recci runs I'd spent hours without seeing a soul. I tried to see it as a rest day as whilst it was the longest so far and still 44 miles there was less ascent, lots of ankle-biting moorlands with no paths, but also some nice runnable distances. I had a good run and the race media starting taking notice as I took 2nd ladies place overall.

The sting was yet to arrive though and Day five took many out. Over 45 miles and a complete traverse of the Black Mountains and the Brecon Beacons including South Wales' highest peak, Pen y Fan. Many failed to beat the cut off times, a few including the leading man got injured. I took a few tumbles early on when the weather was doing its best to blow us backwards whilst pouring down, but by the end of the day, I finished with amazing views. I had gained a good lead on those behind me seeing me good for 2nd ladies place if I could keep going.

The last morning dawned with sunshine and I hung around camp until it was properly daylight as I hadn't been over the last 40 miles and didn't want to make any mistakes. Today was going to be runnable for those who could still run and I was one of the few still able to do so. The route took lovely low level hills into Merthyr Tydfil then more towards Cardiff. Just outside I arrived at a checkpoint of a trig point on a grassy hill and could see Cardiff and the sea in the distance, it was a joyous feeling. Finishing in 2nd place was a dream come true and testament to a gruelling year of training.

So many donated that it made all that training and a very tough week's running worth it! It is important to me to support Mesothelioma UK and all the good work that the whole team do. It's remarkable how much you have achieved since I started working on these claims and it's made such a difference to so many people.

Erin's team walk

At NatWest, we are very big on fundraising and are always making sure that we are doing something for the community. My manager wanted us to do some fundraising, so I put forward doing it for mesothelioma and the whole team were really for it. I put forward the charity as my dad passed away from it in 2019. He was diagnosed in September 2018 and was part of the MARS 2 trial. He wanted to be a part of something so that there may be a better outcome for people in the future.

Unfortunately, due to complications he didn't get better after the operation and passed away in July. It is such an awful disease and after seeing my dad suffer so much I really wanted to raise money for the charity so hopefully in the future, there can be a better outcome for the disease. Also, my colleague Carli's step-father passed away the same year after complications from asbestosis. Since we have both been affected by asbestos, this was the perfect charity

to raise funds for and I'm so proud of us all for being able to raise over £2,000 for such a great cause!

We completed our walk on 17 July which was due to be one of the warmest days of the year so far. I think the temperature got to about 29! We completed it a lot quicker than we thought we would and the whole team got involved, plus family members. I am so proud of the team and how well they have done on the walk, no complaining and now we are inspired to walk more as team.

Chloe's story

Chloe took part in her own challenge in memory of her grandad David. "I did this 10,000 steps a day challenge for my grandad David who we loved so very much but sadly lost his life to mesothelioma. I want to help raise money for this great cause in his honour."

We are so grateful to Chloe for her fantastic fundraising. She raised £210.50!

Badge for Adriana's fundraising

Adriana Sutton is seven years old and she held a tombola and raffle stall to raise money for Mesothelioma UK on 26 November 2022.

Adriana chose this charity as her lovely nanny was diagnosed with pleural mesothelioma back in June.

Adriana is also a brownie which is part of Girl Guiding for 7-10 year-olds, and in raising money for the charity, she has now also gained her Brownie charity badge and she raised an amazing £168.93.

Well done Adriana, you fully deserve your charity badge.

Paul Worgan - Ride Across Britain 2022

I set off for Lands End on Friday 9 September. The ride began the following day with a 106 mile ride to Okehampton in Devon. Day two was a 114 mile ride to Bath and to say I was shattered after those two days would be an understatement. We were sleeping in tents and with 750 other riders in close proximity, sleeping was nigh on impossible for pretty much the duration of the ride. But those first two days were up and down all day and so day three was a welcome relief – except there was hardly any relief to be had as that was tough too (made worse by the fact that I dropped my gloves down the toilet at the first pit stop whilst 'applying some cream' which set me back about 30 minutes).

Days four, five and six were much the same and by the time we got to Scotland, the weather had turned, as had the state of fatigue, transitioning from a physical battle into a mental one. Day seven was brutal and day eight, not much better. Many didn't make it to base camp on those two days and they had record numbers calling for the broom wagon (the bus that sweeps up stragglers at the back of the field). I had no idea what a mental challenge this would prove to be and never again shall I underestimate the mental resilience it takes to complete such an endurance event. But I crossed the finish line at 3.50pm on Sunday 18 September, having completed almost 1,000 miles in 9 days (89 hours and 43 minutes and 11 seconds to be precise), completely and utterly shattered, but totally exhilarated.

The way I've been explaining it to people is that days one and two are a shock to the system. It's hard physically, but at that stage, the lack of sleep takes a back seat to the adrenalin so you don't really feel the effects. My legs ached and I was starting to feel a niggle in my left calf but everyone said that day three should be "an easy day" so I think that helped psychologically. But as I say, it was anything but.

In fact, there were no easy days. Flatter it may have been (though not by much) but it was still long and draining, as were days four, five and six. Apparently, these middle stages are when many people pull out on LEJOG rides, maybe because of the physical exhaustion after two days of going up and down relentlessly whilst at the same time, knowing that you have another seven days ahead of you and that the worst is yet to come. The lack of sleep was really starting to catch up by now as well and try as I might, it was impossible to get more than a few hours sleep each night. If I had four hours, I would consider that a good night!

When we got into Scotland on day six, the weather started to change, but the deterioration in the weather was more than made up by the absolutely stunning scenery. Unfortunately, my photos just don't do it justice which is a shame as you had to see it to believe it. Then it got hard – really hard.

Not only were there mountains to contend with (so far, we had just experienced hills – steep ones granted, but hills nevertheless), but there was also the weather (headwinds and rain mainly) and I would say it was day seven when the mental side really kicked in. That day, we started by going over the Forth Road Bridge at sunrise – it was stunning, but the day got harder and climbing Glenshee mid-stage was brutal. Glenshee is a ski resort and we climbed it in a headwind. By the time we got to the top, it was freezing and I shall never forget the descent, for I was having to pedal hard just to keep moving, such was the strength of the wind that was trying its best to impede our progress.

By the time we got to 80-90 miles, most of us were done. But this was the longest stage and we still had 30 odd miles to go – through the Cairngorms National Park – into headwinds and climbing (there were hills, hills and more hills – always another hill). Those last 20 miles of day seven were the toughest by far, but I just kept looking down, grinding out the miles and by the time I got to basecamp, I knew that that would probably be as tough as it got. And so it was, for that night during the debrief, they told us that in 11 years of running the event, there had only once been a day like it. That made me feel pretty good and I knew at this point, that I only had two days to go so barring an accident or illness, I knew I was going to make it.

Day eight however, was the day I had been dreading from the moment I signed up to the event. There was one reason and one reason only – the "Lecht". Or as they call it in Scotland, "the Mighty Lecht". The Lecht is a brute of a mountain with maximum gradient of 20 per cent. They told us that the majority of people would walk it as it was just too steep for most cyclists. But I had this thing – this determination to ride my bike to John O'Groats at all costs. I said I was going to ride and ride I would – no matter how much it hurt. That's why I was dreading it as I was scared the mountain might beat me, such was the mystique and fear that the organiser had instilled in us all (unintentional I'm sure).

They said it would come early in the day and sure enough, after about eight or nine miles, I rounded a bend to find this wall in front of me. It was heart stopping. I couldn't see how on earth I was going to climb it! But once I was on it, I just kept going, zigzagging across the road in an attempt to ease off the gradient. I got up the first ramp, then it levelled off slightly. The second ramp was just as brutal and then the third ramp was horrible too but I did it. I'd conquered the Lecht and with it, my fear of these brutal mountain passes. The rest of the day was a repeat of the day before, though it was shorter at 109 miles and so I was back at base camp a little earlier.

Day nine then should have been a procession – except it wasn't. The first part was in appalling weather – the worst we'd experienced to date. By the first pit stop, I was soaked through. I started shivering the minute we stopped to refuel so didn't take as much onboard as I should have done. That meant that the middle section was utterly miserable as I started to flag as I hadn't taken on enough food. Thankfully I got to the final pit stop which was on the North Scottish coast and was able to load up. It was then only 30 odd miles to John O'Groats and I knew by this time that I had made it. I crossed the line around two hours later, headed to the infamous sign for the obligatory photo, packed up my bike and got on a coach for Inverness. I stayed in Inverness overnight, ordered the biggest Domino's pizza you've ever seen, and flew home the following day.

It was an amazing adventure. I thought about my Dad a lot obviously and I'd be lying if I said that I wasn't quite emotional when I crossed the line, but it was an fantastic experience and one that I'll be hard pushed to beat. Most of the other riders were cycling for some charity or another, and so I was in good company. There were many of course, who were just doing it for themselves and I was astonished at the age ranges. I'd been told (by my wife mainly) that I was "too old" to be doing something like this, but I'd say I was in the middle of the pack in terms of age. There were people riding well into their 70s and so it does just go to prove that you're as young as you feel (or want to be).

Will I do this again? On day five the answer would have been "yes" (I was even hatching a plan mid-stage to try and drum up some sort of team), but then by day seven it was a definite "no way". Four weeks post event, I'm on the fence. Who knows. Maybe I will, maybe I won't but if anyone wanted to try it for themselves, my advice would be don't hesitate – it will be one of the best experiences of your life!

So a huge, HUGE thank you to all who followed me, wished me luck, encouraged me and most of all, to everyone who donated to this very worthy cause. And of course, an extra special thank you to Mesothelioma UK, without whom, none of this would have been possible.

I've raised around £5.5k so far and my Just Giving page will remain open until March so there may be more donations yet!

Laura takes on the Bristol Half Marathon

Laura Wilkinson, a Senior Associate in the Industrial Disease team at RWK Goodman, pounded the pavements of central Bristol on Sunday 25 September to raise funds for Mesothelioma UK.

Laura spent her summer training for the event that took her and 15,000 other runners past some well-known sights of Bristol, including the Bristol Suspension Bridge.

It was a glorious, sunny day, which made the run even more challenging, especially whilst tackling the long, straight seven mile stretch along The Portway and back – certainly not Laura's favourite part of the run!

With the support of her two children to cheer her on, Laura completed the run in two hours and raised an incredible £375 for Mesothelioma UK in the process with sponsors from friends, family and colleagues. Well done, Laura!

Join our lottery!

There are amazing prizes to be won like a jackpot draw of £25,000 as well as a guaranteed win for one of our supporters each week! Tickets are £1 per week and 50% of the ticket cost goes to help us continue our work and the more tickets bought, the bigger the weekly cash prizes.

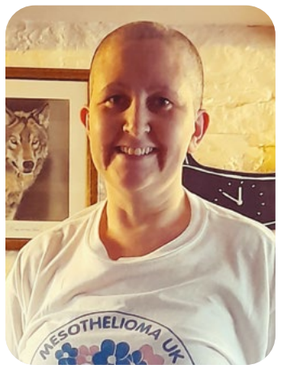
SCAN ME

Grow a Mo for Meso 2022

Oliver Collett, Partner of the Leeds team at Irwin Mitchell, bowed to popular demand and subjected himself to much laughter from colleagues as he tried to once again #GrowaMoforMeso. After a slow start, Oliver's fundraising got a much-needed boost from Liz Darlison, whose selfie magic did the trick! The itchiness was all worth it in the end as Oliver managed to raise a fantastic £220. He is already bracing himself to re-run the fun in 2023!

Heidi's head shave for Meso

I decided I would like to fundraise for Mesothelioma UK as my Dad has the illness and right from his diagnosis he has received incredible support from the charity for which we are all very grateful. I decided on a sponsored headshave as my hair is always long and on 22 October, I put my hair into pony tails to be cut off which was done by my partner who then shaved my head! So far the total raised is £1,095 which has far exceeded my expectations!



Rob's White Collar Boxing Fight

"I wanted to raise a bit of money for Mesothelioma UK in honour of my mother in law, Jen. She was diagnosed with pleural mesothelioma in July 2021 and has been bravely fighting it with a smile on her face ever since.

The diagnosis was devastating and I want to help make sure no more families have to go through this."

Rob's event took place on 3 December. You can view his JustGiving page at www.justgiving.com/fundraising/Deryn-Ballard1

Lynne Hunter, Mesothelioma UK Specialist Nurse's Kilt Walk Challenge

Earlier this year I became aware of many colleagues making a commitment to go the extra mile and raise funds and awareness for Mesothelioma UK. At that time, I was relatively new and wanted to join in but to be honest, the new role, new colleagues and new location were enough to keep me fully occupied. However, I was eager to commit to something and the Kilt Walk seemed to fit the bill. It's a high-profile event in Scotland, gets loads of publicity and thanks to the Hunter Foundation, all monies raised are topped up with an additional 50 per cent. When every penny counts for our fundraising team, the extra cash was a great incentive. I decided early in the process that walking 13 miles or doing the 'big stroll' as the kilt walk put it, would be way more enjoyable if I had some company on the way round, not to mention the extra fundraising! I quickly enlisted the help of my daughter and my friend to create our little team.

The preparation began in earnest. We looked out the walking gear, the strong shoes and water bottles and set off. However, many obstacles were placed in our way... coffee shops that sold great cakes, beautiful sea views that we had to sit and admire, not to mention the dog running off chasing balls and sticks that needed throwing. In truth, the 20,000 steps we do every day as nurses was probably better preparation, but it was all part of the fun.

On the day of the Kilt Walk, we joined thousands of others, with pretty much everyone sporting their kilts as well as t-shirts and banners of the respective charities they were supporting. It is actually quite moving to see the level of support and commitment the third sector gets from ordinary people who just want to help. Throughout the walk, we encouraged each other, spurred each on towards the end and laughed most of the way round. In truth, everyone was having a great time despite the odd blister or spot of cramp. At the end, we received some food and a well-deserved drink, and spent time mingling with other walkers. It was great to share our story and purpose with so many and raise the profile of Mesothelioma UK with lots of other people.

Overall, it was a thoroughly enjoyable thing to do, from the preparation to the event itself. We managed to raise £985.00 which was boosted to £1,477.50 by the Hunter Foundation. Well worth the sore legs the following day in work.

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.

2022 Events

December

15 December - 8pm
Mesothelioma UK Christmas Quiz
www.facebook.com/therealmesouk

2023 Events

January

30 January – 4pm
Webinar – the Pathology of Mesothelioma
www.mesothelioma.uk.com/mesothelioma-matters-webinar/

February

27 February
Webinar – Indwelling Pleural Catheters
www.mesothelioma.uk.com/mesothelioma-matters-webinar/

March

8 March
Ladies' Lunch
To coincide with International Women's Day, we're hosting our third Ladies' Lunch on Wednesday 8 March 2023 at the Manchester MacDonald Hotel. More details to follow.

June

26-28 June
iMig2023 (16th international conference of the International Mesothelioma Interest Group)
Lille Grand Palais
www.imig.org

Please visit our website for information on all our challenge events www.mesothelioma.uk.com/our-challenges/

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