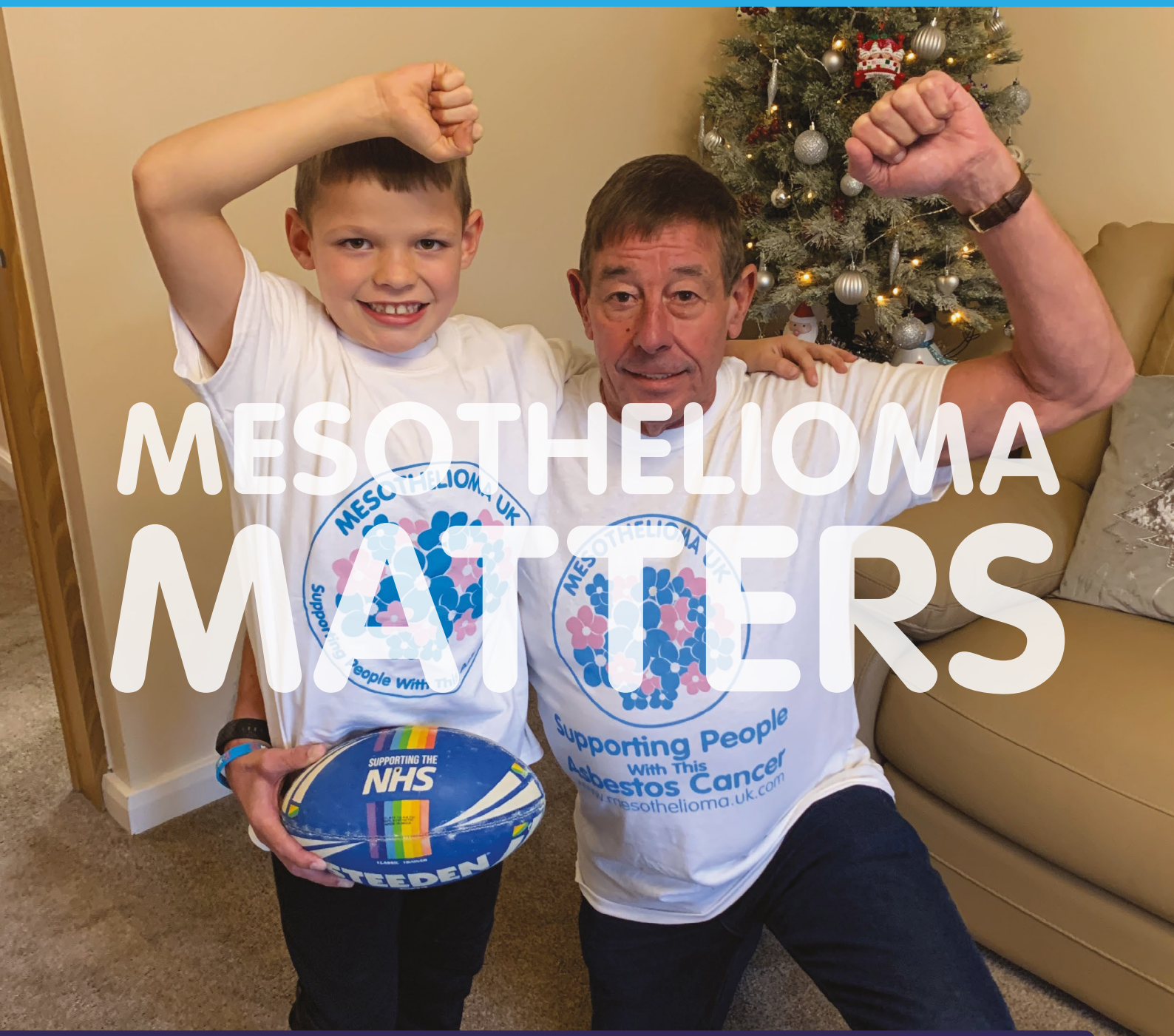
Spring Edition 2022

MESOTHELIOMA UK

MESOTHELIOMA MATTERS



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NEWS

Mesothelioma UK 2020-21 annual report highlights

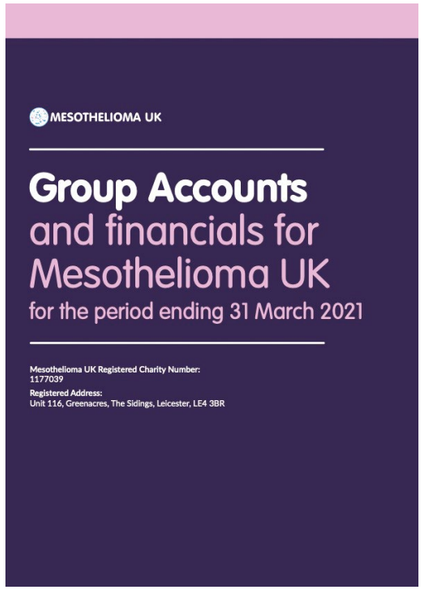
The 2020/2021 annual report has painted an eventful year for Mesothelioma UK despite the disruptions caused by the Covid-19 pandemic.

Key developments
The start of 2020 saw the launch of Mesothelioma UK's first ever legal panel. It consists of eight UK law firms which support and raise awareness of the charity and offer independent legal support to mesothelioma patients and their families.

We published our first Nursing Strategy and with the help of several partners and generous donations, we were able to appoint the 30th Mesothelioma UK Clinical Nurse Specialist. A nurse team leader was appointed for the Scottish Mesothelioma Network and Project Cymru was launched to address the challenges faced by the Welsh mesothelioma community.

Challenges
Working against the backdrop of the Covid-19 pandemic, the nursing team strove to meet the new and unprecedented pandemic-related needs and challenges of cancer patients. Team members had to be flexible and adaptable, were redeployed to intensive care units and assigned to inpatient ward areas, or had to man Covid-19 telephone services and vaccination clinics.

We had to adapt in a similar fashion to maintain contact with our community. Our IT provider and communications team ensured that the operational team was able to work remotely and our education, information and support services were adapted to virtual platforms.



The success of our Patient and Carer Day in October 2020 saw over 200 participants. We also held Facebook Live sessions throughout the year to share guidance and information. Support groups moved their operations online and new groups were also set up. We held a regular quiz and launched the very successful monthly Mesothelioma Matters webinars.

On the research front
In July 2020, we marked a significant milestone with the opening of the Mesothelioma UK Research Centre at the University of Sheffield and in January 2021, we released the first independent grants. The third National Mesothelioma Audit (NMA) funded by Mesothelioma UK was published in May 2020 and plans to secure the ongoing development of the NMA got underway.

In March 2021, following the success of the Supporting our Armed Forces Project and publication of the MiMES (Military Experience of Mesothelioma Study) research, the charity was awarded the HSJ Military and Civilian Partnership Award. The award was given in recognition of the 'Mesothelioma UK – Supporting our Armed Forces' campaign, which was held up as an exemplary holistic package of care that was well-researched and had influenced government policy.

Fundraising
Fundraising underwent a digital transformation as we sought new and creative ways to engage with our donors and drum up support. These came in the form of corporate partnerships, joint appeals with other charities and fundraisers involving individuals, as well as our team of staff. The Covid-19 appeal, which involved our entire team, was a socially distanced walking challenge where each day, for five weeks, we pooled our steps to reach 5,000 by the end of the challenge. Although we could not meet up due to the lockdown, the appeal was successful nonetheless and proved to be a great way to transition to the new methods needed to raise money in the pandemic. The income generated from fundraising amounted to £548,173 while our supporters helped us to raise a total of £1.47 million as a whole. The latter includes funds from grants, legacy income, donations, trading and other sources.

How we spent the funds
Up to 90 per cent of our expenditure, or £1.34 million, went towards conducting charitable activities, while the largest expense was the cost of funding nursing posts. As we now group our activities under different pillars, the cost of funding the nurses fell into the Patient Support Pillar. Of the £692,744 in Patient Support, £626,984 went towards the nursing posts.

A new and significant expenditure for the charity was the cost of the Mesothelioma UK Research Centre in Sheffield which amounted to £114,680.

The contract for the centre will run for three years, amounting to a total of £448,100. We plan to focus on ensuring that the impact of research we have already funded is maximised. The charity employed an additional three members of staff during the year and introduced a new benefits package for all staff which, altogether, raised the staff costs by £86,089 compared to the previous year.

To download a copy of the annual report, go to www.mesothelioma.uk.com/accounts-and-reports/

The year ahead

The year ahead will see Mesothelioma UK publish a new strategy outlining a bigger and better charity. There is much to consider, from the developments in online care that have changed the face of charity work and healthcare in the past year, to the changes in fundraising approaches and donor behaviour that will affect how we raise funds in the future.

As we emerge from Covid-19, we will seek to solidify our team of nurses, with plans to expand in Wales, Northern Ireland and in every Cancer Alliance in England where we do not currently have a presence. The National Mesothelioma Audit will be further developed with possibly a new academic partner and we have ambitious plans to increase the scope and reach of the audit.

We will continue our dialogue with government departments and MPs, amplifying the voices of the mesothelioma community so they are heard by those with the power to enact change.

Mesothelioma in Australia

A report was recently published that details the mesothelioma situation in Australia. The full report, which presents the latest available statistics from the Australian Mesothelioma Registry (AMR), can be read at www.aihw.gov.au/reports/cancer/mesothelioma-in-australia-2020/summary and we have summarised the findings here.

Each year in Australia, between 700-800 people are diagnosed with this rare and aggressive cancer. In the 2018–19 financial year, the estimated health system expenditure for mesothelioma cases was $27.4m (total cancers $11.8 billion) (AIHW 2021). Men were more likely to be diagnosed with mesothelioma than women across all age groups, and the number of cases diagnosed each year for both men and women has steadily increased over the past 40 years. Asbestos, the main cause of mesothelioma, has been banned in Australia since 2003.

The report's main findings included:

- in 642 cases reported to the AMR in 2020, the median age at diagnosis was 75
- between 1988-1992 and 2013-2017, the age- adjusted relative survival of people with mesothelioma has increased
- over 9 in 10 of the exposure assessment participants were assessed as having possible or probable exposure to asbestos
- 696 deaths of people with mesothelioma were recorded on the AMR in 2020 – a rate of 2.1 deaths per 100,000 population

New clinical practice guidelines address management of malignant pleural mesothelioma

The European Society of Medical Oncology (ESMO) has published new clinical practice guidelines with major recommendations for managing patients with malignant pleural mesothelioma. Key highlights in the guidelines which have been published in the *Annals of Oncology*, include descriptions of optimal diagnostic methods, pathological evaluation and staging.

The authors make recommendations on the role of surgery and macroscopic complete resection as part of multimodality therapy and they discuss optimal first-line, maintenance and salvage systemic therapies and immune checkpoint inhibitors. They also cover the role of prophylactic, radical and palliative radiotherapy and optimal supportive care.

The paper has been prepared by a panel of oncologists led by Professor Sanjay Popat, Consultant Thoracic Medical Oncologist at the Royal Marsden Hospital and Professor of Thoracic Oncology at the Institute of Cancer Research.

You can read the new clinical practice guidelines at www.annalsofoncology.org/article/S0923-7534(21)04820-1/fulltext

National 20 for 20 campaign raises over £28,000

The 20 for 20 campaign returned for its second successful outing in September last year. Led by the team at Sarcoma UK, Mesothelioma UK joined 19 other charities which represent rare and less common cancers, to come together to raise awareness and conduct a major fundraiser through this innovative campaign.

All of the charities asked their supporters to sign up to the 20 for 20 challenge and take on 20 challenges over 20 consecutive days.

One of the individuals who decided to take up the challenge was our cover star Reuben Gaunt, an 8-year-old whose grandfather Ray was diagnosed with mesothelioma in June 2021. Upon learning about Ray's diagnosis, Reuben, along with his brother Jake and cousins Zak and Lukas, set up Team Grandad to look out for each other and practice positive thinking to help Ray get through his check-ups and treatments.

Eager to raise funds for Mesothelioma UK because of the help that it had extended to Ray, Reuben and his family decided to complete various activities for a year as part of the challenge. Reuben opted to make 20 rugby passes per day for 20 days, given his enjoyment of the game, but more importantly, it was a way to pay homage to Ray who had played rugby during his time in the Navy when he was awarded a cap. Reuben achieved his target of the 20 days and also roped in a group of friends, family members and players from the Oulton Raiders and Sandal rugby teams. Upon completing their various challenges, Reuben and his supporters raised £760 for the charity.

At Mesothelioma UK, our nurses led the charge with 20 nurses who completed 20 challenges with everything from meditation to open water swims and even cooking up a 20-ingredient dish! This amazing challenge raised over £2,232 for Mesothelioma UK and we hope to team up later this year for another 20 for 20 challenge.

To date, the 20 for 20 campaign has raised £28,146 with 83 supporters and up to 1,254 donations. Details about the last campaign can be found at www.20for20.org.uk. The information about this year's campaign will be announced closer to the date.

Mesothelioma Updates

Newly published research in mesothelioma, compiled by the University Hospitals of Leicester Clinical Librarian Services.

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 to UHL clinical librarians!

New scientific research

Nivolumab versus placebo in patients with relapsed malignant mesothelioma (CONFIRM): a multicentre, double-blind, randomised, phase 3 trial.
Author(s) Fennell, Dean A; Ewings, Sean; Ottensmeier, Christian; Califano, Raffaele; Hanna, Gerard G et al.
Source The Lancet. Oncology; Nov 2021; vol. 22 (no. 11); p. 1530-1540

Clinical utility of diagnostic biomarkers in malignant pleural mesothelioma: a systematic review and meta-analysis.
Author(s) Schillebeeckx, Eline; van Meerbeeck, Jan P; Lamote, Kevin
Source European respiratory review : an official journal of the European Respiratory Society; Dec 2021; vol. 30 (no. 162)

Positron emission tomography-computed tomography (PET-CT) in suspected malignant pleural effusion. An updated systematic review and meta-analysis.
Author(s) Fjaellegaard, Katrine; Koefod Petersen, Jesper; Reuter, Simon; Malene Fischer, Barbara; Gerke, Oke et al.
Source Lung cancer (Amsterdam, Netherlands); Dec 2021; vol. 162 ; p. 106-118

Diagnostic accuracy of the cancer ratio for the prediction of malignant pleural effusion: evidence from a validation study and meta-analysis.
Author(s) Zhang, Ying; Li, Xiaoou; Liu, Junhui; Hu, Xueru; Wan, Chun et al.
Source Annals of medicine; Dec 2021; vol. 53 (no. 1); p. 558-566

Prognostic value of CYFRA 21.1 in malignant mesothelioma: A brief report of the randomized phase II trial NVALT19.
Author(s) de Gooijer, Cornedine J; van der Noort, Vincent; van den Broek, Daan; Baas, Paul; Burgers, Jacobus A
Source Lung cancer (Amsterdam, Netherlands); Nov 2021; vol. 161 ; p. 197-199

Dosimetric Comparison Between Helical Tomotherapy and Volumetric Modulated Arc Therapy in Patients With Malignant Pleural Mesothelioma.
Author(s) Müdder ; Sarria, G.R.; Henkenberens, C.; Holz, J.; Garbe, S. et al.
Source Clinical Oncology; Mar 2022; vol. 34 (no. 3); p. 164-171

DREAM3R: DuRvalumab With chEmotherapy as First Line treatment in Advanced Pleural Mesothelioma: A Phase 3 Randomised Trial.
Author(s) Forde ; Kindler, H.; Zauderer, M.; Sun, Z.; Ramalingam, S. et al.
Source International Journal of Radiation Oncology, Biology, Physics; Feb 2022; vol. 112 (no. 2)

Salvage Therapy for Relapsed Malignant Pleural Mesothelioma: A Systematic Review and Network Meta-Analysis.
Author(s) Tsai ; Chen, Hsiao-Ling; Lee, Tai-Huang; Chang, Hsiu-Mei; Wu, Kuan-Li et al.
Source Cancers; Jan 2022; vol. 14 (no. 1); p. 182-182

Non-incisional pleurectomy/decortication for malignant mesothelioma after cardiac surgery.
Author(s) Miura ; Shimizu, Kimihiro; Hasegawa, Seiki; Koike, Sachie; Matsuoka, Shunichiro et al.
Source Thoracic Cancer; Jan 2022; vol. 13 (no. 1); p. 126-128

Qualitative studies and patient experience

Malignant pleural mesothelioma patients' experience by gender: findings from a cross-sectional UK-national questionnaire.
Author(s) Senek, Michaela; Robertson, Steve; Darlison, Liz; Creech, Lorraine; Tod, Angela
Source BMJ open respiratory research; Jan 2022; vol. 9 (no. 1)

Surveillance of Lung Cancer and Mesothelioma Patients With Noncurative Treatment Intent: A Narrative Review.
Author(s) Fraser ; McNeill, Rob
Source Cancer Nursing; Jan 2022; vol. 45 (no. 1); p. 31-36

Preliminary validation of a questionnaire assessing psychological distress in caregivers of patients with malignant mesothelioma: Mesothelioma Psychological Distress Tool—Caregivers.
Author(s) Bonafede ; Chiorri, Carlo; Azzolina, Danila; Marinaccio, Alessandro; Migliore, Enrica et al.
Source Psycho-Oncology; Jan 2022; vol. 31 (no. 1); p. 122-129

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

UHL Clinical Librarian Service
"bringing you the evidence"

Expert Witness Essentials Training Seminar

Lawyers seek expert witness medical professionals to support various aspects of mesothelioma client claims including causation, care needs, care costs, non-NHS treatment options and treatment costs.

Mesothelioma UK has partnered with the Expert Witness Institute to deliver a bespoke mesothelioma expert witness course that provides all the essential background, knowledge and information.

If you are a health care professional providing treatment and care for people with mesothelioma and would like to learn more about becoming an expert witness, this two-hour seminar, from 6-8pm on Thursday 31 March is for you.

www.mesothelioma.uk.com/product/expert-witness-training/

Expert Witness Essentials Seminar
EXPERT WITNESS INSTITUTE

New drug treatment approved for asbestos-related cancer patients in Scotland

The Scottish Medicines Consortium (SMC), which advises NHS Scotland on the value for patients of newly licensed medicines, has published advice accepting the first new treatment for mesothelioma in 14 years.

Following an assessment of the combined use of immunotherapy drugs nivolumab and ipilimumab, the SMC has accepted the treatment for use by NHS Scotland as a first-line treatment for adults with mesothelioma.

Patients in Scotland with malignant pleural mesothelioma that cannot be removed by surgery will be able to have the treatment on the NHS in Scotland.

As a patient-facing charity, Mesothelioma UK welcomes this decision and commends the SMC on accepting the use of the first new treatment for mesothelioma since 2008.

The nivolumab and ipilimumab combined immunotherapy treatment has been proven in the Checkmate 743 clinical trial to provide significant and clinically meaningful improvement in overall patient survival versus standard-of-care chemotherapy.

Mesothelioma Chief Executive, Liz Darlison MBE commented: "We're absolutely delighted that the SMC has taken the decision to accept this treatment for patients through NHS Scotland. After around 14 years without new treatments for mesothelioma, this is fantastic news for patients in Scotland. We sincerely hope that the National Institute for Health and Care Excellence (NICE) follows the example set by the SMC and approves this immunotherapy treatment for use in the NHS in England. A decision on this is due to be made by NICE in early spring."

Nigel Shaddick, a mesothelioma patient who took part in the Checkmate 743 trial and received this immunotherapy treatment said: "Ipilimumab/nivolumab has given me my life back. I can now look forward and plan for a full, exciting and active future."

Carolyn MacCrae, Mesothelioma UK Clinical Nurse Specialist Team Leader for Scotland and Mesothelioma Clinical Nurse Specialist commented on the SMC announcement: "This is a wonderful and hugely significant treatment development which has the potential to improve outcomes and quality of life for mesothelioma patients throughout Scotland. Thank you to the SMC along with everyone who's made this possible. In particular, thank you to every patient who participated in the Checkmate 743 trial. Clinical trials depend on the willingness of individuals to take part and for some, this includes extra appointments, tests, travel and not least, anxiety. However, they help advance treatment and care and today, everyone who participated has given hope and benefited so many others affected by this disease."

Professor Kevin Blyth, Professor of Respiratory Medicine and Founder of the Scottish Mesothelioma Network University of Glasgow said: "This is fantastic news for mesothelioma patients in Scotland. Combination immunotherapy with ipilimumab/nivolumab has shown clear superiority over chemotherapy and the decision to fund this by the SMC creates a new and routinely available standard of care. We look forward to integrating first line ipilimumab/nivolumab into treatment pathways in the Scottish Mesothelioma Network."

Miles Briggs MSP, Co-chair of Scottish Parliament Cross Party Group on Cancer said: "This is incredibly positive news and a welcome step forward for patients with malignant pleural mesothelioma in Scotland.

"Patient representatives and the charity, Mesothelioma UK have worked incredibly hard to help secure this new treatment for mesothelioma patients. It's absolutely vital that we see progress to develop and secure patient access to innovative new treatments and nivolumab and ipilimumab are positive examples of how that can be delivered."

Patients in Scotland should speak to their healthcare team in the first instance about their suitability for the treatment and can find out more information at www.scottishmedicines.org.uk

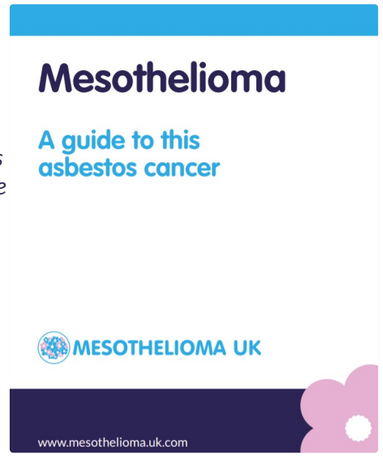
New patient education materials

We regularly evaluate our range of patient information leaflets to ensure that they best meet the needs of those affected by mesothelioma. Existing titles are reviewed every two years which helps to ensure that our information reflects the most current evidence and feedback that we receive from readers.

Sometimes only small changes are needed, but on occasion, we take the opportunity to make significant revisions. This is the case for the newly reviewed leaflet entitled, '*Mesothelioma, a guide to this asbestos cancer*'. Previously called *'What is Mesothelioma?'*, we have added more content that aims to provide a more thorough introduction. It covers everything from diagnosis to causes such as asbestos exposure, as well as getting further financial and emotional support.

We also consider whether there are any topics on which we ought to have more information. Some patients said that they wanted us to demystify how and when new cancer drugs become available.

To address this, we recently published a brand new leaflet called *'How cancer drugs are made available in the NHS'*. This covers aspects of how all new drugs must undergo a number of tests, first in the laboratory and eventually on humans, in clinical trials. If these show that the drug not only works but is also safe to take, then the process of approval and licensing for use in the NHS can begin.



To read this leaflet, visit the downloadable resources section of www.mesothelima.uk.com

The pandemic and our nurses

Our UK Head of Nursing, Lorraine Creech, looks back at the last two years and the impact of the pandemic on our team of clinical nurse specialists…

As we proceed through 2022, we are looking forward to a brighter year. However, at Mesothelioma UK, we are also thinking about the challenges that Covid-19 has presented to us as a charity and within our clinical roles. Clinically, the uncertainty of how new variants will affect us, the restoration of cancer services, vaccination programmes and the global threat remain a concern. As a charity, we are focusing on how we can get fundraising back on track to improve services.

As we turned into 2021, we celebrated reaching 30 Mesothelioma Clinical Nurse Specialists which was an amazing achievement. At the start of 2022, we now have 34 nurses and we are well on our way to reaching the target of 38 nurses by 2023, with a nurse in every Cancer Alliance throughout England and networks in the devolved administrations.

We continue to focus on how we can improve the information available on the Mesothelioma UK website and we have launched two new online support groups. One for carers known as the 'Carers' Hour' and a 'Younger Patients' Group' for patients under the age of 55.

The launch of the Clinical Trials App has also made a tremendous difference, literally allowing us to have information about clinical trials at our fingertips.

The previous Mesothelioma UK Information Line has changed its name to the Mesothelioma UK Support Line and we hope the name change leads to a better understanding of the services that we are offering.

Dr Sarah Hargreaves at the Mesothelioma Research Centre at the University of Sheffield carried out a survey on the impact of Covid-19 on mesothelioma and lung cancer specialist/advanced practice nurses in the UK. The survey looked at views and experiences since January 2021 and was commissioned by Lung Cancer Nursing UK.

Lorraine Creech

Initial findings demonstrate that:

- the pandemic has had a significant impact on working, workload and on mental and physical health in nurses
- patient pathways have been negatively impacted by delays and access to services with strong concerns about the lack of face-to-face interactions
- whilst there have been hardships and negative impacts, there is also evidence of resilience, innovation and supportive team working

We have done our best to support our nurses and I was particularly proud to read a comment from one of the Mesothelioma UK nurses in the survey saying: "I think the camaraderie within the [Mesothelioma UK] CNS team has been amazing. The support for each other in chat and other virtual facilities and the understanding of what colleagues have been experiencing has been so important. This has helped to address and support each other's fears and experiences."

I sincerely hope that this support within the nursing team translates into how we care and support patients as of course, patients are our main priority and reason for being.

We are facing challenges to improve services such as taking Project Wales forward and establishing a footprint of specialist services in Northern Ireland. We will meet these with forethought and determination, and as always, we are grateful to have the wider mesothelioma community by our side.

Mesothelioma UK Project Cymru/ Wales

We are now entering the final six months of Mesothelioma UK Project Cymru. We have assessed what we have learned so far and how that informs what we do next. Given the scale of the challenge highlighted in the scoping work and the example of the Scottish Mesothelioma Network, it suggests that we need to secure significant funding and additional support to move forward.

The project has raised awareness of mesothelioma throughout Wales and emphasised the need for an all-Wales approach. The project has identified the need for increased knowledge and awareness of the disease, as well as the importance of national guidelines to ensure all patients in Wales receive appropriate access to the best diagnostics, treatments, trials and care available.

Mesothelioma is a rare cancer, with around 100 new cases diagnosed each year in Wales. As a devolved nation, NHS Wales does not have the appropriate safeguards in place as seen in NHS England and NHS Scotland, such as national service specifications, optimal pathways, and quality performance indicators for the diagnosis, treatment and management of mesothelioma.

As part of Project Cymru, Sarah Morgan, our Mesothelioma Senior Clinical Specialist Nurse and Project Lead for Wales has worked closely with Asbestos Awareness Support Cymru (AASC) to ensure support is available throughout Wales for patients and families of those affected by mesothelioma. CafeAASC is a virtual support group via Zoom and was set up in October 2019 as a response to the Covid-19 pandemic. This monthly forum has proven to be invaluable in providing specialist support and advice for all those attending the meeting.

In August 2021, we submitted an application to the Welsh Health Specialised Services Committee ('WHSCC') for the inclusion of mesothelioma as part of the Specialist and Tertiary commissioned services in Wales, and we hope to receive a decision by April 2022.

WHSSC was established in 2010 by the seven Health Boards in Wales to ensure that the population of Wales has fair and equitable access to the full range of specialised services. In establishing WHSSC to work on their behalf, the seven Health Boards recognised that the most efficient and effective way of planning these services was to work together to reduce duplication and ensure consistency.

Project Cymru has prioritised engagement with those affected by mesothelioma, as well as all those involved in the management of mesothelioma, to advocate a voice for change in Wales.

In December 2021, Sarah Morgan, was asked to appear on BBC News Cymru to comment on the incredibly sad case of Jason, a 45-year-old father who died within six months of receiving a mesothelioma diagnosis, resulting from occupational exposure to asbestos as an IT worker.

This story had a huge impact and the BBC were able to quote a Welsh Government spokesperson as saying: "The Welsh Health Specialised Services Committee has agreed to begin commissioning mesothelioma services to achieve a single national approach to treatment. A single multidisciplinary team for Wales will be established next year."

We are eagerly awaiting more news on the outcome of the WHSSC discussions.

We are hugely excited about the potential to massively improve services and support for patients and their families across Wales. Giving patients a voice is key to developing these services.

Energy price rises

Many of you will be aware that energy prices have increased dramatically due to high global demand. Standard energy tariffs have increased by as much as 54% and many suppliers have ceased trading. Ofgem have raised the energy price cap by £693 from April 2022 (excl. Northern Ireland) which will bring the average annual household energy bill to £1,971.

There are several pre-existing and new schemes that can help to reduce the cost of your energy bill. These schemes can be combined to get the maximum discount on your energy bills.

New schemes

People whose homes are in Council Tax bands A to D in England will get a £150 council tax rebate in April to help towards energy costs.

All households in the UK will receive £200 off their energy bill in October 2022 but that discount will then have to be paid back by £40 per year over five years from 2023.

Local authorities will receive £150 million to make discretionary payments to those most in need.

£565 million will be made available to Scotland, Wales, and Northern Ireland which they can use to cut Council Tax.

Existing Schemes

Warm Home Discount

Have you checked to see if you are eligible for the Warm Homes Discount scheme? You could get £140 off your electricity bill for winter 2022-2023. If you are in receipt of a disability/ill health benefit, you are likely to qualify.

You can check if you qualify here:

www.gov.uk/the-warm-home-discount-scheme

Unlike Winter Fuel Payments, the Warm Home Discount is not awarded automatically unless you receive the Guarantee Credit element of Pension Credit, so don't forget to register with your energy supplier! Many energy suppliers only accept applications for a limited period so please check with your supplier when applications open for 2022/2023.

Due to the unprecedented energy rises, more schemes and options may become available in the coming months. Accurate and reliable advice can be found here:

www.citizensadvice.org.uk/consumer/energy

UKNAR's successful crowdfunding for a national asbestos database

At the end of 2021, UKNAR raised almost half a million pounds via the Ethex crowdfunding investment platform for social enterprises. This will enable UKNAR to build and promote a national database to store the hundreds of thousands of asbestos registers that exist in the UK, for workplaces where asbestos is known to be present. UKNAR's Asbestos SMART technology will allow these vital documents to be freely accessible to tradespeople and other on-site occupants 24/7, 365 days per year simply by scanning a QR code, thus greatly reducing the risk of accidental asbestos exposures.

Andrew Paten CEO and Co- Founder says: "We have been delighted by the level of support and enthusiasm that we have received for our mission from such a wide range of stakeholders. Indeed, we feel honoured and surprised by how organisations like Mesothelioma UK, IOSH, UKATA, the Mavis Nye Foundation and many others have been willing to actively support us. We even managed to get the proposal for a national database into the current Parliamentary Inquiry into the UK's management of asbestos, where the concept was almost universally endorsed.

"Now our big challenge is to grow from having hundreds of properties in the UK National Asbestos Register to thousands – all using Asbestos SMART to prevent asbestos exposures."

UKNAR is currently running free webinars which outline the key challenges of managing asbestos safely in situ until it is removed. The webinars also demonstrate how UKNAR's Asbestos SMART approach can help dutyholders fulfil their responsibilities more easily.

UKNAR has focused on targeting professional property management companies and educating management within schools, 75% of which still contain asbestos. These webinars have been well received, generating significant interest from over 100 estate directors and other people responsible for managing asbestos safely in almost 1,000 schools.

UKNAR will replicate this approach with NHS Trusts and hospitals, over 80% of which contain asbestos across their aging property estates.

If you know anybody responsible for managing older properties (pre 2000) that may contain asbestos, please pass on our details and encourage them to attend one of our short (45 minutes) FREE webinars. They can see for themselves how UKNAR can help them and how cheap and easy it can be to make their lives easier and people's lives safer.

For further details, please contact Stuart Towers on 07912 268613 or Stuart.Towers@uknar.org. Please also see our website www.uknar.org and visit our live events page.

Mesothelioma UK receives 5% of UKNAR CIC's Asbestos SMART annual licence fees. UKNAR aims to raise many thousands of pounds in support of all the wonderful work that they do.

Tony's Story

Mesothelioma UK was contacted by the family of a mesothelioma patient, who sadly passed away on the 1 January 2022 following a four and a half year battle with pleural mesothelioma. We hope to work with the family to raise awareness of mesothelioma and improve services for patients in Northern Ireland.

Tony was diagnosed in July 2017, at the age of 60. He was a non-smoker, lifelong non-drinker and to date, we have no idea when or where he was exposed to asbestos, working as a social worker all his life.

He underwent pleurectomy and decortication surgery in August 2017, followed by chemotherapy with carboplatin and pemetrexed for four cycles, which was completed in December 2017.

Subsequently, Tony did very well with stable CT scans until April 2019.

At this time, disease progression was noted and as he was feeling well with no symptoms, he was advised to take on a watchful waiting approach while awaiting possible admission to the CONFIRM trial.

This went ahead in August 2019 and Tony commenced fortnightly infusions in Belfast City Hospital.

Initial scans appeared to show some disease regression and then ongoing stable chest appearances until August 2020 when further spread was noted.

An MRI was also carried out in June 2020 due to persistent backache and Tony had one session of radiotherapy due to a concern about imminent cord compression.

The trial was subsequently unblinded and we discovered he had been in the placebo group.

Funding was then approved for Nivolumab treatment and he attended for this until August 2021 when he was admitted for two weeks to hospital with pneumonitis and pneumonia. Treatment was therefore suspended indefinitely while he recovered.

Unfortunately after a few good weeks at home, his condition deteriorated again leading to a further hospital admission in November.

Further disease progression was confirmed and palliative treatment recommended.

Tony's family are now keen to raise awareness of this aggressive malignancy and improve services offered to patients in Northern Ireland, including access to specialist treatment and clinical trials, and establishing a pathway for referral to NHS colleagues in mainland UK as appropriate. Our vision is to have a similar task force to that already working in England and Scotland with weekly mesothelioma MDT meetings, including the involvement of clinical nurse specialists and a benefits advisor.

To aid us on this journey, we are very grateful to be working in conjunction with Mesothelioma UK, linking in with the Northern Ireland Cancer Network, local cancer charities and raising the profile of this important work within NI, via media outlets, corporate partners and legal teams specialising in asbestos claims. The development of a Project NI task force is underway and fundraising efforts have already commenced.

We also hope to instil some positivity to other patients and families embarking on this journey. A positive mental attitude was second nature to Tony and without a shadow of a doubt, played a vital role in managing his illness.

Laura Rodgers and family

Equine therapy

In partnership with Macmillan Cancer Support, Spirit and Soul Equine Assisted Therapy offers free places for anyone living with or beyond cancer. Horses are used during the therapy to help cancer patients deal with the emotional aspects of the illness.

Spirit and Soul operate at various locations around the country including Derbyshire, Cheshire, Somerset, East Yorkshire, Lincolnshire, Bromsgrove and Leicestershire. Patients can receive four free one-hour sessions, funded by Macmillan, with the horses and a facilitator.

Interested parties can self-refer through the website at www.spiritandsouleaac.co.uk/ and contact Lisa@spiritandsouleaac.co.uk for more information.

Armed Forces Memorial

The ‘Mesothelioma UK – Supporting our Armed Forces’ memorial is a unique concept, depicting the building blocks of life, engraved with vital awareness information about mesothelioma, asbestos and our Armed Forces.

We want the families and friends of those affected to be able to visit the memorial and pay their respects or celebrate a key milestone.

We’re looking for your support through donations as this will help us to create and build the memorial, and one day bring together family, friends and donors to remember our heroes at a grand unveiling.

The memorial will be made up of over 60 blocks. Our target is £40,000 and we’re thankful to everyone who has donated so far.

We’re accepting donations from as little as £10, right up to sponsoring a block for £500. You can support the creation of the new memorial by:

- sponsoring a block (or blocks) at £500 each
- donating any amount to help us reach our target

To donate, please call our support line on 0800 169 2409 or visit www.mesothelioma.uk.com/armed-forces-memorial-donation/

CLINICAL TRIALS

An interview with… Dr Anna Bibby

Anna Bibby

Leah Taylor

Dr Anna Bibby is the Chief Investigator for the ASSESS-MESO study. In this article, she talks to Mesothelioma UK Team Leader, Leah Taylor about this important research.

Leah:
Can you explain the ASSESS-MESO study and what you are hoping to achieve?

Anna:
ASSESS-meso is a study for people with all types of mesothelioma, in which we collect information and biological samples from people over time as they receive their care. We want to understand why mesothelioma behaves so differently in different people. By collecting clinical information, information about symptoms, and samples of blood and fluid, we hope to understand why some people live longer with mesothelioma, why some people respond to treatment and others don’t, and whether we can identify markers of response or progression via blood tests.

We are also collecting radiology imaging, such as chest x-rays and CT scans, and sharing these with artificial intelligence experts to try and develop better ways of measuring and monitoring mesothelioma tumours on imaging. Lastly, we are using ASSESS-meso as a platform for other sub-studies and trials, so participants are frequently screened for eligibility for other research and offered the chance to participate in additional studies if they wish.

Overall, I hope ASSESS-meso will help us to understand more about mesothelioma and help us to offer better treatments and pathways to people diagnosed with it.

Leah:
What influenced you to develop this study?

Anna:
A couple of things. I wanted to develop a study that was open to everyone with mesothelioma, regardless of age, functional ability, tumour type or location. Lots of clinical trials have quite strict eligibility criteria and although there are often good reasons for these criteria they can mean that some people are excluded from research. It also means that the results of the trials are not necessarily generalisable to the wider population of people with mesothelioma. I wanted to create a study that gave everyone the opportunity to participate in research if they wanted to and that also generated results that were representative of the ‘real-world’ mesothelioma population.

When I set up ASSESS-meso, I was also testing a new type of trial design where participants in ASSESS-meso were chosen at random to be offered a trial of a new treatment. Traditionally randomised trials either involve placebos or telling participants that they have not been chosen to receive the trial treatment. This can be quite upsetting, particularly if the treatment is something that is not available on the NHS. The design I was testing (called Trials Within Cohorts or TWICS) meant that only people selected to receive the trial drug knew about it, reducing disappointment for others.

The trial didn’t work, but ASSESS-meso was a really positive legacy from it!

Leah:
What drew you to work with people with mesothelioma?

Anna:
It was a case of right place, right time, I think. I was a junior respiratory registrar working at North Bristol NHS Trust with Professor Nick Maskell when we noticed that people with pleural effusions (where fluid builds up around the outside of the lung) seemed to live longer if that fluid got infected. We conducted a study looking into it and found that the association was particularly strong in people with mesothelioma. This was around the time that interest was growing in immunotherapy and our findings tapped into that, suggesting that the bacteria causing infection were also stimulating the immune system to attack the tumour.

From there, I started looking into mesothelioma and was really saddened by the lack of progress in treatment since the landmark Pemetrexed trial in 2003. Not for the want of trying, of course! Lots of very clever people had been working extremely hard to develop and test new treatments. But I think I arrived at a really opportune moment, where the momentum had been building for some time. Now, research funders were paying an interest, and drug companies were more willing to test their drugs in mesothelioma. It felt like a real crest of a wave. Happily, there have been massive developments in the understanding of mesothelioma and treatment options over the last five years. I can’t claim any credit for them, but I’ve felt very lucky to be a small part of that momentum.

Leah:
The study is now recruiting in 16 different Trusts across the UK. Congratulations to you and the study team on this excellent achievement. When you were setting it up, did you think so many centres would want to be involved?

Anna:
Thank you! It’s so brilliant that we’ve had the interest we have and I’m really pleased that by having so many sites open, we’ve been able to involve so many patients in the study. It wouldn’t have happened without the support of some key parties though. Firstly, Professor Kevin Blyth in Glasgow who enabled the most recent wave of site expansion by including us in his amazing PREDICT-meso network. We’ve also been really supported by Mesothelioma UK and the network of specialist nurses, several of whom are Lead Investigators for the study at their own sites.

cont’d

And that's been great too, because traditionally it's often doctors who lead these studies, but there's no reason why nurses shouldn't do it. In fact, they often do a better job than us disorganised doctors! Finally, the study started at around the same time as the British Lung Foundation established its Mesothelioma Research Network, courtesy of a donation from the Victor Dahdaleh Foundation, and that has really helped us link in with different researchers and mesothelioma teams around the country, generating interest and enthusiasm at loads of different sites.

So, I guess with all those amazing people involved, I'm not surprised that things are going so well, but I am very pleased. Our original plan was to open 10-15 sites, and by opening more than that, we've been able to include a mix of big specialist hospitals and smaller district general hospitals. This means that we're reaching people who wouldn't normally have the opportunity to join a research study and also means that we are recruiting a more representative group of people.

I don't want to stop here though! Don't tell my R&D department, but I've got plans to open at least another five sites before the study ends, if not more!

Leah:
What do you enjoy most about working on this study?

Anna:
I really love having the opportunity to work with such a mixed group of people, from patients to research teams to academic leaders in their field. It's been fascinating to link in with researchers from all sorts of different backgrounds, from laboratory scientists wanting to study circulating tumour DNA in blood, to palliative care clinicians investigating pain and how it changes over time, to qualitative researchers looking at the mental health implications of mesothelioma and what interventions can be developed to help. It's inspiring (not to mention educational) to work alongside such people and I feel very lucky that ASSESS-meso has created those collaborations. I'm also pleased that ASSESS-meso is providing a platform to support other people in their research – by collaborating and sharing this resource we can move things forward even faster in terms of our understanding of mesothelioma, and continue to improve the lives of people diagnosed.

Leah:
If your research could change one key aspect of mesothelioma care, what would it be?

Anna:
Well, it's ambitious, and I don't think ASSESS-meso is going to achieve this alone, but it comes down to phenotyping disease and providing personalised medicine. We've known for some time that mesothelioma is an incredibly variable disease and there are clearly different types of tumour that behave differently; more or less aggressively, more or less responsive to chemo etc. I hope that ASSESS-meso will allow us to understand those different disease types in more detail and work out who has which type of disease right at the outset. So we could say to people "you have this type of tumour, that responds best to this treatment, or may be doesn't need any treatment at all at the moment". We've done this in lung cancer, by identifying tumour markers and genetic mutations that determine which treatment is best and I really think we can do this with mesothelioma as well. Alongside Professor Dean Fennell's MiST trial and Kevin Blyth's work around mesothelioma pre-cursors and development, ASSESS-meso can help to achieve this goal. By providing information about lots of very varied people, ASSESS-meso will allow us to describe the different disease types, and test and interpret the findings of these other trials. It's very exciting!

We are grateful to Dr Bibby for talking to us about ASSESS-MESO. If you would like more information about this important study, please download our clinical trials app or visit the clinical trials section on our website at www.mesothelioma.uk.com/clinical-trials/

Scan here to download the clinical trials app

The free app can be downloaded in the Apple App Store or Google Play Store by searching 'Mesothelioma UK'.

LEGAL PANEL

Fieldfisher – landmark mesothelioma trial

In a landmark trial at the High Court this month, Mr Justice Ritchie gave judgment based on Scots law for the family of a man who died from asbestos cancer contracted while employed at the ICI factory in Ardeer, Scotland in the 1970s.

The ICI factory manufactured explosives and it is accepted that while David Haggerty worked for the company, he was required to handle asbestos without adequate warning or protection.

Mr Haggerty was diagnosed with mesothelioma in the summer of 2018 and died in January 2019. He met his future wife, Charmaine Haggerty, in 2015. Mrs Haggerty had three children from previous relationships and Mr Haggerty had two. Mr Haggerty became a stepfather to Mrs Haggerty's children.

As the illness progressed, Mrs Haggerty looked after her husband at home as he became increasingly unwell and later died. She gave up her job as a teacher to care for her husband.

Although the defendant originally denied liability, it later accepted that Mr Haggerty had been exposed to asbestos at the factory. Dushal Mehta progressed a claim on Mrs Haggerty's behalf and on behalf of her three children. Two days before the trial, additional family members joined Charmaine's claim for damages - Mr Haggerty's two children, his two sisters and one grandchild - for the loss of society award permitted by Scots law but not English law.

Dushal and Counsel John-Paul Swoboda argued that the claim should be based on Scots law even though the claimants reside in England. The defendant originally objected to the application of Scots law to this claim brought in England. However, days before the trial on this issue, the Defendant conceded that Scots law would apply to this case. The case progressed to a trial on quantum which took place recently.

In such cases, Scots law allows an award for loss of society and also allows extended family members to claim for their loss, unlike in English law. There is no equivalent in the Fatal Accidents Act. Under Scots law, a loss of society award can be claimed on behalf of a wide range of family members to include as in this case, adult daughters, sisters, grandchildren and stepchildren. Charmaine was able to recover a loss of society award of £115,000 and her children recovered substantial sums also.

These claims could not have been advanced had English law applied to the assessment of damages. A complicating factor in the case was that for claims dating back to the 1970s, the common law rule was that while Scots law determined the heads of loss, English law determined the assessment of those heads of loss. However, the Claimant's approach to the assessment was agreed by the Defendant which meant Scottish case law to be taken into account in determining 'loss of society awards'.

Despite the fact that Mr and Mrs Haggerty had not been together for long, the judge said he accepted that they would likely have been together for the rest of their lives had Mr Haggerty not contracted mesothelioma. He had lost over 20 years because of the illness. Despite the defendant arguing for a much lower sum at the trial, the judge awarded Mrs Haggerty and her children over £600,000 for their losses. Further awards had been agreed one day before trial for the other claimants (the extended family members).

Dushal said this was the first time such a judgment under Scots law has been allowed in the English courts in a mesothelioma case.

The sometimes hidden victims of mesothelioma

By Sarah James, Senior Associate in the Asbestos Team at Slater and Gordon

Sarah James

As a solicitor specialising in asbestos-related disease claims, I have seen over the course of many years the devastating impact that this illness has on all those affected by it. It is imperative that we acknowledge that, whilst mesothelioma is a rare disease, the distress it causes is invariably life altering, and not only for those suffering with the disease but also family, friends and loved ones.

A person diagnosed with mesothelioma is not just a statistic but a spouse, partner, mother, father, grandmother, grandfather, aunt, uncle, friend. And this condition impacts emotionally on loved ones, as well as the patient. It goes without saying that lost loved ones can never be replaced. And in a sometimes hidden way, the impact in practical terms can be very keenly felt where a mesothelioma patient is also a carer for a loved one.

We are finding it increasingly common to be instructed to investigate a claim on behalf of a mesothelioma patient who is, at the time of diagnosis, the primary carer for a loved one. We have seen cases of clients who have dependent children, clients who care for grandchildren, clients who care for a disabled relative and most commonly, clients who care for their spouse. The care described to us by our clients relates to both mental and physical conditions but either way, our clients have expressed concerns to us that without them being there to provide the care, they worry about the future safety and wellbeing of their loved one.

Receiving a diagnosis of cancer is understandably distressing and stressful for anyone at any time. The shock of receiving such a diagnosis can understandably lead to anxiety, depression and anger. We have seen that this anxiety can be particularly devastating and overwhelming for those in a caring role. As well as all of the usual feelings that accompany receiving such a diagnosis, there is the added strain arising from the concern as to what will happen to the loved one for whom they care. It is a testament to our clients that their concern is for the wellbeing of their loved ones and how they will be provided for, despite having just received a mesothelioma diagnosis themselves.

Our paramount concern is to support both mesothelioma patients and their families, to remove as much of the stress regarding the unknown as we possibly can, enabling our clients and their families to focus on those things that matter most, including spending quality time with family and friends, and their treatment programme. We understand that when someone is a carer for a loved one, they will wish to ensure that suitable provision continues, wherever possible, for as long as their loved one requires care, assistance and support.

One of our clients, recently diagnosed with mesothelioma, is his wife's primary carer, providing assistance with personal care and also taking care of all domestic tasks including meal preparation, laundry, cleaning and shopping. He takes care of his wife's medication and transports her to and accompanies her at all medical and other appointments. In addition to providing practical hands-on care, his role also involves background supervision to ensure safety. He provides the prompts and cues necessary for his wife to remain in her daily routine in the family home. Because he is there, he and his family feel that their loved one is safe.

In such situations, we will always do our utmost to ensure that funding to best replicate the care and assistance that would have otherwise been provided is recovered as part of the claim; whether that be funds for the family to employ a live-in carer or funds for residential or nursing care. Recovering these costs can lead to difficult conversations and decisions during the compensation claim, but we never shy away from those conversations, particularly where delaying the settlement of a claim is likely to result in a recovery of a settlement sum significantly more valuable than what can be recovered during a patient's lifetime. That the law requires these conversations at all is a travesty and we will continue to campaign for change on this front.

We recently recovered substantial damages in a claim where the mesothelioma patient was the primary carer in circumstances very similar to those outlined above. Our client was 90 years old when he developed mesothelioma. Our evidence asserted that he would have been able to meet his wife's care needs arising out of her dementia diagnosis for another three years beyond his diagnosis. Although strongly disputed by the Defendant, in the end we were able to recover full-time residential care home costs of over £150,000 as part of the settlement, which ensured the safety and comfort of our client's wife, his primary motivation when deciding to pursue a claim in the first place.

Another recent settlement agreed on behalf of one of our clients was for the husband of a client who had sadly succumbed to her mesothelioma. Due to an accident at work, he had been left permanently disabled and had come to rely heavily on his wife with most aspects of daily living. Cleaning, gardening and the like were also out of the question. In addition to the emotional toil of being diagnosed, our client worried greatly about how her husband would manage without her, with no other family living locally. In the end, we recovered substantial damages to ensure that our client's husband was able to remain in the family home whilst having his injury-related care needs, as well as all other needs fully met.

We know and have seen first-hand the huge difference that securing compensation for replacement care can provide to all of those affected by mesothelioma. If this is a situation familiar to you or someone you know, then please remember the importance of consulting one of the specialist firms of experienced asbestos lawyers forming the Mesothelioma UK legal panel at the earliest opportunity following your diagnosis. We are all here to listen, guide and assist in any way possible.

RESEARCH

Mesothelioma UK awards £150,000 funding for new research studies

Mesothelioma UK is supporting five new research studies which will focus on issues affecting the treatment and care of mesothelioma patients. The research will be funded from the charity's first grant round since successfully becoming a member of the Association of Medical Research Charities.

The research studies that have been successful in this round of grant funding include:

- North Tees and Hartlepool NHS Foundation - Understanding the patient journey for those with mesothelioma: A review
- Northumbria Healthcare NHS Foundation Trust - Diet and physical activity in patients with mesothelioma
- University of the Highlands and Islands - Improving the patient diagnostic pathway for mesothelioma

- University of Leicester - A test to diagnose and predict clinical outcomes in mesothelioma
- University of Sheffield - Improving symptom control in mesothelioma

Liz Darlison, Mesothelioma UK Chief Executive commented: “Our mission is to fund world-class mesothelioma research that makes a significant impact on patient treatment and care, outcomes and patient experiences.

“We’re delighted to be able to award these five research teams the funding to enable them to carry out their important studies and we look forward to seeing the results and impacts of the research.

“We are extremely grateful to the charity’s fundraisers and donors; without their support, these grants would not be possible.”

Mesothelioma UK is committed to supporting research into all aspects of treatment and care related to mesothelioma and has funded research and audits since 2015, both independently and through partner organisations. The charity offers a range of grant opportunities to universities, medical schools and research institutes within the UK and Northern Ireland that fund research that explores patients’ experience of care, through to research on patient diagnosis, treatments and outcomes of care.

Research priorities to improve patient experiences

The University of Sheffield’s Mesothelioma UK Research Centre (MURC) launched a research prioritisation exercise last year to identify unanswered questions about the mesothelioma patient and carer experience. The study was conducted to pinpoint research areas of most importance.

This led to the publication of a Research Priority Statement which listed 11 research priorities. The first five priorities relating to the patient and carer experience were identified as the most urgent. These include symptom management, receiving a mesothelioma diagnosis, palliative and end of life care, experience of treatments and barriers and facilitators to joined-up provision.

A further six research priorities relating to the mesothelioma patient and carer experience were also identified as important and they include care delivery, living with peritoneal mesothelioma, mental health and wellbeing, experience of clinical trials, experience of caregivers and compensation.

The priorities will influence the research agenda and in turn, impact policy-setting and practice to improve outcomes for mesothelioma patients and their carers and families.

Further information about the Research Prioritisation Exercise can be found at www.sheffield.ac.uk/murc/our-research/research-prioritization-exercise

Improving mesothelioma follow-up care in the UK

A study led by Dr Catherine Henshall, and funded by Mesothelioma UK in partnership with Lung Cancer Nursing UK, has recently been completed and the results published in the BMJ Open

Dr Catherine Henshall

Dr Henshall, a Reader in Nursing at Oxford Brookes University, carried out the study to identify best practice for patient follow-up care to help mesothelioma patients lead fulfilling lives and ‘live well’ with their condition. The study explored the patient experiences of care in three National Health Service (NHS) Trusts to develop recommendations for practice.

The study began with a documentary analysis of reports, guidance and policy documents relating to follow-up pathways at the trusts to establish what services were in place, enable comparisons between trusts and to inform the patient interviews.

21 mesothelioma patients receiving follow-up care were then interviewed to explore their experiences of follow-up, the type and frequency of support received from health professionals and how this aligned with their treatment pathways and symptom control.

Finally, consultation meetings with stakeholders were held to discuss the findings, make recommendations for policy and practice, and to propose a preferred, patient focused, follow-up service that is evidence-based, collaborative and inclusive. The first meeting was with patients/carers, the second with Mesothelioma UK nurse specialists; the third with local commissioners and clinical leads.

The study found that mesothelioma pathways were not always distinct from lung cancer care pathways. All trusts provided follow-up information and resources but there was varied information on how to access local support groups, research or clinical trial participation. Five themes were developed relating to people; processes; places; purpose and perception of care. Co-produced recommendations for improving mesothelioma follow-up pathways were developed following the consultation meetings.

Key findings also highlighted a need for patients to have access to a specialist mesothelioma team within a streamlined mesothelioma care pathway. This ‘pyramid of care’ consists of a mesothelioma specialist nurse, respiratory consultant, multidisciplinary team members (including oncologists and lung cancer nurse specialists), community and palliative care teams, support services and support groups.

The recommendations were:

1. All mesothelioma patients have access to a mesothelioma specialist nurse within a respiratory led mesothelioma care pathway.
2. Timely information regarding diagnosis, prognosis, and follow-up care is provided in a supportive environment.
3. Patients are equipped with necessary information to guide treatment and care decision-making.
4. Streamlined integration between secondary, palliative and community care services.
5. Patients are provided with appropriate information resources from diagnosis throughout their care pathway.
6. Facilitate personalised care links between secondary care and community support services.

Palliative care study updates

Researchers at the Mesothelioma UK Research Centre in Sheffield have completed a research study on the role of Mesothelioma UK Clinical Nurse Specialists in meeting the palliative care needs of people living with mesothelioma and their families. This update is further to the article about the study published in *Mesothelioma Matters* (Winter 2021).

The recent palliative care study explored the palliative care needs of mesothelioma patients and the role of Mesothelioma UK Clinical Nurse Specialists in providing palliative care. We are pleased to announce that the final report is now available for free download: www.sheffield.ac.uk/murc/our-research/palliative-care-and-role-clinical-nurse-specialist

We are working with Mesothelioma UK to disseminate the findings and recommendations, for example, developing new or updated resources for patients and families about what palliative care is, and how it can help both patients and families. Once developed, the new resources will be available on the Mesothelioma UK website.

We have been disseminating findings in a poster, and a new paper:

- A poster about the palliative care study was presented at the British Thoracic Oncology Group conference in January 2022 by Professor Clare Gardiner
- A paper written with Liz Darlison (Mesothelioma UK CEO) about the experiences of end-of-life care from the perspective of bereaved family caregivers has been accepted for publication in the Journal of Palliative Care - *'Understanding the experiences of end-of-life care for patients with mesothelioma from the perspective of bereaved family caregivers in the UK: A qualitative analysis'* by Madeleine Harrison, Liz Darlison, and Clare Gardiner.

Clare Gardiner

Peritoneal patients and carers needed for new study

Are you living with peritoneal mesothelioma? Are you a family member or close friend of somebody who is living with peritoneal mesothelioma? If so, the Mesothelioma UK Research Centre (MURC) needs you for a new study.

There is an increasing awareness that people living with peritoneal mesothelioma may have different experiences to those living with pleural mesothelioma. Evidence suggests that it takes longer for patients with peritoneal mesothelioma to be diagnosed and that there is variability in access to and experiences of care in people living with peritoneal mesothelioma in the UK (Senek, 2021).

This mixed methods study aims to explore variability in the care pathway of people with peritoneal mesothelioma and to explore the patient experience of the care pathway. This project is being undertaken in collaboration with Hampshire Hospitals NHS Foundation Trust.

MURC is currently conducting the first stage of the study which involves the completion of a questionnaire. The team has had a fantastic response from the peritoneal mesothelioma community so far and would like to thank those of you who have completed and forwarded the questionnaire. However, they are still looking for more participants. The more patient and carer experiences that they can capture, the more information they have to improve future care.

If you are living with peritoneal mesothelioma or are a family member or close friend of someone who is living with peritoneal mesothelioma or has died from peritoneal mesothelioma, please complete one of the questionnaires at the link on this page. Your participation will be kept confidential.

Patient questionnaire link: https://bit.ly/35nrGdI

Family member or close friend questionnaire link: https://bit.ly/3tbCYdk

If you would like to find out more about this project, please visit the study page on the Mesothelioma UK Research Centre website: www.sheffield.ac.uk/murc/our-research/variability-patient-pathways-and-experiences-care-peritoneal-mesothelioma

Senek, M., Robertson, S., Tod, A., & Squibb, M. (2021). Mesothelioma: exploring gender differences in time to diagnosis, seeking legal advice and occupational risk. Cancer Nursing Practice. https://doi.org/10.7748/cnp.2020.e1745

APPOINTMENTS

Two more nurses join our team

Anna Morley

Tollene Riley

Mesothelioma UK is delighted to welcome two more nurses to its team of Mesothelioma UK Clinical Nurse Specialists.

Anna Morley is based at the Southmead Hospital, part of the North Bristol NHS Trust and Tollene Riley is based at the Epsom and St Helier University Hospitals, part of the Epsom and St Helier University Hospitals NHS Trust.

The appointments mean that we can add the Bristol, North Somerset and South Gloucestershire Cancer Alliance and the Royal Marsden Partners Cancer Alliance to our list of alliances which include a Mesothelioma UK Clinical Nurse Specialist.

Anna's post has been made possible thanks to funding from the Avon Mesothelioma Foundation. Anna and Tollene will provide nursing care and support for mesothelioma patients and families, and link up with colleagues across their regions to promote equitable access to mesothelioma specific support and treatment throughout the region.

Commenting on her new role, Anna said: "I am passionate about providing excellent care and support to mesothelioma patients and their carers at each stage of their journey and I'm excited to have been offered this new role. I feel privileged to be joining such a fantastic team at Mesothelioma UK and am looking forward to the opportunity to learn more about mesothelioma from the team. I'm extremely grateful to Mesothelioma UK and Avon Mesothelioma Foundation for their support of this post."

Tollene said: "During the last year in my new role as Lung Cancer Clinical Nurse Specialist, I have met a number of patients who have been diagnosed with mesothelioma. I wanted to be able to offer informed support and I am therefore very pleased to have been adopted by Mesothelioma UK and have the opportunity to learn from the wealth of expert knowledge available through the charity.

"I'm keen to develop the service we offer patients with mesothelioma and my adoption by Mesothelioma UK, and the chance to work with the Royal Marsden and Partners Cancer Alliance, will have a positive impact on the care of our patients."

Lorraine Creech, Head of Nursing for Mesothelioma UK, added: "Mesothelioma UK welcomes Anna and Tollene to our growing team of 34 clinical nurse specialists, adding to our coverage of Cancer Alliance regions around the UK and bringing the benefits of her research experience."

New Finance Assistant Appointed

Mesothelioma UK is delighted to welcome Dumitrita Gulian to the operations team as a Finance Assistant where she will support the team to maintain financial records and review and reconcile bank statements.

Dumitrita Gulian

Dumitrita is originally from Moldova where she graduated from Financial Banking College as an accountant. Shortly afterwards, in 2018, she moved to the UK where she worked as an e-commerce assistant for Watches of Switzerland.

Dumitrita decided to further her studies and began a remote AAT accounting course while working full time. She has now completed the Foundation Diploma in Accounting.

Dumitrita said: "Working in finance is something I always aspired to do and working in an organisation that helps to make other people's lives better is even more appealing. I feel so proud now working with Mesothelioma UK and seeing all the support it has to offer, knowing that I am part of it."

FUNDRAISING

Is our future bright... ?

The last couple of years have been very hard for most charities including Mesothelioma UK and the impact lockdown has had on our traditional fundraising income has been huge, but as our ongoing journey evolves with a sense of normality in a post-pandemic world, we are cautiously optimistic about the future ahead. Income is slowly beginning to rise as our wonderful supporters take huge strides to help us by taking part in challenges and holding their own fundraisers in the most innovative of ways.

Sally Reedman couldn't hold her annual open day, raffle and garden party for Mesothelioma UK due to the pandemic so Sally and her daughter, Emma, who were not to be beaten, had the vision to collect and sell goods online locally. Of course, it was all in keeping with the recommended government guidelines and they raised an amazing £2,345 which is a true testament to the strength and commitment of our wonderful supporters and with your continued help, **yes, our future will be bright!**

Jill Lemon
Senior Fundraiser,
Legacy & Challenges Officer,
Mesothelioma UK

'Challenge Yourself 2022' For Mesothelioma UK

It's that time of year when we all feel tired and sluggish but there's a touch of spring in the air. The nights are getting lighter and we are slowly coming out of hibernation and starting to think about getting those running shoes dusted down, ready to embrace the coming months.

Like Sally and Emma (see above), you too can help us by taking a fundraising step forward.

We have a host of challenges to choose from - 5ks, 10ks, half and full marathons, walks, obstacle races, inflatables, cycling and so much more, both locally and nationally, that may just be up your street. Or you may be holding your own fundraiser, coffee morning, quiz or supporting our campaigns.

Whatever it is, we will be there to support you all the way!

And don't forget to ask your boss if they are part of the **Matched Giving Scheme**. Lots of places now have this scheme up and running to help support their staff.

We have filled our London Landmarks Half Marathon charity places which will take place on 3 April but don't despair, we still have charity places in the London Vitality Big Half on 4 September so if you want to support us, get in touch and put your name down as places will go quickly. And the best bit is that the Mesothelioma UK Fundraising Team will be there at both events with our 'Meso Cheer Station' to support our fantastic runners, so do come and seek us out and let's get cheering!

Contact us at fundraising@mesothelioma.uk.com or call 0800 169 2409 and press option 2.

Volunteer Programme

Our volunteer programme is well and truly underway. We have had such a wonderful response, held our first inductions and our volunteers are raring to go, but it's never too late get involved so come and join us. Volunteering is good for the soul and there are so many different things with which you can get involved, from photography, proofreading, bucket rattling, cheering our runners on to helping us at our events such as the Patient & Carer Day. It's a great asset on your CV too! www.mesothelioma.uk.com/volunteer-for-us/

Contact us at fundraising@mesothelioma.uk.com or call 0800 169 2409 and press option 2.

Mesothelioma UK Free Will Service

Anyone can take advantage of our Free Wills Service. We have a dedicated team of solicitors that offer this service for free. All we ask is for you to consider leaving a gift in your will to Mesothelioma UK. We aim to be there to support anyone through their mesothelioma cancer journey and the Power of Your Pledge will help us to do just that.

www.mesothelioma.uk.com/leave-a-gift-in-your-will/

Celebrations in 2022

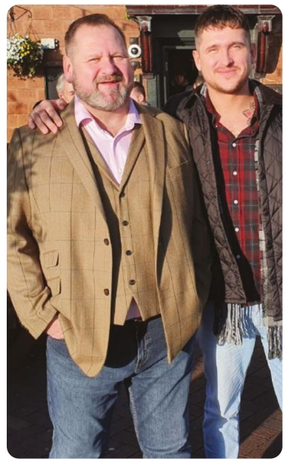
Are you celebrating a **wedding**, an **anniversary** or a **big birthday** this year? If so, don't forget that we can help you to make it special while supporting your favourite charity!

Give the fundraising team a call on **0800 169 2409** and select option 2. We have balloons, napkins, pins, forget-me-not seeds and much more.

Muffins for Meso

Muffins for Meso will be back for spring, but with a twist! Instead of taking place across the whole month of May, we will be doing a big baking extravaganza on one day. Keep Thursday 19 May 2022 free and watch this space for more details to come!

Will's run for Mesothelioma UK



When I decided to do a charity run, I chose Mesothelioma UK as it's very close to my heart and something I feel very passionate about.

I had never heard of mesothelioma until my Dad was diagnosed in 2015. He learnt it was caused by the asbestos he worked with and was surrounded by when just a teenager, and had laid dormant for the majority of his life. The prognosis was not good, but Dad had a few bouts of chemotherapy to keep it at bay and he managed to enjoy the next few years before his cancer returned with a vengeance.

Sadly, in the early summer of 2020, it had spread uncontrollably and he passed away on 11 August.

I want to raise awareness of this strange, horrible, and often sporadic disease to help support others as well as finding treatments and one day, a cure. Charities like Mesothelioma UK are vitally important in the fight with the support they provide and I'm proud to be associated with them.

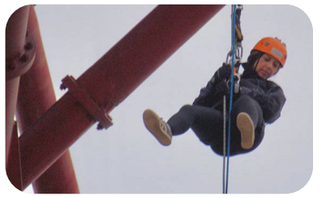
Will is running 56 miles throughout February, if you would like to donate, you can view his page at www.justgiving.com/fundraising/william-abbott1

Fieldfisher braves the heights with the highest freefall charity abseil

Legal eagles from Fieldfisher's asbestos team, along with barristers from 12 King's Bench Walk, scaled the heights of success in a charity abseil event down the Arcelor Mittal Orbit sculpture in the Queen Elizabeth Olympic Park in Stratford.

Renowned as the UK's highest freefall abseil from the UK's tallest sculpture, the adrenaline-fuelled event was held to raise funds for Mesothelioma UK and HASAG.

Each team member successfully made a daring descent, raising more than £6,500 for the two charities. The team was moved by the generosity of sponsors who spurred them on to complete the challenge, which certainly proved to be a memorable one. Despite the terror they felt as they stepped backwards off the ledge 80m above ground, they all agreed that the experience was brilliant and one not to be missed.



You can watch Charlotte Thorpe, a solicitor who is part of Fieldfisher's Personal Injury and Industrial Disease teams, taking her first tentative steps to gradually making a triumphant descent at www.youtube.com/watch?v=tkkGzlP-CIk&t=414s

Reuben's 20 for 20 challenge!

Hello, my name is Reuben and I am 8 years old. In June 2021, my Grandad Ray was diagnosed with mesothelioma. Whilst he was in hospital, we were not allowed in to visit him, so I made signs to hold up to him whilst he looked out of his hospital window. When Grandad told us that he had mesothelioma and explained what it was and how he had got it, we set up a group called Team Grandad. In this group was myself, my older brother Jake and my two cousins Zak and Lukas. Team Grandad looked out for each other and had positive thinking to help Grandad get through his check-ups and treatments.

I decided that I wanted to do something for charity so I asked my mum if I could do something to raise money for Mesothelioma UK as they helped my Grandad so much. We decided that as a family, we would do various events for a year to raise money.

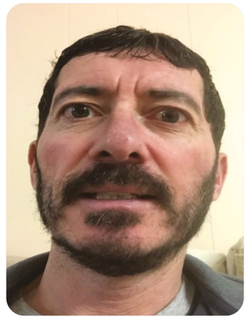
We looked on their website and saw the 20 / 20 challenge. I wanted to do this to start off our fundraising. I decided that I would try to do 20 rugby passes a day for 20 days as I enjoy playing rugby and my Grandad played rugby before when he was in the Navy (he has got a cap for playing for the Navy at Twickenham).

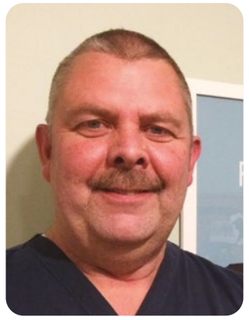
I managed to do all 20 days and lots of different people helped me out with it including my friends and family, and mine and my brother's rugby team, Oulton Raiders and Sandal. I was so happy that I had managed to raise £760.

Read more about Reuben and the 20 for 20 challenge on Page 5 of this edition of Mesothelioma Matters.

Grow a mo

Our annual Grow a Mo campaign took place in November. We had lots of people take part from across the country, plus some participants from the US! As usual, our supporters did not disappoint and grew some expert beards, moustaches and even mohawks! The campaign raised over £3,000. We are so grateful to everyone who donated and took part, and here are some progress pictures of a few of the participants...





Graham Thornton's golf day for dad

On 1 June 2021, my dad rang me with the news that he had just been diagnosed with asbestosis. I wasn't sure what to make of the news and the only take away I had was that the news 'wasn't good'. He would always tell me things would be ok. So, to hear that things weren't good was a pretty big deal.

From that call, I went home and researched what I had just been told, only to find bad news in every article. The next two weeks were a blur and my dad passed away on 11 June 2021. I was amazed at how quickly this could happen and how so little could be done.

The only thing I knew was the support my dad got in those last two weeks was amazing.

My dad was a golf fanatic and was a founder member of Heyrose Golf Club near Knutsford nearly 30 years ago. Over those 30 years, he made some very special friends as well as playing at other courses to win the prestigious Thornton Cup (see photo with my uncle and cousin in the green jacket), an annual event played for the last 12 years.

With all that had happened, I wanted to organise a golf day for all his friends at Heyrose whilst raising donations for Mesothelioma UK to support continuation of research into this terrible disease.

So on 15 October, Heyrose played host to the Roy Thornton Golf Day in which 32 of his closest family and golf friends got together to toast my dad and play some golf in the most amazing sunshine that greeted us on the day.

Along with a raffle on the day, we raised over £1,000.

Ashleigh's wing walk in support of Grandad

Very sadly, my Grandad, Charles Cawley (Joe) was first diagnosed with mesothelioma in 2020. I was due to get married that year, but unfortunately, had to postpone the big day like many others, due to COVID-19. To give my Grandad a positive boost and something to look forward to, I asked him if he would walk me down the aisle alongside my dad, his son, in July 2021 when the wedding had been re-arranged.

He couldn't have been more honoured and I was so lucky to have the privilege of having him walk me down the aisle on one of the most important days of my life. He was so determined not to let anything, or his illness, get in the way of stopping him from being there.

After the organising of the wedding came to an end, at that time I had watched his brave battle against this aggressive cancer for over a year when I had an overwhelming feeling that I needed to do something to raise awareness and to help other people and their families in the same circumstance.

My goal was to raise money to contribute towards the wonderful work this charity does - my thoughts were, wouldn't it be so nice if, when diagnosed with this disease, people in the future would not necessarily be given a terminal diagnosis? With more research that is continually ongoing, I hope that one day there will be a cure for this type of cancer, so that other people do not have to go through the same journey that my Grandad has had to endure.

I wanted to do something big and out of my comfort zone, so decided on doing a wing walk at Headcorn Aerodrome, which took place on 17 October 2021. My goal was to raise £250, but amazingly I managed to raise £1,332 for Mesothelioma UK. My Grandad came along to watch on the day; it gave me so much courage knowing he was there to show me his support and there was no way I was going to let him down.

Even when strapped to the top of the airplane and on the runway ready for take-off, I thought to myself, no matter how scared I was at that moment, that feeling I had would be nothing in comparison to how people must feel when they are diagnosed with a terminal illness such as mesothelioma.

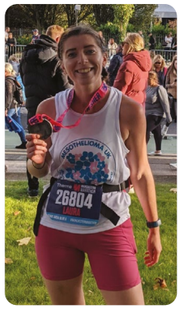
Knowing how proud I made him, along with the rest of family, will bring me great comfort for the rest of my life.

Ashleigh Brown (nee Cawley)

Laura runs the Manchester Marathon

Last October, I ran the Manchester Marathon for Mesothelioma UK in memory of my grandad. He passed away after his battle with mesothelioma last February during lockdown. To remember him, I wanted to do something to both raise awareness of the disease and fundraise for an amazing cause.

Raising money for Mesothelioma UK started so many great conversations with both friends and strangers - including a fellow Mesothelioma UK fundraiser on race day! I am so grateful to everyone who sponsored me, and hope that I made my grandad proud.



Laura raised over £800 in memory of her grandad; thank you for your support!

Spring challenges

If your New Year's resolution was to take on a new challenge or get involved with fundraising, then there's plenty on in spring with which you can get involved! Check out the events calendar below to see what's coming up in the next few months. You can get involved in races like the Asda Foundation Leeds Half Marathon, Hampton Court Palace 10K or try your hand at an inflatable race! Whatever level of experience you have, there will be something for you. If you are interested in taking part in any events or would like to find out more information, contact us at fundraising@mesothelioma.uk.com or call 0800 169 2409 and press option 2.

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

28 March 2022
Mesothelioma Matters Webinar
www.facebook.com/mesouk

3 April 2022
London Landmarks Half Marathon
www.mesothelioma.uk.com/london-landmarks-half-marathon/

9 April 2022
Easter 50 Challenge
www.ultrachallenge.com/easter-challenge/

25 April 2022
Mesothelioma Matters Webinar
www.facebook.com/mesouk

30 April – 1 May 2022
Isle of Wight Challenge
www.ultrachallenge.com/isle-of-wight-challenge/

14/15 May 2022
Jurassic Coast Challenge
www.ultrachallenge.com/jurassic-coast-challenge/

30 May 2022
Mesothelioma Matters Webinar
www.facebook.com/mesouk

11/12 June 2022
Lake District Challenge
www.ultrachallenge.com/lake-district-challenge/

Remember there are dozens of runs all around the country which you can run for Mesothelioma UK – visit www.mesothelioma.uk.com/local-challenges/ to find one near you.

Many thanks to our Mesothelioma UK Legal Panel supporters

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