



MESOTHELIOMA UK

Supporting People With This Asbestos Cancer

Health Professionals Guide to the Mesothelioma Care Passport

The passport is intended to help patients navigate the health system after they have been given a diagnosis of mesothelioma. It is not intended to replace their medical records, but to empower patients with information about their diagnosis and treatment assisting them in communicating to their wider healthcare professional team.

There are four main sections:

1. Useful contacts
2. Medical details
3. Treatment to date
4. Care Plan

It is expected that the patient will initially need the help of their nurse/ key worker to fill in sections 1-3 and that they will then bring this passport along to all appointments / health care assessments.

There is a place

in section 4 for record keeping as well as space to note any questions or unresolved issues.

This passport document should be used in conjunction with the Mesothelioma UK patient information literature.

It would be preferable to select only the information literature that is relevant to that patient at the current time. For example, information on peritoneal mesothelioma will not be relevant to all patients, and the information on the role of the coroner might not be appropriate for the initial post diagnosis discussion.

You should encourage the patient to take ownership of the passport document and to ask for records of their clinic letters, CT results and blood tests, so that they may keep them in the holder with the passport.

Patients should receive a minimum of 4 items when they are given the passport:

1. Information pack / holder
2. Mesothelioma Care Passport
3. Feedback form
4. Information Checklist

Introduction Pages

This is intended to be an introduction to the patient on what the passport is for, and how to use it, but you can supplement this with an explanation of your own.

There is also a video aimed at explaining the guide to patients which can be found on our website. Please feel free to refer patients to this.

We have also left a space on the left-hand side for the patient details – you may find it convenient to use the NHS sticker here.

**Patient details
/ NHS sticker**

What is this?

This pack is designed to help you keep up-to-date with the planned care that you have discussed and agreed with your health care professionals. We hope that it will help you to keep track and make sense of what is happening. Please bring it with you to all appointments, as well as when meeting any health professionals involved in your care. This may be in your own home and at any community clinics or if you attend hospital for any reason.

It is intended to be a concise record of your care to date, enabling you to understand and discuss with anyone you choose, for example, your GP, clinical nurse specialist physiotherapist, community nurse, consultant, emergency doctor, clinical trial advisor or anyone else in whom you wish to confide.

If you have requested access to your clinic letters, you can store them here, along with your scan and x-ray reports. You can also keep your most up to date prescription and other documents you feel may be useful here. For ease of use, we suggest you store the most recent on top.

There is also a section for you to store any relevant written information that has been provided to you. A list of this available information is located at the back of this pack.

The Care Plan section is for you to use as you wish.

You may prefer to ask your nurse or health care professional to write a summary of your recent discussion/consultation, including what the next steps are for you, or you may like to make a note of any questions you have for your next appointment.

Useful Contacts and Medical Details

This section can be filled out in conjunction with the patient, to ensure they have the details they need. We found that patient often felt daunted by having to remember details such as site and subtype, so it can be very useful to record this with the patient.

Useful contacts	Medical details
Mesothelioma UK CNS	Diagnosis
.....
Lung CNS	Date of diagnosis
.....
Other	Site
.....
	Subtype

	Allergies



	Any other health conditions



Your Care Plan

This is the main section of the passport, where patients and HCP can record what happened at each appointment or visit. Patients can also add in any questions after the appointment, as a reminder.

Your care plan

	When _____		When _____
	Who _____		Who _____
Where _____		Where _____	
Summary _____		Summary _____	
Questions _____		Questions _____	
_____		_____	


Notes Section

This section is for anything that doesn't fit in the above categories and can be used in any way that the patient would like.

<p>Notes</p>	
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Information Checklist

This should be included with each pack, in the information holder with the passport and any other information literature given.



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AVAILABLE PATIENT INFORMATION

1	Mesothelioma UK	<input type="checkbox"/>
2	Asbestos and the Diseases It Causes	<input type="checkbox"/>
3	Concerned About Asbestos Exposure	<input type="checkbox"/>
4	What is Mesothelioma?	<input type="checkbox"/>
5	Surgery for Malignant Pleural Mesothelioma	<input type="checkbox"/>
6	Indwelling Pleural Catheter	<input type="checkbox"/>
7	Local Anaesthetic Thoracoscopy	<input type="checkbox"/>
8	Sweating in Mesothelioma	<input type="checkbox"/>
9	Pleural Effusion	<input type="checkbox"/>
10	Ascites	<input type="checkbox"/>
11	Percutaneous Cordotomy	<input type="checkbox"/>
12	Peritoneal Mesothelioma	<input type="checkbox"/>
13	Cough	<input type="checkbox"/>
14	Diet & Mesothelioma	<input type="checkbox"/>
15	Immunotherapy	<input type="checkbox"/>
16	Choosing the Right Solicitor	<input type="checkbox"/>
17	Wills & Legacies	<input type="checkbox"/>
18	Mesothelioma and The Coroner's Role	<input type="checkbox"/>
19	About Mesothelioma A5 Flyer	<input type="checkbox"/>
20	Mesothelioma UK Research Fund	<input type="checkbox"/>
21	DVD – Insight and Experiences	<input type="checkbox"/>

Information line: 0800 169 2409 Website: www.mesothelioma.uk.com
email: info@mesothelioma.uk.com

**MESOTHELIOMA UK PROVIDES
SPECIALIST, IMPARTIAL, UP TO DATE
SUPPORT AND INFORMATION**



To sponsor or donate contact:

Mesothelioma UK
email: info@mesothelioma.uk.com
freephone: 0800 169 2409
www.mesothelioma.uk.com

Mesothelioma UK, Unit 116, Greenacres,
The Sidings, Leicester LE4 3BR

CIO No 1177039

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