

#### **Mesothelioma UK**

How does Mesothelioma UK support patients?

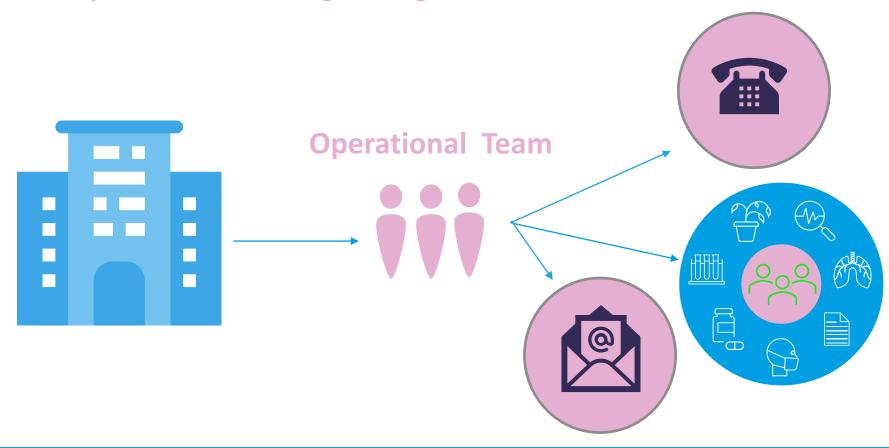
Mesothelioma in the Midlands Thursday 27th June 2024

Jill Lemon
Community Relations &
Fundraising Manager

### **Mesothelioma UK**



**Headquarters based in Loughborough** 



#### **Information Resources**



Mesothelioma UK have a range of downloadable and paper resources covering all aspects of mesothelioma



Mesothelioma
UK is accredited
by the Patient
Information
Forum (PIF). The
PIF TICK is the
UK-wide quality
mark for health
information

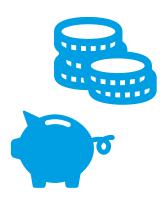


#### **Benefits Advice**



Mesothelioma UK funds a specialist benefits advisor

Sarah Thomas, Senior Benefits Officer, North East

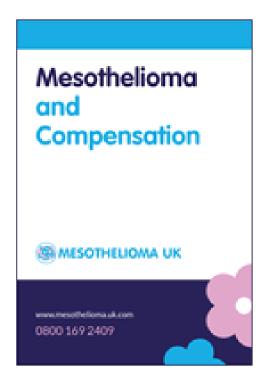


# **Legal Advice**



Mesothelioma UK provides guidance on legal issues and information on our legal panel





#### **Patient Travel Grants**



Mesothelioma UK has a travel grant to help patients with the cost of attending clinical trial appointments

Travel grants awarded in 2019/2020

£24,779

Travel Grants awarded in 2020/2021

£12,000

Travel grants awarded in 2021/2022

£13,332

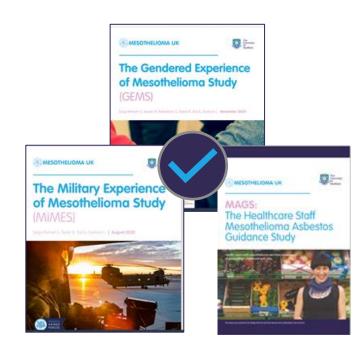




## **Research Centre**



Established in 2020, research to benefit the care and experience of patients





**Completed Research** 

**Current Research** 

### Mesothelioma UK Research Funding



Mesothelioma UK independent research grants

#### **Four Themes**

- 1. Diagnostic pathway
- 2. Symptom control/QoL
- 3. Monitoring & follow up
- 4. Improving access







# **Specialist Services**



Our dedicated Armed Forces Service includes information, specialist nurses and research





We fund the only clinical nurse specialist dedicated to the care of patients with peritoneal mesothelioma

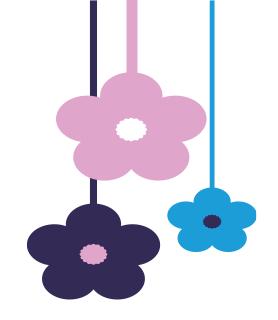
# Amplifying the patient voice



Research
Patient Stories
Patient & Public Involvement
Trial Management Groups
Projects & Campaigns





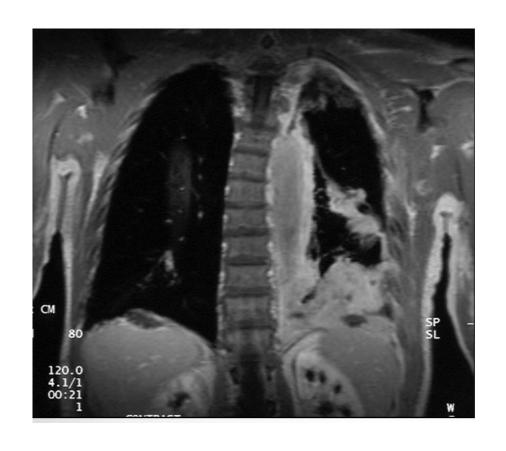


### **Mesothelioma CNS**

Mairead Dixon
June 2024

# Malignant Mesothelioma

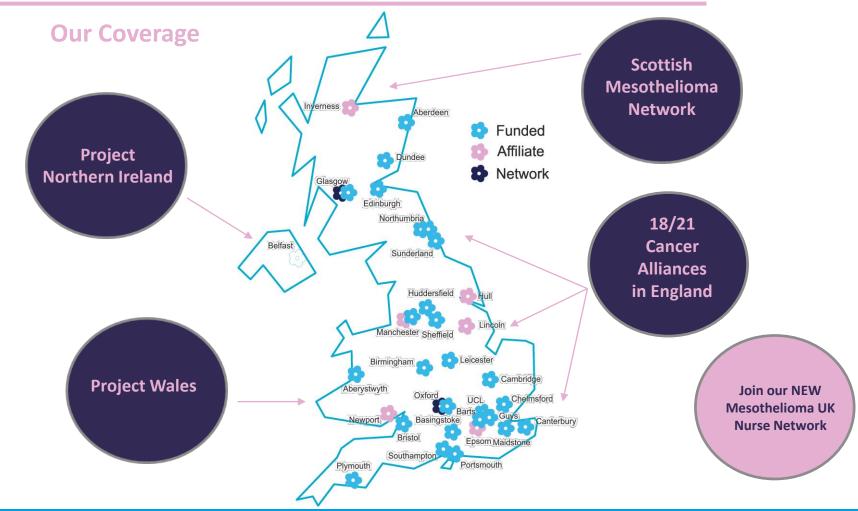




Cancer originating from mesothelial cells.

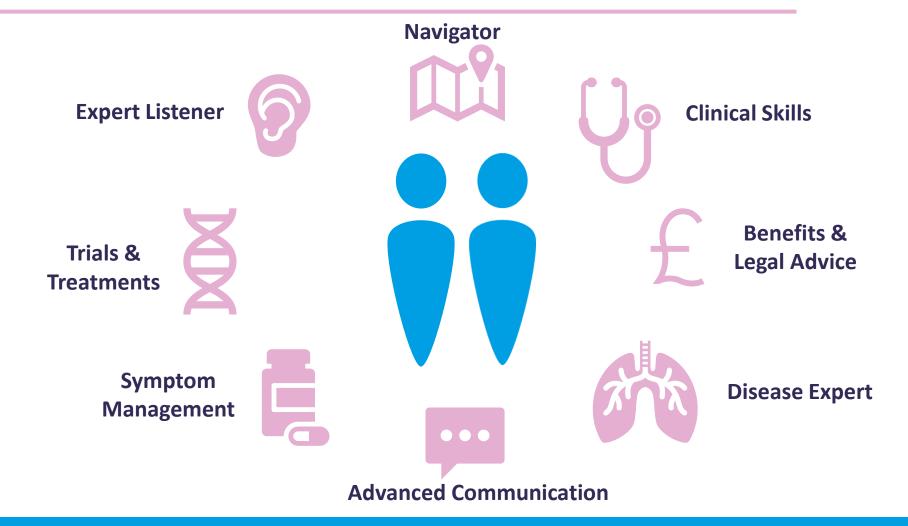
### Mesothelioma UK CNS Workforce





### Mesothelioma UK CNS





# **Support Line**



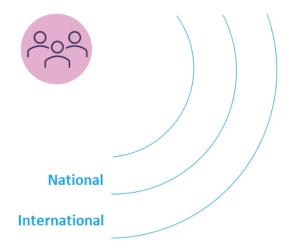
Freephone Support Line – Monday to Friday 9am – 4pm

- ✓ Emotional Support
- **✓** Signposting
- **✓** Information
- **✓ CNS**



support@mesothelioma.uk.com





#### **Treatments**



#### **First Line Treatment**

Immunotherapy – uses the immune system to kill the cancer Drugs used: Ipilimumab & Nivolumab

#### **Second Line Treatment**

Chemotherapy - destroys cancer cells
Drugs used: Cisplatin/Carboplatin & Pemetrexed

#### **Third Line Treatment**

Chemotherapy
Clinical Trials
Private treatment



## **Patient Journey**



74 yr old man who worked in a power station

Diagnosed November 16

Passed away June 24

8 lines of treatment including chemotherapy and immunotherapy.

Participated in 2 trials

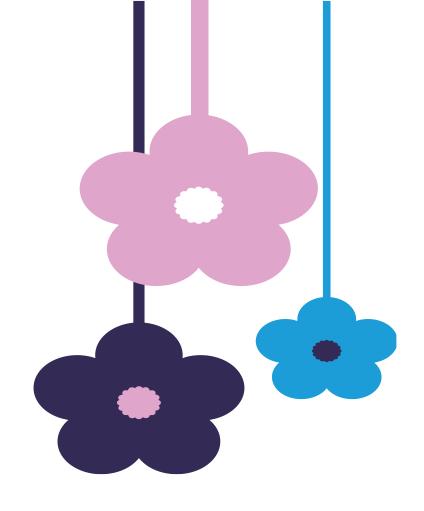
Attended the support group and AMD days.

Supported many other patients along the way.

# Thank you

08001692409

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# **Mesothelioma UK Nurses**

**July – Dec 2023** 

Area	<b>Episodes of Care</b>	New Patients	Support Group Attended
Aberdeen	658	9	4
Dundee	407	10	6
Edinburgh	256	19	3
Glasgow	1165	7	2
Northumbria	299	20	12
Sunderland	207	12	10
Harrogate	1408	52	18
Manchester	3262	55	10
Leicester	642	52	18
Birmingham	1269	32	7
Cambridge	344	26	6
Chelmsford	125	28	10
Oxford	799	31	7
UC London	175	5	0 New group
Guys London	738	22	8
Bristol	305	13	6
Basingstoke	401	23	10
West Kent	1425	33	11
East Kent	232	20	6
Portsmouth	406	33	6
Southampton	2189	38	12
Plymouth	469	14	12
Wales – New post started Dec 4 <sup>th</sup> 2023	16	5	1



# Thank you

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