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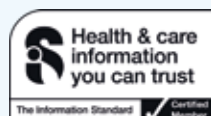
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COUGHING

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Supporting People With This Asbestos Cancer



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Introduction

The aim of this booklet is to give you information if you have a cough due to mesothelioma or you care for someone with this problem. Coughing is a common symptom that can be caused by many conditions but this booklet focuses on coughing relating to mesothelioma specifically.

“Coughing at night time seems to be the worst... when I’m lying there...and it can be a prolonged bad cough. I could be sick, but I’ve not been. But it’s that sort of feeling that you just cough and cough and cough. The cough is the worst thing”

Coughing and mesothelioma

One of the commonest symptoms of mesothelioma is a cough. We think it affects nearly half of all mesothelioma patients. Unfortunately, little research has been conducted

on coughing and its treatment in mesothelioma patients but there is now increasing awareness by doctors and nurses that it is a symptom that needs more attention if we are to improve the quality of life of mesothelioma patients. A cough can be particularly difficult if you are trying to cope with mesothelioma. It can cause physical symptoms such as pain, tiredness and vomiting as well as emotional symptoms such as anxiety and stress. Many patients feel distressed by their cough. This booklet aims to give you information about coughing in mesothelioma and explain some strategies that may help you cope with it.

Causes of coughing related to mesothelioma

The exact causes of coughing in patients with mesothelioma are not known. Very little research has been conducted in this area. It is likely that several different reasons for coughing

exist, even within one patient. Patients with mesothelioma often develop fluid around the lung (a pleural effusion). This is known to cause coughing in some patients. It may be that the lung is compressed by the fluid and that this makes coughing more likely. Some of the nerves supplying the lining of the lungs (pleura) may also be damaged by the tumour, triggering coughing. Patients with mesothelioma are likely to suffer from chest infections more commonly than a healthy person. Chest infections commonly cause coughing.

Causes related to mesothelioma treatment

Both radiotherapy and chemotherapy can cause coughing. This is because both these treatments can cause inflammation and scarring of the lung. Usually, this is mild and settles down quickly following treatment avoiding any further intervention.

Physical effects

We know that a cough can affect mesothelioma patients in a number of ways, making it much harder to manage even daily tasks such as washing and dressing. Patients often report that coughing can cause significant tiredness, either because the effort required to cough makes patients tired or because a patient’s sleep is disturbed by coughing.

Some patients also report that coughing can cause pain either in the chest or elsewhere in the body. It is sometimes difficult to take painkillers to improve the pain because coughing can vary so much day to day. It is not always easy to predict when a cough is likely to cause pain.

Breathlessness is often made worse by coughing. That can be very frightening sometimes because a bout of coughing can make it hard for you to catch your breath.

Sometimes coughing causes retching and vomiting. This can be very embarrassing if you are in a public place such as a restaurant or theatre. Dizziness can sometimes be caused by coughing. Very rarely, patients can pass out if the cough is very severe. This can be very frightening and make simple daily tasks extremely difficult. Occasionally, some patients report difficult bladder control as a result of coughing. It means that urine sometimes leaks out of the bladder during coughing. This tends to be more common in women but can occur in men too. It is often difficult to talk to health care professionals or even close friends or family about this effect of coughing because many patients find this both distressing and embarrassing. You may find that coping with the physical effects of your cough difficult. It is important

to discuss any physical symptoms that you may have as a result of your cough with your doctor or nurse to ensure that you are on the best treatments to improve these symptoms.

Emotional effects

Coughing can cause significant distress in some patients with mesothelioma. They worry that if the cough worsens, it may be because the mesothelioma is getting worse or because treatment for the disease is not working. Although this is not always the case, it is hard for some patients not to be anxious. Coughing can also affect patients because it can be a reminder of their diagnosis. It can also be an outward sign of illness to others. This can be especially difficult for some patients, particularly if they want to keep their diagnosis private from some people or protect their carers from anxiety.

Anger and irritability relating to the cough are common in patients who have mesothelioma. These symptoms are often made worse when a patient is in pain and tired. Sometimes a cough makes patients feel anxious, particularly if they worry that it is present because the disease is worsening.

If you recognise some of these symptoms in yourself, it is important that you speak to the doctors and nurses looking after you to ensure that you have the support in place to minimise these symptoms where possible.

Social effects

It can be very hard to go out if coughing causes social embarrassment. Unfortunately, some patients restrict their social life due to their cough. Sometimes the fear of coughing in public venues or even the prospect of coughing during the night in a hotel room is a cause of anxiety. That means

that you may find it hard to continue to pursue the activities you enjoy with your family and friends. Talking to family or friends on the phone is difficult since coughing interrupts conversations and the effort needed to talk can lead to more coughing. This can make you feel isolated from those you love and your support network.

Controlling coughing and throat clearing

Repeated coughing or throat clearing can cause inflammation and irritation of the airways, which can make you cough much more easily. Because of this some patients find that techniques that help them suppress the cough, to protect their throat and airways from irritation due to the cough, improves their cough.

Take a few days monitoring how often you cough and/or clear your throat. Try to remember how it feels just before you cough.

Once you are aware of how it feels just before you cough or clear your throat, try one of the following 3 techniques:

- 1) Take a sip of water
- 2) Sniff then swallow
- 3) Swallow

It may take a few attempts at the controlling technique for a few seconds relief before the urge to cough returns. The key is to persevere. If the urge to cough returns, repeat again. You can use a combination of approaches. There is no right or wrong approach. Choose whichever technique you feel most comfortable with and whichever works best for you. Once you have learnt how to control your cough a few times, it will become easier.

Avoidance of coughing triggers

Coughing can be caused by a number of triggers. They vary from patient to patient. These

might include steam, smoke, strong perfume, cold air or even aerosols. It is not always easy to avoid situations that lead to your cough being triggered. However you can try some of the techniques below:

- 1) Wear a scarf over your mouth when going outside on a cold day
- 2) Where possible, use alternative preparations to aerosols such as roll-on deodorants
- 3) Use water that is slightly cooler than normal to reduce the steam from a bath or shower.
- 4) Use scent-free soaps rather than strongly perfumed soaps to wash.
- 5) Consider changing your washing powder to a non scented washing powder and avoid using strongly scented fabric conditioner.
- 6) Avoid smoky environments

Clearing phlegm

Some patients cough more because it is hard for them to bring up phlegm. Sometimes it is because the phlegm is very thick. Loosening the phlegm can make it easier for patients to cough up the phlegm and then for the cough to settle. Below are some ways to try to loosen the phlegm:

Steam inhalation - Take a large clean bowl and fill it with water that has just boiled. Sit at a table with the bowl of water placed in front of you. Place a large towel over your head and around the sides of the bowl. Breathe in the steam from the bowl for a few minutes.

Huffing - Take a big deep breath, filling the lungs as completely as possible. Blow the air out in forceful bursts through an open mouth while saying "huh," as if you are blowing steam onto a mirror. Repeat as many times as needed to clear the loosened mucus from the airway.

Easing coughing at night

Some patients find it extremely difficult to sleep well at night because their cough significantly disrupts their sleep. Sometimes the cough is worsened by certain positions such as lying flat in bed or lying on a particular side. Try sleeping in different positions, including propped up with more pillows.

Simple cough remedies

Although it is possible to buy many different over the counter cough remedies, there is little research to suggest that any is effective. However some patients do sometimes report relief using some of the remedies suggested below.

Menthol drops: These can be bought to use with steam inhalation. Use according to the manufacturer's recommendations.

Cough sweets: Several cough sweets are available to buy. We cannot recommend any specific

brand. We suggest that you try different types to see if any is helpful to ease your cough.

Honey and lemon drink:

Squeeze the juice of half a lemon and pour into a mug. Add a teaspoon of honey. Add hot water. You may find hot drinks relaxing, particularly before sleeping.

If despite trying these strategies to ease coughing, your cough is still difficult to cope with, you may wish to seek advice from your doctor or nurse for further help.

Medicines for coughs

Several medications can be prescribed for your cough. These can be used together with the strategies described in the previous section. Below is a list of medications which may help to ease your cough.

Simple Linctus: Cough syrup is taken orally in liquid form. It can be used several times a day to improve your cough.

Painkillers: Several painkillers can also be used to control cough. These can be taken in tablet form, by injection or in liquid form. There are 2 main types of painkillers that may be of help. One type might be a morphine-type medication such as codeine linctus, pholcodine, morphine or methadone.

Steroids: These can reduce inflammation of the lung airways. They can be taken in inhaled, oral or injection form.

Anti indigestion drugs (proton pump inhibitors): These medications can ease coughing by reducing indigestion. It is thought that sometimes coughing may be due to indigestion. The medications can be taken orally.

Bronchodilator drugs: These drugs help open up the airways and ease cough. They can be given via inhalers or nebulisers. Nebulisers deliver a liquid drug as a fine mist through a specialised mask for you to breathe in.

Sterile salt water nebuliser

(saline): Saline can be given via a nebuliser

Carbocysteine: This can be taken as a tablet to loosen thick phlegm to make it easier to cough up.

If you would like more information on medicines for cough, it is important that you speak to your doctor or nurse. These medicines are only available on prescription. These medicines are not suitable for all patients with a cough and mesothelioma.

Complementary therapies

There are a number of complementary therapies that are available to manage symptoms. They might include reflexology, acupressure, acupuncture and aromatherapy. No complementary therapy has yet been shown to improve coughing in a clinical research trial however some research

in this field is ongoing. Despite this, some patients find them relaxing and helpful.

Your feelings

If you are finding it difficult to cope with your cough or if you feel anxious or low in mood, counselling may help you. Many patients find that talking openly about how they feel with a trained counsellor can improve their ability to manage day to day. There are many different counselling services that are available to cancer patients.

Counselling services vary in availability between different areas. You can ask your hospital doctor, nurse or GP to tell you which services are available in your area. They can also make a referral for you to a specific counselling service.

Caring for someone with a cough and mesothelioma

If you are looking after someone with a cough, it may be helpful to encourage them

to try the strategies included in this booklet to ease their cough. Coughing can be extremely tiring and distressing. Sometimes even the simple daily tasks such as washing and dressing can be difficult. It may be possible for you to help them with these tasks.

It is also sometimes very difficult for patients to socialise when they have a severe cough. Some patients find it embarrassing to cough in public, particularly if in restaurants or theatres. Patients often worry that their cough disturbs others. If this is the case, plan activities with them that might lessen these anxieties and embarrassment such as eating nice meals at home or sharing time with them in an outside environment such as a park or the countryside.

Encourage your friend or relative to discuss their symptoms with their doctor or nurse. They may want you

to attend the appointment with them so that you can understand more about what causes their cough and how best to support them to ease their cough.

Caring for someone with a cough and mesothelioma is not always easy. If you share a room with them, their cough can significantly disturb your sleep and can be a constant reminder of their illness. This can add to the stress and anxiety of caring. It is important that you also look after yourself. You may need to ask help from others in order to avoid becoming extremely tired. This is not always easy if you don't want to let your relative or friend down but it is important to avoid becoming exhausted to care for them as well as you can.