

A-Z

Of tips and information for those with aspergillus diseases

A

ABPA (Allergic bronchopulmonary Aspergillosis)

This is a condition which produces an allergy to the spores of the Aspergillus moulds. It is quite common in asthmatics; up to 20% of asthmatics might get this at some time during their lives. ABPA is also common in cystic fibrosis patients, as they reach adolescence and adulthood. The symptoms are similar to those of asthma: intermittent episodes of feeling unwell, coughing and wheezing. Some patients cough up brown-coloured plugs of mucus. The diagnosis can be made by a combination of X-ray and CT scan, sputum, skin and blood tests. In the long term ABPA can lead to permanent lung damage (fibrosis) if untreated.

The treatment is with steroids by inhaler or mouth (prednisolone), especially during attacks. Itraconazole (Sporanox), and oral antifungal drug, is useful in reducing the amount of steroids required in those needing medium or high doses. This is beneficial as steroids have side-effects like thinning of the bones (osteoporosis) and skin and weight gain, especially when used for a long time.

AIR CONDITIONERS AND FILTERS

Use of air conditioners inside the home or in a car can help prevent pollen and spores from growing by reducing humidity BUT if badly maintained they can harbour growing fungi thus making the situation worse – CLEAN REGULARLY. Various types of air-filtering devices may help reduce allergens produced in the home, as part of the heating and cooling systems and as portable devices that can be used in individual rooms – the latter especially helpful in reducing animal allergens. The size needs to be sufficient to exchange the air in the room five or six times per hour; therefore the efficiency of the filtering device should be determined in part by the size of the room. The filtering should be of HEPA quality. Be wary of exaggerated claims for very small appliances which cannot remove dust and pollen. The machine's ozone output should be checked, as ozone can irritate the nose and airways of persons with allergies.

ANTIBIOTICS

Necessary at times to suppress severe infections, but AVOID taking them unless absolutely necessary, as they create conditions which fungus love by wiping out good as well as bad bacteria from the gut and allowing yeasts and fungus to grow. (See Bacteria notes.)

ASPERGILLOMA

This is a very different disease from ABPA also caused by Aspergillus mould. The fungus grows within a cavity of the lung, which was previously damaged during illness such as tuberculosis or sarcoidosis. Any lung disease which causes cavities can leave a person open to developing an aspergilloma. The spores penetrate the cavity and germinate, forming a fungal ball within the cavity. The fungus secretes toxic and allergic products which may make the person feel ill.

The person may have no symptoms early on, but later weight loss, chronic cough and feeling run down are common. Coughing of blood (haemoptysis) can occur in up to 50-80% of affected people. Diagnosis is by X-rays, scans of the lungs and blood tests.

Treatment may be by oral itraconazole (Sporanox) which helps symptoms for many people, but rarely kills the fungus in the cavity. Sometimes surgical removal is possible. Sometimes other antifungal drugs (especially amphotericin B) can be injected directly into the cavity by a tube which is put into position under local anaesthesia. Up to 10% of cases get better without treatment, especially if there are no symptoms.

ASPERGILLUS SINUSITIS

Aspergillus disease can occur in the sinuses leading to Aspergillus sinusitis. This happens in a similar way to aspergilloma. In those with normal immune systems, stuffiness of the nose, chronic headache or discomfort in the face is common. Drainage of the sinus, by surgery, usually cures the problem, unless the Aspergillus has entered the sinuses deep inside the skull. Antifungal drugs and surgery are usually successful.

B

BACTERIA

'Good' bacteria in the gut can be encouraged by eating live natural yoghurt or taking Acidopholus in tablet form. This is one way of trying to counteract the negative effects of taking antibiotics and steroids.

BONE SCAN (See also OSTEOPOROSIS)

You may need a bone scan if you have been on oral steroids for some time, as they deplete bone density. If you are diagnosed with osteoporosis you should look at the website of the National Osteoporosis Society for information (www.nos.org.uk/). Many of their leaflets are to be found in the Orthopaedics Departments in hospitals.

BRITISH LUNG FOUNDATION

This organisation can provide help with breathing problems and they run support groups called Breathe Easy Groups which Aspergillus patients could usefully join. There is also a Pen Pals Breathe Easy Group, and a Baby Breathe Easy network is being developed. There is plenty of useful information here on things such as a bronchoscopy and a nebuliser. (www.lunguk.org/)

C

CALCIUM

If at risk of osteoporosis it may be necessary to ensure a good supply of calcium daily by eating fruit, green vegetables, oily fish, seeds, dried figs and apricots, dairy produce and cereals. Your daily intake should not exceed 2000 – 2500 mg of calcium. The National Osteoporosis Society (www.nos.org.uk) has an excellent booklet on diet and bone health.

CANDIDA

This is a yeast infection, which some people with Aspergillus disease also suffer from, as it is more likely to occur where antibiotics and steroids have weakened the natural gut flora. You may find it necessary to reduce intake of sugar severely to improve your condition if you develop Candida infections regularly; also intake of carbohydrates (bread, pasta, rice, potatoes) must be watched, as they convert to sugar in the body. The National Candida Society is a useful source of information (www.candida-society.org) .



CPNA (Chronic Necrotising Pulmonary Aspergillosis)

You may also hear this referred to as 'Chronic Invasive Pulmonary Aspergillosis' or 'Semi-Invasive Pulmonary Aspergillosis (and others – see the 'Treatment' section of the aspergillus website <http://www.aspergillus.org.uk>). Sufferers usually have a normal or only slightly impaired immune system but often have underlying diseases such as diabetes, alcoholism, prolonged steroid therapy, AIDS, CGD. Common symptoms include chronic productive cough, weigh loss, malaise, coughing up blood, and these can continue for years. Treatment is via antifungal medication, minimising steroid use and occasionally surgery.

CORTICOSTEROIDS

These drugs are often used to control inflammation in the lungs of people with Aspergillus disease. Some cannot live comfortably without taking them orally, while others manage with inhaled steroids or a combination of inhaled and oral. There are side-effects which are often more noticeable in women as their hormones react to steroids. Weight gain, sleeplessness and mood change are frequently reported by those taking oral steroids. It may be preferable not to take steroids late at night, to avoid sleep problems.

You must never come down from a high dose of steroids too quickly, as your adrenal glands will not cope with the sudden demand to come back into action, and this can be dangerous. You must reduce the dosage by small amounts each day, until your body has adjusted.

The book 'Coping with Prednisone' by Eugenia Zukerman, St Martin's Press, 1997 is a useful one.

CASPOFUNGIN

One of the newest antifungal drugs and the first of its type (Echinocandins). Administered intravenously its chief advantages seem to be fewer adverse effects compared with older drugs such as Amphotericin.

DIFLUCAN

A drug which works on Candida. It does not have a beneficial effect on Aspergillus however.

ENERGY

This is something most people with Aspergillus disease have a reduced amount of. Sporanox may make you feel very tired when you first take it. Allow yourself plenty of time to rest, if possible. Eat healthily and try to work out what you can accomplish without over-tiring yourself.

EOSINOPHILS

These are a type of white blood cell and take up the red dye, eosin, when blood is examined under a microscope. They accumulate wherever allergic reactions like those in asthma take place. Their natural role is to defend us against parasites, and in fact allergies such as asthma are probably a malfunction of our protective mechanism against parasites. Blood is made up of liquid (plasma) and microscopic cells, one type of which is the eosinophil (see <http://www.globalnet.co.uk/~aair/eosinophils.htm> for details). ABPA



D
E

sufferers may have symptoms just like sufferers of ordinary asthma at first, though an unusually high eosinophil count in the blood compared to most asthmatics should make the doctor suspicious.

F

FLOODS

Cleaning up thoroughly after a water leak or a flood in your home, school or office is essential to maintain a mould free environment. You should never leave an opportunity for mould to develop and take hold in wood, plaster board, furniture or soft furnishings.

FLUTTER

This is a small device, a short white plastic pipe with a stainless steel ball bearing in the angle. You blow into the pipe to create a vibration which passes through the lungs and should help to loosen phlegm. The device produces an oscillating positive expiratory pressure or PEP, designed to improve lung function and sputum clearance. You should not use a flutter if you cough up blood. Some people find it works for them, others do not.

G

GARDENING

Digging soil and tidying up dead leaves and rotting vegetation are occupations which may cause lung problems for people with Aspergillus disease. It could be helpful for people wishing to garden to wear a respirator to the correct standard for keeping out spores and other particles which may affect their condition. (Particulate respirator to BS EN 149)

H

HEPA FILTERS

These are the only type of filters able to filter out minute particles such as spores. Vacuum cleaners with HEPA filters could be advisable in the homes of Aspergillus sufferers.

HOUSE PLANTS

If you have an Aspergillus disease it is probably preferable to give away your houseplants, as the soil and decomposed plant products encourage growth of mould which could affect you adversely.

IgE

Immunoglobulin E are antibody proteins, one of five different types which fight pathogens. IgE is found in lesser amounts in the blood than the other types, but it is very potent. The primary biological function is in the immune reaction and defense against parasitic worms, such as tape worms and round worms. In some humans the immune response to airborne materials (including spores), some foods and drugs, and substances that contact the skin involves the production of specific IgE antibodies rather than other types. This IgE response in turn triggers the allergic responses, causing heightened inflammatory reactions. The E in IgE refers to the E antigen on the surface of ragweed pollen, the structure that induces the most severe allergic response to this allergen.

IgE levels are sometimes measured in Aspergillus patients to check their vulnerability, and antifungal drugs may reduce the levels. Individuals with ABPA have very elevated levels of IgE. This level fluctuates and can go up in periods of poor health and down in periods of relatively good health. Xolair, an Anti-IgE drug, has been produced and been used with asthma and hayfever sufferers. It remains to be seen whether it is effective for Aspergillus sufferers.



INDOOR AIR QUALITY

Traditional methods for preventing infection include proper hand washing, disinfection of surfaces and good housekeeping practices, but these methods may not be sufficient to control infections spread by ambient bioaerosols (fungal spores for example). Patients exposed to certain bioaerosols are at risk of infection following inhalation of the spores of fungi such as *Aspergillus*. Nosocomial infections, or hospital-acquired infections, are increasing as many life-saving procedures carry risks unless special precautions are taken.

In hospital units for high-risk patients there should be a capacity to minimize fungal spore counts via maintenance of high-efficiency air filtration, directed room airflow, positive air pressure in the patient's room in relation to the corridor, properly sealed rooms, and high rates of room-air changes.

Other methods to maintain indoor air quality include damp-dusting of horizontal surfaces, regular cleaning of ceilings and air-duct grates, and maintaining adequate window seals. Exposure of high-risk patients to construction and renovation activities should be avoided, and adequate barriers erected. Patients should not be exposed to floor or carpet vacuuming that may cause spores to be aerosolized. There should be no exposure to environmental sources of *Aspergillus*, eg *Aspergillus*-contaminated food, potted plants, flower arrangements. Birds should be prevented from gaining access to hospital air-intake ducts.

INDOOR MOULD CONTAMINATION

This can be a significant threat to health. Yeasts, moulds and mildews need organic food sources and water to grow. Damp plasterboard and woodwork can supply these conditions. Moulds can grow on cloth, carpets, leather, wood, sheet rock, insulation, and on human foods, when moist conditions exist. People may become exposed either by direct contact on surfaces, or through the air, if mould spores, fragments or products are aerosolized (bio-aerosols).

The impact of fungi, such as *Aspergillus*, on human health is in relation to the amount and duration of an individual's exposure to the mould and the specific susceptibility of the individual exposed. The health effects are in four categories: allergy, infection, irritation (mucous membrane and sensory), and toxicity. Reactions can range from mild, transitory responses to severe, chronic illnesses.

You are best advised to treat all dampness immediately, and remove materials that have become contaminated with mould. Treating areas with bleach may be sufficient, but plasterboard – for example – which has become contaminated should be replaced, and if the contamination is so extensive and long established that toxicity is suspected then it may be best to leave the premises for safety, rescuing only items that will not attract mould. Good guidelines can be found at the US Environmental Agency – <http://www.epa.gov/iaq/molds/index.html>

INVASIVE ASPERGILLOSIS

Many people with a damaged or impaired immune system die from invasive aspergillosis. Their chances of living are greatly improved the earlier the diagnosis is made but unfortunately there is no good diagnostic test. Often treatment has to be started when the condition is only suspected.



This condition is usually diagnosed in a person with low defences such as after a bone marrow transplant, with low white cells after cancer treatment, AIDS or major burns. There is also a rare inherited condition that gives people low immunity (chronic granulomatous disease) which puts affected people at moderate risk. People with invasive aspergillosis usually have a fever and symptoms from the lungs (cough, chest pain or discomfort or breathlessness) which do not respond to standard antibiotics. X-rays and scans are usually abnormal and help to localise the disease. Bronchoscopy is often used to help confirm the diagnosis.

Sometimes the fungus can transfer from the lung through the blood stream to the brain and to other organs, including the eye, the heart, the kidneys and the skin. Usually this is a bad sign as the condition is more severe and the person sicker with higher risk of death. However, sometimes infection of the skin enables the diagnosis to be made earlier and treatment to be started sooner.

Treatment is with antifungal drugs, usually amphotericin B (newer versions are less toxic for patients experiencing side-effects) or Itraconazole (Sporanox). The earlier the treatment is started the better the chances of survival. In patients with low numbers of white cells (infection fighters), recovery of these cells can be important in stopping the growth of the fungus. Sometimes surgery is also required. Overall, about a third of patients survive invasive aspergillosis if treated and none survive if they are not treated.

JOKES

We have found that having a good laugh is one of the best ways of offsetting depression about how we feel with an Aspergillus disease. Similarly a little bit of other people's wisdom may change our mood from time to time and make it all bearable: Life is not measured by the number of breaths we take, but by the moments that take our breath away.

KNOWLEDGE

Knowledge of what constitutes the Aspergillus disease we have is of primary importance to all of us. We should never allow ourselves to be satisfied with less than full information about our condition and how best to treat it – even if we have to do some of the research ourselves.

LIVER ENZYMES

An initial step in detecting liver damage is a simple blood test to determine the presence of certain liver enzymes in the blood. Under normal circumstances, these enzymes reside within the cells of the liver. But when the liver is injured, these enzymes are spilled into the blood stream, raising the enzyme levels in the blood and signaling the liver damage. Patients taking Sporanox are asked to have their blood tested at regular intervals to check for liver damage.

MUSHROOMS

Should people who have an allergy to a fungus, or are infected by one, be eating them? There are varying opinions. Some sufferers report a negative reaction to mushrooms or food/drink the production of which requires a fungus, such as wine, beer and soy sauce. If the fungal intereaction is complete, and the mushrooms well cooked there should be little to worry about, but it is entirely up to personal response, and it may be worth taking note of how you react to such produce and eliminating items which seem to be causing a negative reaction accordingly.



N

NASAL IRRIGATION

To help drain the sinuses during fungal infections, using a sinus flooding technique is advised by many. An article about 'How to do a Sinus Irrigation' is available on <http://altmedicine.about.com/cs/allergiesasthma/a/SinusIrrigation.htm> . Perhaps you should ask your consultant about this first.

NATIONAL ASTHMA CAMPAIGN

Most people with ABPA and CNPA also have a history of asthma. Asthma UK is the organisation which can give you advice and support on asthma (www.asthma.org.uk) .

O

OBSTRUCTED AIRWAYS

People suffering from a variety of pulmonary diseases, including bronchiectasis, cystic fibrosis, bronchial asthma and allergic bronchopulmonary aspergillosis, may find their bronchial tubes blocked by mucus thickened by evaporation or absorption of fluid and the breakdown products of inflammatory cells. Sometimes complete casts of the tracheobronchial tree are coughed up (PLUGS). Inability to clear such casts results in pulmonary complications including impaired air exchange, chronic or persistent infection, and permanent tissue damage. Mucus hypersecretion, which occurs as a response to inflammation secondary infection and tissue damage, further exacerbates the incidence of mucus plugging and cast formation. Retained secretions provide a culture medium for bacterial pathogens, which can set up a recurrent cycle of infection. In addition to medications, patients should practice daily bronchial hygiene, including airway clearance therapy.

ORAL ANTI-FUNGAL DRUGS

If it appears that absorption of anti-fungal drugs such as Itraconazole is not sufficient, then the tablets may be replaced by a liquid form of the drug. Absorption levels should be tested to indicate the long-term effectiveness of the drug.

OSTEOPOROSIS

Loss of bone density may occur due to long-term taking of corticosteroid tablets (and also through early onset of the menopause in women). Doctors, therefore, may advise patients to have a bone density scan (a very simple procedure from the patient's point of view) in order to assess bone density in the hip and lower spine. Medication may need to be given to improve bone density, usually a once-a-week tablet of a drug such as Risedronate. Unfortunately these tablets almost always have slight side effects such as headaches. Risedronate must be taken with a full glass of water at least 30 minutes before eating, drinking or taking other medication, while the patient is in a sitting or standing position. No dairy products or Calcium supplements must be consumed for several hours after taking. This does require a small reorganisation of one day a week, but the long-term gains are worth the effort.

OZONE

Although ozone technically clears the air of some particles, unfortunately machines described as 'ozone generators' produce ozone molecules, blow them into the air to 'clean' the room, and may be producing more than the acceptable standard. Ion-type cleaners produce ozone as a byproduct, but at a lower level. "When inhaled, ozone can damage the lungs. Relatively low amounts can cause chest pain, coughing, shortness of breath, and, throat irritation. Ozone may also worsen chronic respiratory diseases such as asthma and



compromise the ability of the body to fight respiratory infections.” This a quotation from the US Environment Protection Agency.

P

PEAK FLOW METER

The small peak flow meter you may be given by your doctor allows you to work out roughly your usual air intake, and to monitor whether your lungs are worse than usual and needing medical attention. To learn how to use your peak flow meter, go to: www.netdoctor.co.uk/diseases/facts/asthmapeakflowmeter.htm .

POSTURAL DRAINAGE OR AIRWAY CLEARANCE THERAPY

This is important for maintaining chest health, and requires breathing exercises and learning to clear mucus from different areas of the lungs by lying with the head lower than the legs and percussing the chest, changing the angle you are lying at to drain different sections. Techniques of percussion must be discussed with your doctor or physiotherapist prior to starting to use them.

PREDNISOLONE

This is the corticosteroid used most commonly, either in small inhaled doses or larger systemic (oral) doses to treat ABPA. As well as reducing inflammation, the reason it is used, it does have the negative effect of suppressing the immune system and leaving patients more open to infections of other sorts, such as by Candida (yeast).

PSEUDOMONAS

Pseudomonas aeruginosa is a Gram-negative bacterium that is noted for its environmental versatility, ability to cause disease in particular susceptible individuals, and its resistance to antibiotics. The most serious complication of cystic fibrosis is respiratory tract infection by the ubiquitous bacterium *Pseudomonas aeruginosa*. Cancer and burn patients also commonly suffer serious infections by this organism, as do certain other individuals with immune systems deficiencies. Unlike many environmental bacteria, *P. aeruginosa* has a remarkable capacity to cause disease in susceptible hosts. It has the ability to adapt to and thrive in many ecological niches, from water and soil to plant and animal tissues. *P. aeruginosa* can produce a number of toxic proteins which not only cause extensive tissue damage, but also interfere with the human immune system's defense mechanisms. These proteins range from potent toxins that enter and kill host cells at or near the site of colonization to degradative enzymes that permanently disrupt the cell membranes and connective tissues in various organs. This bacterium is also noted for its resistance to many antibiotics.

POSACONAZOLE

One of the newer antifungal drugs from the 'azole' group. Others include Itraconazole, Voriconazole. All have slightly different properties and are effective against *Aspergillus* as well as a range of other fungi. Currently in one of later drug trial stages and sometimes available to doctors on special request.

PILLOWS

Make sure you change your pillows regularly, as they develop high levels of *Aspergillus* over time.



Q QUESTIONS

Questions people ask regularly include:

Will I ever be free of aspergillus disease? The answer is unfortunately no, for people with an allergic reaction.

R REFLUX

Acid reflux gives you a burning sensation in the oesophagus, and this may be experienced if you have been taking steroids for a long time and have become susceptible to Yeast/Candida in the gut. Diflucan can be given to ameliorate the condition, but the best remedy is probably to cut out all sweet foods or most of those which revert to sugar (pasta, rice, potatoes, bread) for a while until the symptoms have gone. Drinking plenty of water will also help. Keep up a reduction in sweet/starchy foods to avoid recurrence, but there probably isn't any need to cut them out altogether.

S SICK BUILDING SYNDROME

A sick building can result from the presence of large quantities of multiple fungi such as Aspergillus. Individuals who would normally not experience ill effects from contact with normal levels of these fungi become reactive to the large quantities in the sick building and are said to have 'sick building syndrome'. Many other causes of sick building syndrome have been described, most without any involvement of fungi.

SINGULAIR

This drug, a Leukotriene Antagonist, is an oral anti-inflammatory mediator blocking medication that works by blocking the binding of the Leukotriene LTD₄ to its receptor site on cell walls. Singulair's binding of the LTD₄ receptor site prevents the release of mediator agents that trigger inflammatory reactions in the airways. These inflammatory reactions include airway narrowing, local airway swelling and excess airways mucus production. This drug is successful in helping some asthma and Aspergillus sufferers avoid allergic reactions.

Side effects. It has been associated with the Churg-Strauss syndrome, a tissue disorder which if untreated can destroy organs. Some of the symptoms are: rash, flu-like symptoms, numbness or tingling of the arms or legs, or severe sinusitis. However, in 1998 it had been reported in fewer than 20 patients of the 600,000 who had taken the drug.

As this drug acts against only one leukotriene and there are 20, it does not always work.

SPORANOX

This is a name for itraconazole, the antifungal drug which can be used to fight Aspergillus infection.

T TRANSPLANTS

There is a slight risk that transplant patients, both major organ and bone marrow, may contract a serious Aspergillus lung infection. See the leaflet: 'How can I reduce the risk of Aspergillus infection?'



TESTS

Diagnosing Aspergillus infection and allergy may include the following tests:

1. Getting a sputum sample (phlegm) to look for Aspergillus spores and fungus
2. PCR test (polymerase chain reaction test – a very sensitive blood test for the detection of infecting agents) – may not be available yet.
3. Blood tests for:
 - a) blood proteins (IgE antibodies) that are developed to counteract Aspergillus;
 - b) Aspergillus substances (antigens) that are produced by the fungus during infection.
4. X-ray and CT (computerised tomography) scan give information about lung abnormalities.
5. Skin prick tests against Aspergillus – these check an allergic reaction to Aspergillus and many other fungi and pollens etc. They are not useful for IA or CPA.
6. Bronchoscopy, where a telescope attached to a tube is inserted into your lungs via the nose to have a view of your lungs' air passages.
7. Biopsy – a tissue sample of the lung taken to check for IA.

U

USING YOUR INHALER

Start a slow breath before inhaling. Hold the breath. Inhale to total lung capacity. Wait at least 30 seconds between inhalations. It is important to use your inhaler correctly. Some inhalers have different instructions; make sure you read your instructions carefully and follow them.

V

VEST

The ThAIRapy vest system consists of a close-fitting inflatable jacket and an air pulse generator to create external chest wall oscillation in order to improve lung function and sputum clearance. This is used by cystic fibrosis sufferers when needed, and has also been used by ABPA patients whose lung function has required it.

VORICONAZOLE

This is a drug used to help people with severe ABPA or AFS. One side effect may be impaired vision, especially in the evening, but some people do not experience this, and it is a temporary effect.

W

WATER

It is recommended by nutritionists that you take about 8 glasses (approx 2 litres) of water a day to flush out the system and keep the kidneys in good condition. One way of taking in a good amount without having to measure it is to keep a couple of litre bottles filled with water and drink them during the day.

X

XOLAIR

A new drug being used to treat asthma patients. It works by binding to and disabling IgE, the class of antibodies that causes allergic asthma and hay fever. Delivered by subcutaneous injection (ie under the skin and not into a vein), once or twice a month, Xolair blocks allergens from activating the immune system. Unlike current therapies, Xolair selectively targets the underlying causes of disease, not just the disease symptoms.



Y

YEAST

Candida is the name given to the yeast which infects many people who regularly take steroids. It can be treated with Diflucan. Irritation of the skin may be helped by use of Zinc cream. Avoiding too much sugar or carbohydrate in the diet is important.

Z

ZEST FOR LIFE

Try to keep it, no matter how many problems you have with your Aspergillus disease.



Nothing contained in this leaflet is intended to be any form of medical advice and must not be taken, or relied upon, as such. Individuals must seek all such advice personally in relation to their particular circumstances.

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