



**Clydeside Action
on Asbestos**

Frequently Asked Questions

Living with an Asbestos Related Condition.



Freephone: 0800 089 1717

www.clydesideactiononasbestos.org.uk

FAQs

Living with an Asbestos Related Condition.

Introduction

It can be difficult to take in all of the information that your doctor tells you about your diagnosis and you may have questions about your illness, about how to manage it and where to go for information and support.

As there are different asbestos related conditions, it is important that you know not only the name of your condition, but understand it. The following frequently asked questions were taken from our support group members and may help to answer some of your concerns.

However, if you do not know which condition you have been diagnosed with or have any questions about your health, it is advisable to speak to your GP or your consultant if you have one.

Knowing what you have been diagnosed with will help you to address any concerns that you have about your health.

What are the typical symptoms of an asbestos related condition?

There are different asbestos related conditions that are recognised in the UK as being caused by exposure to asbestos; pleural plaques, pleural thickening, asbestosis, asbestos related lung cancer and mesothelioma.

Pleural Plaques

It is very unusual to have any symptoms as pleural plaques are not physically within your lungs and do not affect the way your lungs work. It is important, however, that if you develop persistent chest symptoms, you should consult your GP.

Pleural plaques do not become cancerous. However, it is important not to smoke as the combination of past asbestos exposure and smoking can lead to an increased risk of developing lung cancer. Attending for repeated chest x-rays and regular reviews are seldom necessary.

Pleural Thickening

If wide spread, pleural thickening can cause breathlessness or chest tightness with effort. Pleural thickening does not become cancerous. There is a small risk that pleural thickening can progress, so in some circumstances your doctor may advise regular follow ups.

If there is a change in your chest condition, you should consult your GP or nurse. With pleural thickening the most common signs are likely to be repeated episodes of pleurisy and an increase in breathlessness. It is important not to smoke as the combination of past asbestos exposure and smoking can lead to an increased risk of developing lung cancer.

Asbestosis

The most common presentation of asbestosis is a persistent cough and breathlessness with effort. Asbestosis is a slowly progressive condition and a person with asbestosis may gradually become more breathless over time. Nowadays, milder cases of asbestosis are more easily diagnosed now that doctors use CT scanners more commonly. Such asbestosis is rarely severe and cases of advanced asbestosis are unusual.

The risks of lung cancer in people with asbestosis are very high, so if you smoke it is important to explore every opportunity to stop. If you have been diagnosed with asbestosis and there is a change in your condition you should consult your GP or nurse.

Lung Cancer

Typical symptoms can be a cough that doesn't go away, a cough you've had for a long time that gets worse or changes, feeling breathless for no reason, a chest infection that doesn't clear up, coughing blood, losing weight that wasn't intentional, chest or shoulder pains, unexplained tiredness, lack of energy or a hoarse voice.

Having one or more of these symptoms does not mean that you have lung cancer but it's always worth getting checked out by your GP.

Mesothelioma

Symptoms that can develop are caused by the cancer producing a pleural effusion (a build up of fluid around the lung) or by the cancer growing and pressing on a nerve or an organ of the body.

Symptoms of **Pleural Mesothelioma** can include becoming more breathless, pain in the lower back or side of the chest, sweating, a persistent cough and losing more than 10% of your weight when not dieting.

Symptoms of **Peritoneal Mesothelioma** can be pain in the abdomen (tummy), swelling in the abdomen, feeling or being sick, poor appetite, losing more than 10% of your weight when not dieting, diarrhea or constipation.

The above symptoms can be caused by illnesses other than mesothelioma but if you have any of these symptoms please make an appointment to see your doctor, particularly if you are aware of being exposed to asbestos. If you have been diagnosed with lung cancer or mesothelioma, and there is a change in your condition, you should consult your lung cancer nurse specialist or GP.



Are medications usually prescribed to treat an asbestos related condition?

There are no medications which can cure asbestos related conditions. Treatments are usually in response to managing the symptoms of the condition. All medication and treatment options can be discussed with your GP, respiratory consultant or nurse.

Does having a diagnosis of an asbestos related disease always lead to developing another asbestos related condition and / or cancer?

No. It is more common but not necessarily related. Depending on the type of asbestos and the amount a person has been exposed to, there is an increased risk of developing lung cancer and mesothelioma. The risk relates to past asbestos exposure and not the presence of pleural plaques and/or pleural thickening.

Why do some people develop mesothelioma and not pleural plaques, pleural thickening or asbestosis?

Available evidence suggests that the risk of mesothelioma increases based on the dose of asbestos that a person is exposed to. The dose relates to both the concentration of asbestos fibres inhaled, and the duration of the exposure. However, there is no level of exposure below which there is no risk. The type of asbestos a person was exposed to can also influence the development of mesothelioma with crocidolite (blue asbestos) and amosite (brown asbestos) carrying the greatest risk. However all types of asbestos can cause mesothelioma. Another factor is that some people may be more susceptible to developing mesothelioma.

I wore my work clothes home. Are my family at risk of developing an asbestos related disease?

This is theoretically possible where someone has shaken out clothes that have been covered in asbestos dust and fibres. However, this is rare.

Can asbestos related conditions be passed on?

The simple answer is no. Asbestos related disease is related to exposure to asbestos and develops many years after a person has inhaled asbestos fibres. You cannot pass an asbestos related disease onto another person.

Does a person with an asbestos related disease have to make major lifestyle changes?

There are different asbestos related conditions and not everyone with an asbestos related condition will have any symptoms. For those that do, it may be useful to think about your daily routine and think about planning your activities for the day or week in advance. Prioritise what you would like to do in that time and give yourself enough time to do it. As with any health condition having a healthy lifestyle can help you to keep well. If you do have symptoms that are affecting your daily life or would like advice on keeping well, speak to your GP, nurse or consultant if you have one.

My GP has suggested that I lose weight. How can I lose weight when my mobility is limited due to breathlessness?

Exercising with a lung condition

Activity and mild breathlessness is good for everyone, including those with chronic lung conditions. However, pacing of the activity is very important, and the level of breathlessness brought on by the activity (exercise, housework, anything that involves moving about) should be mild and you should still be able to talk. If you are too breathless to talk, the pace of the activity should be slowed down. Further information can be found on the CAA self-management DVD.

Is weight loss achieved through exercise alone?

Weight loss will also be influenced by diet. A human body is like a machine and the amount of fuel put into that machine should equal the amount of fuel required by that machine for the activities carried out. If we eat more than we need for the activities we do, we will put on weight. If we eat less than we require for the activities we do, we will lose weight. The type and amount of food we eat will influence weight loss, in association with the right amount of exercise or activity. A sensible balanced diet with sensible sizes of portion will help.

I have been diagnosed with an asbestos related condition. Is it safe to have sex with my partner even if I become breathless?

The two most common symptoms of asbestos related lung disease are breathlessness and fatigue. It is normal to become breathless with activity, but as with any activity, avoid becoming breathless to the point that you feel distressed.

What can I do to help myself?

- Monitor your symptoms and know when to get help. You will know what is normal for you.
- Look out for signs of a chest infection such as feeling generally unwell, increased breathlessness, feeling feverish, nasal congestion, increased coughing, and changes in sputum (phlegm) such as increased amount, colour and consistency.
- If there is phlegm, ensure that chest clearance exercises are used to clear the chest of phlegm two to three times daily. If you have not been taught these techniques ask your GP for onward referral to a Physiotherapist.
- Minimise the risk of infection by having an annual flu vaccine. Also check if you have had a pneumonia vaccine.
- Attend a health check with your GP or nurse at least once a year.
- Make the most of health appointments by writing down questions to ask beforehand.
- Take another person with you to health appointments if you like.
- Drink plenty of fluids (around 2-3 litres per day), especially in hot weather.
- Try relaxation and/or a forward leaning position to ease breathlessness and panic.
- Consider the three P's – pacing, prioritising and planning. If there is a big event coming up, try to conserve energy by resting the day before the event.
- Avoid extreme weather conditions, and wrap up well when outdoors in cold weather. Consider wrapping a scarf around the nose and mouth to warm and humidify the air that is breathed in.
- Keep active.

Where can I find information and support for myself and my family?

Clydeside Action on Asbestos (CAA) provides a range of services to support you following your diagnosis, including advice about benefits and compensation. CAA also has support groups throughout Scotland, and has publications that can help you to manage your condition.

You may need more information regarding your condition as it is sometimes difficult to take in or remember everything that your doctor tells you when they are explaining your diagnosis.

If you are not sure which asbestos related condition you have been diagnosed with, or if you have questions about your condition, speak to your GP, nurse or respiratory consultant. This will help you to understand what you have been diagnosed with and help you to explain your diagnosis to your family. Your doctor may also be able to provide general advice about managing your condition and healthy living.

If you have health problems that require more support at home, your local social work department can provide additional care and support services. An occupational therapist can assess your needs in your house and suggest appropriate support for you.

Will I have to stop driving?

As long as you feel well enough and comfortable, there is generally no reason to give up driving solely because you have an asbestos-related condition. You should check with your nurse, GP or the DVLA if you are in any doubt or have any questions regarding your ability to continue driving, particularly if you have been prescribed medication or are undergoing treatment.

Is it safe for a person with an asbestos-related disease to travel by plane?

The type of asbestos related condition, the extent of it and whether a person has other medical conditions means that there is no single answer. If you have any concerns or questions about your ability to fly, seek medical advice from your GP before organising a trip by plane. If you are travelling abroad, it is very important that you get travel insurance before you go and that you tell your insurance company about any medical conditions you have. If you do not, and become ill abroad, it is extremely likely that you will have to meet costs associated with treatment, care and travel, which can be considerable. If you would like information about travel insurance, contact CAA.

Am I entitled to compensation?

If you have been diagnosed with an asbestos related condition, you may be entitled to benefits and compensation from the government. You may also be able to pursue a civil case for compensation. There are time limits for pursuing this so it is important to seek legal advice as soon as you are aware that you have an asbestos related condition. A civil claim for compensation must be brought within three years of the date you were told, or first became aware that you had an asbestos related condition. Contact CAA to find out what you are entitled to.



Further information about our services can be found at:

www.clydesideactiononasbestos.org.uk

Contact us

Freephone: **0800 089 1717**

Email: **admin@clydesideaction.co.uk**

The questions in this leaflet have been provided by our support group members who were asked to share the concerns and questions they had when they were diagnosed. A common theme was how difficult it was to take in what the doctor was telling them about the condition they had been diagnosed with. For our members, understanding their condition and addressing any concerns they had about any impact this would have on their life was important. The questions included in this leaflet reflect this.

CAA would like to thank the healthcare professionals who contributed to this leaflet.

The information in this leaflet is not intended to be medical advice, a replacement for medical advice or an instructional manual. Any information contained within is for information purposes only and are undertaken at your own risk without any liability to Clydeside Action on Asbestos.

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