

Aspergillosis

A hidden threat

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Understanding Aspergillosis

What is Aspergillosis and how is it caused?

Aspergillosis is a disease caused by *Aspergillus*, which is a variety of mould found in the air and soil. We all breathe in *Aspergillus* spores every day, and for the vast majority of people these spores are harmless. However, they can cause problems for those with immune deficiencies (many as yet undetectable) or lung conditions such as severe asthma, bronchiectasis, cystic fibrosis, COPD and TB.

Diseases caused by *Aspergillus* are called aspergillosis and can take several forms. The severity of aspergillosis – from allergy-type illness to life-threatening generalised infections – is determined by various factors, but one of the most important is the state of the person's immune system.

Chronic forms of aspergillosis, suffered by people with a normal immune system, are the result of the fungus gaining a foothold in the body and slowly growing and irritating the surface of delicate tissues that they come into contact with (such as the lungs or sinuses) and causing them to change in a way that impacts a person's health. Delicate tissue in the lungs help us to breathe by allowing the efficient exchange of gases to and from the blood supply which runs just below the membranes. But the fungus irritation causes it to inflame, thicken and scar, which compromises this important functionality of the lungs.

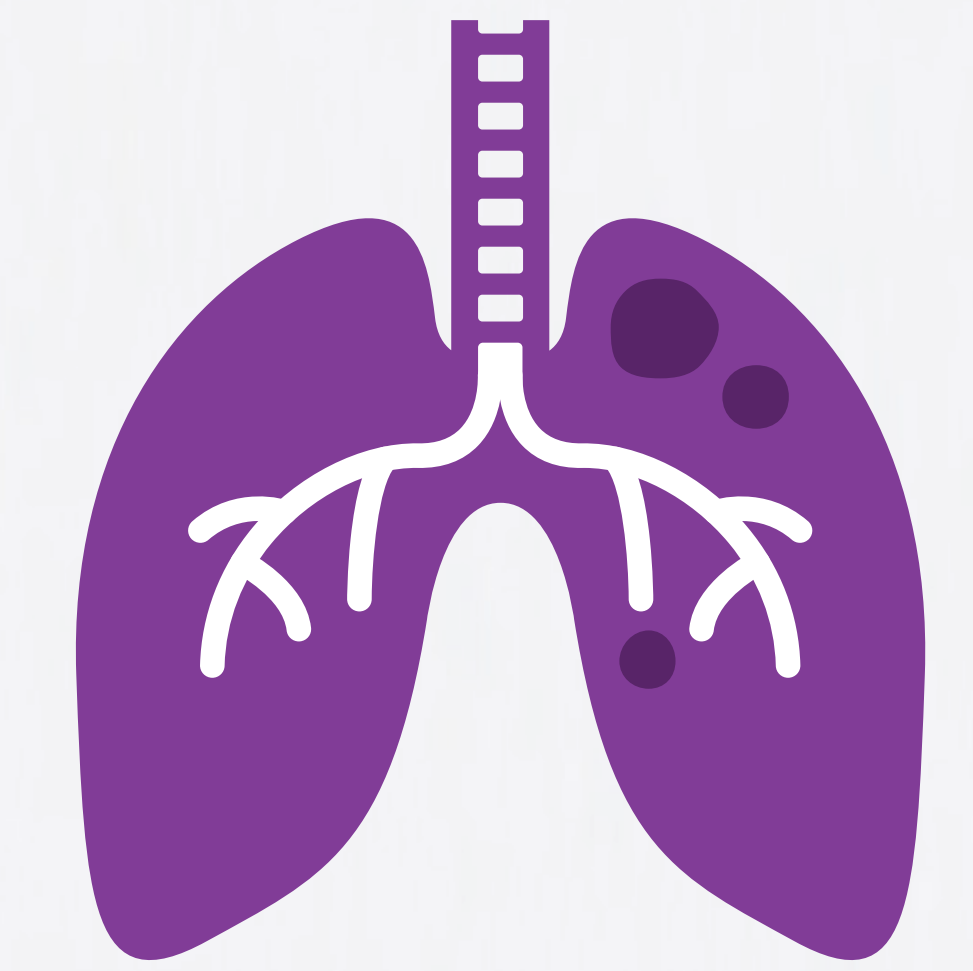
Types

Aspergillosis infections

- IA Invasive aspergillosis
- CPA Chronic pulmonary aspergillosis
- FRS Fungal rhinosinusitis

Aspergillus allergies

- ABPA Allergic bronchopulmonary aspergillosis
- SAFS Severe asthma with fungal sensitivity
- Fungal sensitisation from a damp home



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Symptoms

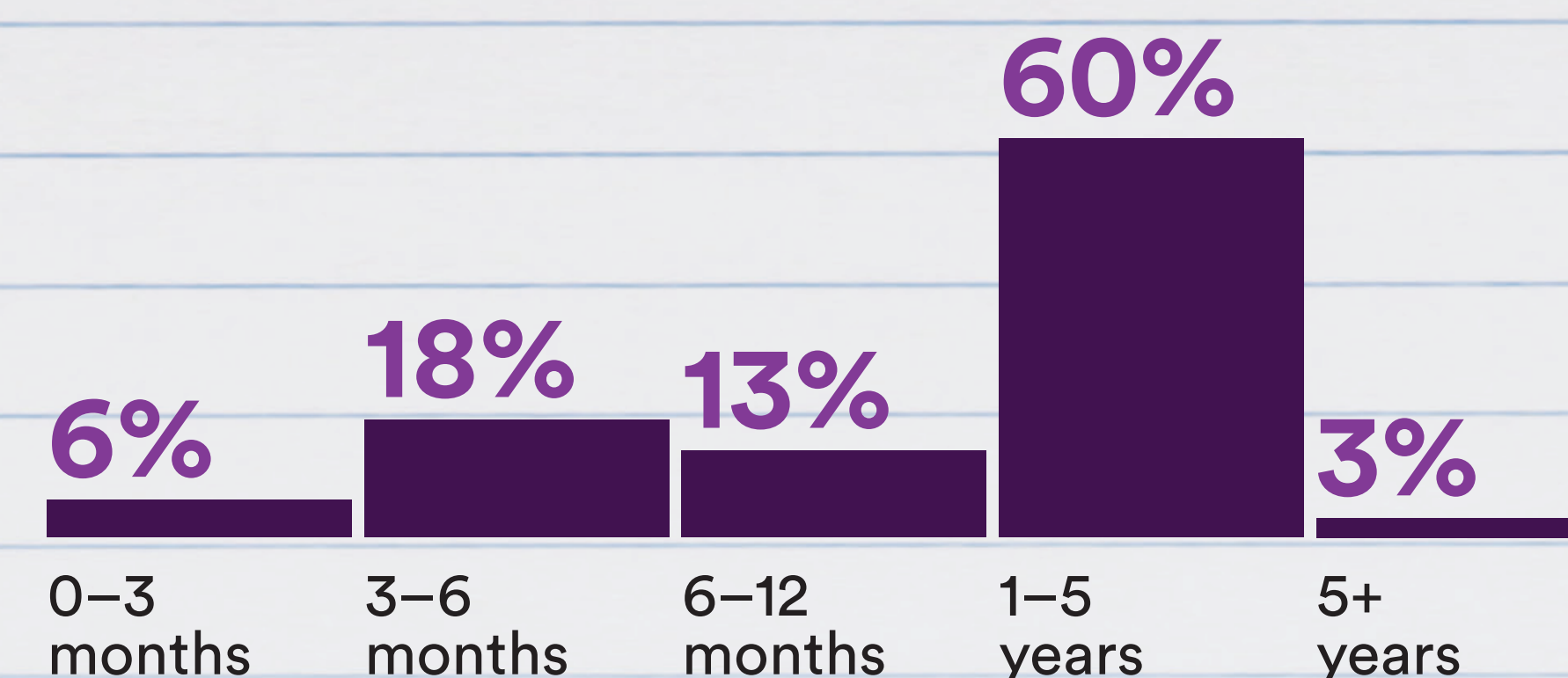
Symptoms vary depending on the type of aspergillosis a person has. Somebody with an aspergilloma (a fungal ball in the lung) may have few symptoms or just a cough, but another may cough up large quantities of blood and require urgent medical attention. It's not the same for everyone, but people with aspergillosis can experience:

- Weight loss • Fatigue • Fever • Cough**
- Coughing blood (haemoptysis)**
- Breathlessness • Mucous plugs**

Diagnosis

Early diagnosis makes treatment easier and improves outcomes. But aspergillosis diseases are difficult to diagnose. We know that the diagnostic odyssey (the time from initial disease recognition/symptom onset to a final diagnosis), is real. People with aspergillosis have told us that they are repeatedly misdiagnosed or not listened to.

We surveyed 128 people with aspergillosis and **60% told us that from the first visit to their GP, they waited 1-5 years for a diagnosis:**



Treatment

It is important to reduce or prevent inflammation, so steroids are typically prescribed. Antifungals such as itraconazole, voriconazole or posaconazole are also used. And although they cannot eradicate the infection, they do reduce symptoms quite markedly in many cases. However, these drugs are expensive and can bring unpleasant side effects. Some people with aspergillosis will find themselves on antibiotics from time to time, as secondary bacterial infections are common.

How people with aspergillosis feel

“Going from being desperate for information to being terrified of information”

“I often have low energy levels, severe wheezing, difficulty with breathing and doing everyday tasks”

“Went from a fit, working man to struggling to cope day to day and living on benefits”

“The worst fear is not knowing how long the medication will keep working”

The future People with aspergillosis want:

- More research and new antifungal drugs with fewer side effects
- Better awareness among healthcare professionals
- Earlier diagnosis of new cases to enhance quality of life, improve outcomes and reduce mortality
- An understanding that aspergillosis is a hidden condition, people can be very ill but look well
- Remove geographical barriers to treatments – people are often too ill to travel to specialist centres like the one at Wythenshawe
- Collaboration, communication and compassion from healthcare workers

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