



My Pneumothorax Journey

Primary spontaneous pneumothorax

Patient information leaflet



Disclaimer

This information has been written by patients with lived experience of a pneumothorax and healthcare professionals. It is specific to medical practice in the United Kingdom and may not be applicable in other countries. This information cannot replace a consultation with a healthcare professional. There may be individual circumstances which influence decision making on a case-by-case basis. This information should always be used alongside the information provided by a patient's medical team.

When should this patient information be used?

'My Pneumothorax Journey' provides information for patients affected by a primary spontaneous pneumothorax. This definition is explained on the next page of this document. There are different ways of managing this condition. 'My Pneumothorax Journey' aims to help patients understand more about different treatment options and how they might think about the right treatment for them. There are other types of pneumothorax (e.g. a secondary spontaneous pneumothorax, traumatic pneumothorax) which are not covered in this leaflet. Your healthcare professional will inform you if you have one of these other types of pneumothorax and how it can be managed.

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My Pneumothorax Journey

1. What is a 'pneumothorax'?

Usually, the lungs are pressed-up against the inside of our rib cage. A 'pneumothorax' is when air 'escapes' or 'leaks' through the outer lining of the lung (pleura) through a small tear, a small hole or a few tiny little holes and the lung slowly deflates like a balloon. The air which escapes is then trapped between the lung and the rib cage.



2. What is a 'primary spontaneous pneumothorax'?

A spontaneous pneumothorax is when the air escapes through the outer lining of the lung without any reason like trauma or injury to the chest.

A primary spontaneous pneumothorax

happens in lungs that are healthy without any known lung problems. This often occurs in younger people, particularly those aged under 50.

A secondary spontaneous pneumothorax happens in lungs with underlying problems like Chronic Obstructive Pulmonary Disease (COPD, damage to the lungs from smoking) or fibrosis (scarring of the lungs). A secondary spontaneous pneumothorax is much more common in people aged over 50. Treatment options for this type of pneumothorax are not covered within this leaflet.

3. Is a primary spontaneous pneumothorax dangerous?

No. A primary spontaneous pneumothorax can be painful (sometimes very painful) and cause disruption to normal life for a few days or weeks, but it is very unlikely to be dangerous to life. Following a pneumothorax, there might be limitations on certain activities such as flying and scuba diving. These limitations may be very short lived or for a longer period of time. Always seek medical confirmation before undertaking these activities.

4. What symptoms does it cause?

Pain. Pain in the chest, back and shoulders is a very common symptom of a pneumothorax. It is important to mention that the degree of pain is NOT related to the size of the pneumothorax or how it is managed. Everyone's experience of pain can be different. Pain can feel like:

- Tightness across the chest and/or back
- Stabbing pain in the chest and/or back
- Anything from mild to severe pain.

Breathlessness. This is a common symptom and can range from feeling a little breathless to feeling very breathless. This can be scary but it is important to know that as this is a primary spontaneous pneumothorax, the lungs are healthy and can cope very well with this even if one of them has deflated.

Other symptoms. Everyone's experience of a pneumothorax will be different. It is important to let the medical team know how you feel so they can care for you.

5. What will happen to me in hospital?

Most patients with a primary spontaneous pneumothorax attend the hospital with symptoms of breathlessness and/or chest pain. Following an assessment with a health care professional, tests are performed including blood tests, chest X-ray (CXR) and heart tracing (an ECG). A primary spontaneous pneumothorax is diagnosed on a chest X-ray. At this point the medical team will discuss the available treatment options and this leaflet supports that information.

6. What treatments are there for a primary spontaneous pneumothorax?

Pain killers. Pain killers are really important and will help to manage the pain you experience with a pneumothorax. Ask your medical team about which pain killers would be best for you.

Some of the treatments described below can be dependent upon having the right expertise and team at your local hospital and are not always available. The right treatment for you might also be determined by the severity of your symptoms. The medical team will discuss all the available options with you.

Monitoring. The lung will heal itself eventually and some experts feel that they heal quicker whilst the lung is deflated. When the tear/hole is fixed, our bodies reabsorb the escaped air slowly over several weeks and the lung re-inflates itself. This is sometimes referred to as 'wait and watch' or 'observation only'. Your medical team can talk to you about whether this is a safe option for you. **Release the trapped air and re-inflate the lung.** This can be done by several different types of procedure all of which can be done with some local anaesthetic and small needles/tubes. All these procedures aim to release the escaped air that is trapped and allow the lung to re-inflate (quicker than it would if left to resolve by itself). These procedures include:

An 'ambulatory device'. This means inserting a small tube going through the skin and muscles of the chest and into the space between the lung and rib cage. It is connected to, or has an inbuilt one-way valve that allows air out but doesn't let air in.

The type of ambulatory device you are offered can vary but they all work in the same way. You can walk around with this device and go home with it. When all the escaped air has been removed and the tear/ hole on the lining of the lung has healed, the device can be removed. If the device does not work, you may need to come into the hospital for a different procedure (e.g. a chest drain).

You must feel comfortable having a device in place whilst at home and be confident you can seek help by calling the right team at the hospital if there are any problems with the device or your symptoms get worse. A 'needle aspiration'. This is where a small needle is used to place a small tube into the trapped air between the lung and rib cage. This connects to a circuit so air can be sucked out through a syringe repeatedly until as much trapped air has been removed as possible. If it works you can go home after the procedure without being admitted to hospital (this is possible in around half of patients that have this procedure). If it doesn't work, you may need to be admitted to hospital and have a chest drain.



Safety netting. If you choose a treatment that allows you to be at home (monitoring, an ambulatory device or after a successful needle aspiration), it is important that you, and the people that live with you, can seek help by calling the right team at the Hospital if you start to feel unwell or your symptoms return. If you are worried, then you must return to the A&E department.

A 'chest drain'. A small thin tube is placed into the trapped air between the lung and rib cage using a small needle and local anaesthetic. The tube is stitched in place so it cannot fall out and is connected to a bottle with water in it – called an underwater seal drain. The trapped air bubbles out through the water in the bottle. Whilst you have a chest drain you need to be in hospital. This is normally for a few days at least but your medical team will discuss this with you.

If you have a chest drain, your medical team might use a special device that replaces the underwater seal drain because it has a digital display which helps doctors to monitor your pneumothorax. This information can help your medical team to make decisions on your recovery and when they can remove the chest drain so that you can go home. **This device is called a 'Thopaz+ Digital Chest Drainage and Monitoring System'**





7. Surgery

In certain situations, surgery might be considered for a primary spontaneous pneumothorax. This involves a keyhole operation under a general anaesthetic which the medical team will discuss with you. An operation is considered in the following situations:

- At the time of a pneumothorax, if the lung is still leaking air despite treatments like a chest drain,
- After a pneumothorax has healed, but it has happened more than once.
- After a pneumothorax has healed but has involved both lungs .

8. What's the best treatment?

There is no best treatment just the right treatment for you. Some advantages and disadvantages of different approaches are provided below:

Treatment option	×	\checkmark
Monitoring	 Breathlessness likely to take a little longer to get better Several hospital check-ups after going home If things get worse, might need to be admitted to hospital and have a chest drain 	 No needles or procedures Can go home straight away No stay in Hospital
Ambulatory device	 Procedure needing local anaesthetic and small needles Several hospital check-ups after going home Need to have a small device in your chest at home & a small risk the device can become blocked or malfunction meaning your symptoms may come back and you may need to return to hospital If it doesn't work, likely to be admitted to hospital and have a further procedure e.g. chest drain 	 No stay in hospital (if the device works well) Breathlessness may improve quicker than monitoring option
Needle aspiration	 Procedure needing local anaesthetic and small needles If it doesn't work, likely to be admitted to hospital and have a chest drain (50% of the time) 	 No stay in hospital (if it is successful) Breathlessness may improve quicker than monitoring option
Chest drain	 Need to be in hospital for a few days Procedure needing local anaesthetic and small needles 	 Breathlessness may improve quicker than monitoring option Unlikely to need a second procedure if air leak settles Likely to be the preferred option if symptoms are severe or a patient feels very unwell due to the pneumothorax

9. Does anything increase the risk of a primary spontaneous pneumothorax?

There are some common risk factors listed below but a primary spontaneous pneumothorax can happen to anyone.

Smoking. The single biggest risk factor for a primary spontaneous pneumothorax is smoking tobacco. **Stopping smoking is also the single most important thing someone can do to reduce the risk of it happening again.** If you do smoke, it can be difficult to stop but help and treatment is available.

For more information:

- a. Visit the NHS quit smoking website at <u>https://www.nhs.uk/better-health/quit-</u> <u>smoking</u>
- b. Download the NHS Quit Smoking App
 <u>Quit smoking Better Health</u> NHS (www.nhs.uk)
- c. Call the free Smokefree National Helpline on 0300 123 1044

Height. A primary spontaneous pneumothorax seems to happen more often in tall people. We don't fully understand why, but it might be because tall people have longer lungs which may be more prone to having weak points in the surface that could 'tear' and let air leak out. **Genetics.** Sometimes we can inherit genes from our parents that make it more likely we will suffer a pneumothorax. It is important that your medical team is made aware if anyone in your family has ever suffered a pneumothorax. If you are not sure about your family history, please ask your family members.

Other medical conditions. A

pneumothorax can sometimes (very rarely) be associated with other medical conditions (one example is endometriosis) so it important to discuss your full medical history with your medical team.

10. Further resources

<u>Thopaz+ Digital Chest Drainage and</u> <u>Monitoring System</u>

<u>Thopaz+ and the MedTech Funding</u> <u>Mandate (MTFM)</u>

WMAHSN supporting the implementation of MTFM technologies