Patient Information:

Allergic Bronchopulmonary Aspergillosis

(ABPA)



Provided by the Fungal Infection Trust



The purpose of this booklet

This booklet will provide some useful information about the serious infection caused by *Aspergillus* and its prevention.

Nothing contained in this booklet 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.

The Fungal Infection Trust 2018

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What is Aspergillus?

Aspergillus is a common mould (a fungus). It is made up of narrow threads called hyphae. Hyphae grow and develop branches, to form a mesh called the mycelium. The mycelium develops structures called spores, which contain cells that can reproduce. These spores are so tiny that they are dispersed by the slightest draught, and normally cannot be seen. The fungi require dead organic matter for food and a damp environment to grow. They commonly grow on fallen leaves, compost heaps, air conditioning units, household dust, animal hairs and in damp housing. Aspergillus is found all over the world. There are many different species of Aspergillus, only some of which are associated with human disease.





Allergic bronchopulmonary aspergillosis

What is ABPA?

The small spores produced by the *Aspergillus* fungus can be easily inhaled into the lungs. *Aspergillus*, in particular *Aspergillus fumigatus*, can 'live' in the lungs of some people to cause allergic bronchopulmonary aspergillosis (ABPA). The body reacts to the *Aspergillus* by producing a long term allergic reaction and inflammation.

ABPA occurs when the fungal hyphae & spores colonise the airways and/or the alveoli (air sacs) deep in the lungs. The hyphae & spores evade the immune mechanisms normally used by the lungs to clear foreign organisms, so they can persist and cause an inflammatory response by cells called eosinophils. Normally these cells arrive quickly and then disappear once the infection is cleared up, but in ABPA the infection doesn't clear up. This damages the airway.

Aspergillus causes illness in only a few humans and animals, though people with a history of Asthma or Cystic Fibrosis may be more susceptible, especially if exposed to large quantities of spores in a damp environment.

Although *Aspergillus* is always in the air around us, it makes sense to avoid potentially high levels of spores, as found in the situations described here and elsewhere in this leaflet.



Allergic fungal sinusitis may also occur, alone or with ABPA. In the long term ABPA can lead to permanent lung damage (fibrosis) if left untreated.

Sufferers may experience wheezing, cough, fever and tiredness. Some may cough up dark plugs of mucus.

Who gets ABPA?

ABPA was first recognised in the United Kingdom in 1952. Not everyone exposed to *Aspergillus* develops the disease. Those who are susceptible to ABPA are mainly people with asthma and cystic fibrosis.

1-2% of adults with asthma develop ABPA and 10-15% of patients with cystic fibrosis develop ABPA.

Other people at risk include those who have a tendency to develop allergies, and those who are frequently exposed to *Aspergillus*, such as farm workers.

How is ABPA diagnosed?

Symptoms give clues to the diagnosis – specifically the coughing up of hard plugs. The doctors will also wish the patient to undergo various tests to confirm the diagnosis of ABPA and to rule out other possible illnesses.

These tests may include:

 Sputum samples to check for the presence of the Aspergillus fungus



- Blood tests
- Chest X-ray and/or CT scan
- Bronchoscopy, where a small camera is inserted into the lungs via the nose

What is the treatment for ABPA?

For ABPA the following medications are usually used:

- Steroids taken regularly with an inhaler or in tablet form to ease symptoms during an acute attack.
 Steroids have side-effects such as weakening of bones, possible weight gain and a risk of suppressing adrenal function.
- The antifungal drug, Itraconazole (Sporanox), can often lead to a reduction in symptoms and reduce the amount of steroids required. Close monitoring of drug levels, liver & kidney function is required.

How is ABPA treated?

Good management of your asthma/COPD is important. Treatment also includes chest physiotherapy to help clear the mucus, antibiotics, bronchodilators (to open your airways), steroids, immunisation against other infections such as influenza and pneumococcus and advice to stop smoking. The antifungal drug (Itraconazole) may be given. Doing your best to avoid fungi and reduce your exposure to areas with lots of fungal spores is also important.



Antifungal nebulisers (amphotericin) may be used if you cannot tolerate Itraconazole. This is given under supervision of the physiotherapist at the hospital initially as it can make you wheezy.

Will I ever be free of ABPA?

Unfortunately ABPA cannot be cured as the colonisation of the airways cannot be completely cleared by antifungal drugs.

What can I do to protect against acute attacks?

- It is very important to take your asthma medication, particularly inhaled steroids, as your doctor has prescribed.
- Try to avoid areas with lots of fungal spores eg: bird droppings, dusty environments, poorly ventilated environments, heating systems with dirty filters, soil (including pot plants), dead leaves, compost heaps, cereal harvests, and building or renovation sites.
- HEPA filter air purifiers and vacuum cleaners can help improve air quality.
- Using a mask that will filter spores when gardening could be helpful (a particulate respirator to BS EN 149).



 Maintaining a balanced and low sugar diet, and taking regular exercise are important for a healthy lifestyle.

What further help is available for ABPA patients?

- There are several very active support communities on Facebook (moderated by NAC staff) where many of your questions will be answered www.facebook.com/groups/Aspergillussupport/
- We also have a face-to-face meeting every first
 Friday of the month at the Altounyan Suite at
 12:30pm ask at clinic reception for directions and keep an eye out for the Aspergillosis Community
 Booklet available in clinic.
- The Aspergillosis Patients and Carers website is very informative. Go to <u>aspergillosis.org</u>





Complications of Allergic Bronchopulmonary Aspergillosis (ABPA): Bronchiectasis and Bacterial superinfections

Once you have been diagnosed with ABPA you are likely to be treated by your GP and a specialist in the hospital. The damage to your airways (bronchiectasis) and the use of steroids suppress your immune system and increase the likelihood of developing bacterial infections like *Pseudomonas, Klebsiella* and MRSA.

Bronchiectasis

Damage to your airways (bronchi) includes widening and thickening of the wall. It develops gradually and results in airways that are permanently dilated and scarred. It can occur in patients with chronic obstructive pulmonary disease (COPD), asthma or cystic fibrosis.

Symptoms to look out for are; chronic productive cough, sputum may be difficult to clear, shortness of breath, chest pain, sometimes fever and wheeze. Occasionally people may cough up blood; if this happens you must let your doctor know.



Bacterial Infections

These include *Pseudomonas* and *Klebsiella*. The signs and symptoms of these infections are similar to those of bronchiectasis but develop over a shorter period of time. It is important to be aware of these e.g. feeling unwell, weakness, increase in breathlessness and cough, worsening chest pain, high temperature and a change in sputum colour and amount. You should contact your doctor if you develop signs of infection; they will normally want to test a sputum sample to find out what is causing the infection and the best way to treat it. Several antibiotics are available for treatment, some oral and some that will need to be given in hospital as they can only be given intravenously (via a "drip" in your arm).



How can I reduce the risk of Aspergillus Infection?

How can I reduce Aspergillus exposure?

Aspergillus cannot be completely avoided in the environment but the risk of exposure can be reduced:

- Avoid places where Aspergillus spores are abundant forests, gardens, compost heaps, damp bark or wood chippings, grain stores, rotting vegetation, dead leaves, and building construction or renovation areas.
- The household environment and furniture surfaces should be kept clean, dust-free and dry to minimise the accumulation of fungus and moulds. (see <u>aspergillosis.org/damp-homes/)</u>. Remove any potted and ornamental plants in the household.
- Avoid activities with a high risk of Aspergillus exposure, such as gardening, compost making, building construction, and house cleaning.
- Wear a mask that filters spores, if a high risk environment is unavoidable, could be helpful (HEPA specification for tiny particulates FFP2 or FFP3).
- Change your pillow regularly (ie 3 monthly and before discharge from hospital after chemotherapy or transplantation), as research has indicated that pillows are



- harbourers of Aspergillus.
- Always ensure you take your medical prescriptions as instructed and attend your doctor's appointments. See your doctor promptly if you feel worse or develop new symptoms.
- If on immunosuppressive drugs, you may be asked to attend for blood tests regularly. It is good advice to faithfully attend every appointment, as any changes in your immune system's ability to fight off infection can be quickly spotted by blood tests (i.e. neutrophil count changes) and advice given to avoid/treat infections before the infection becomes more serious.
- In addition, good hygiene and a healthy lifestyle will help improve your body's immune defence against Aspergillus and other infections.
- Eat a balanced diet. The body and immune system needs optimum nutrition in order to function well. Try to eat fresh food, at least five portions of fruit and vegetables per day.
- Take regular exercise, get enough rest and sleep every day.
- There is some evidence that stress can further weaken our immunity and also reduce our well-being. While many life stresses cannot be totally be avoided, you can discover your own means of relaxation. Some complementary therapies such as massage and meditation can be very relaxing, and mindfulness can



help control stress.

How is Aspergillus infection diagnosed?

Symptoms give clues to the diagnosis. The doctor may perform tests to check your lung functions and airflow regularly. Some special tests may also be performed to confirm suspected *Aspergillus* infection and rule out other illnesses.

Tests may include:

- Getting a sample of sputum (phlegm) to look for Aspergillus spores and fungus.
- Blood tests for:
 - 1. Blood proteins (antibodies) that are developed to counteract *Aspergillus*.
 - 2. Aspergillus substances (antigens) that are produced by the fungus during infection.
- X-ray and computerised tomography (CT) scan gives information about lung abnormalities.

Further information about these tests can be provided by your doctor.



What is the treatment for aspergillosis?

- 1] Anti-fungal drugs these can reduce the activity of the fungus and improve symptoms
- 2] Surgery- these are used to the single fungus ball in the sinuses or in a single lung cavity in one lung may need to be surgically removed. However, lung function in patients with such problems may preclude safe surgery.
- 3] Embolisation the main associated problem, namely haemoptysis (bleeding), can be dealt with via embolisation. Embolisation is probably now the method of choice for treating the haemoptysis in virtually all cases. Often the haemoptysis will recur due to new blood vessels developing but it is possible to repeat the procedure.



A guide to Nutrition and Health

Nutrition and the immune system

Maintaining a healthy weight for your height is also important but is not always easy to do when you have a chronic health condition. This is often expressed as Body Mass Index (BMI) or weight in kilograms over height in metres squared (eg 60Kg person, 1 m68 tall, BMI= 60 divided by 2.82= 24).

A BMI between 20 and 25 is healthy, lower than this and you may be underweight and undernourished, over this you are likely to be overweight. Being seriously underweight (BMI 16 and below), or significantly overweight (BMI of 31 and above) can weaken the immune system.

Vitamins and minerals are essential in boosting your immune system and helping you fight off infection. Having a good intake of vitamin and mineral rich foods: colourful fruit and vegetables, wholegrains, eggs, meat, fish is important. Frozen vegetables are also high in vitamins.

- 1. Cooking eggs well and avoiding undercooked/raw eggs, e.g.: in home-made mayonnaise and mousses.
- 2. Cooking meat well especially chicken and pork.
- 3. Eat all foods within best before and use by dates.



- 4. In your fridge, store meat and poultry well away from food which will be eaten raw.
- 5. Also choose cafes/take-aways/restaurants carefully. Places to avoid are those with visible litter, dirty tables, where staff handle food and money without washing hands/wearing gloves, cold food served lukewarm. Good practice includes hygienic looking premises, food hygiene certificates on display, staff not handling money and food, hot food trays emptied completely before fresh food is added, high turnover of customers (food is less likely to be kept over for the next day).
- Also see the Food Standards Agency website (www.food.gov.uk) for more useful information on food safety.

Exercise has been shown to boost the immune system in a variety of diseases. Regular exercise may help, even relatively gentle activity can be beneficial: walking, gardening, cycling, and swimming. Exercise in the swimming pool helps reduce impact on joints.

Diet and your energy levels

Energy is linked to many things e.g. emotions, sleep levels, exercise and diet. Where diet is concerned it may help to bear in mind the following:



- Regular meals help maintain even blood sugar levels and therefore a constant supply of energy. Also aim to have a breakfast consisting of a source of protein (eggs, baked beans/yoghurt) and of starch (porridge/toast) as it seems that by mixing these two nutrients, better energy levels are maintained. Main meals tend to naturally consist of a mixture of the two e.g jacket potato (starch) and baked beans and cheese (protein) or a sandwich with some form of protein filling (egg/ cheese/meat/fish).
- Maintain even sugar levels: by not going for more than 3-4 hours without food, and avoiding high sugar foods. There is growing interest in the Glycaemic Index (GI) of different starchy foods (the amount of insulin released as a result of eating a particular food). The higher the GI, the more insulin is produced, sugar levels drop and this can result in fatigue. Choose low GI foods where possible e.g. wholemeal /wholegrain bread, wholegrain /Basmati rice, al dente pasta, jacket potato (not mash). Having a starchy food with a source of protein can also lower its GI, for example have a jacket potato with tuna or bread and ham in a sandwich.
- Drink fluids throughout day, you need about 3-4 pints or 1.5-2 litres per day. This should not all be taken as caffeine/sugar containing drinks.



 If eating makes you breathless or your appetite is small, smaller more frequent meals may be better & easier for you to tolerate.

Diet and steroid therapy

- If you are on long term, or frequent steroid therapy, you may experience side effects: weight gain or sometimes loss, also weakened muscles and bones.
- To protect muscles, aim for a good protein intake (have a source of protein at each meal). Exercise will also help: walking regularly, lifting gentle weights, and swimming.
- For bones, calcium and vitamin D are important. Calcium is found most abundantly in dairy foods. Three portions a day should cover most adults' needs e.g. one yoghurt, one helping of cheese and a milky drink. However if you do not like dairy foods then fish with bones (e.g. sardines, pilchards, whitebait), white bread, scones, spinach are also good sources. For vitamin D, eat oily fish with bones e.g. sardines, pilchards, herrings, tuna, trout, and also vitamin D supplemented margarine (most brands are supplemented). Vitamin D is also synthesised by the skin as a result of sun exposure. 10-15 minutes per day is the minimum needed for your daily dose.
- The evidence on the benefits of calcium and vitamin
 D supplementation via tablets (over and above the



daily recommended amount for these nutrients) for those on long term steroid therapy is difficult to interpret. Different studies (done on patients with conditions such as chronic inflammatory bowel disease and asthma) draw different conclusions. If you are concerned about potential bone loss, discuss the possibility of supplements with your specialist doctor. This may be most appropriate if you do not eat calcium and vitamin D rich foods regularly.

If you are gaining more weight than you are happy with, the following could help:

- Cutting down on high fat foods. These include cheese, most puddings, fried foods, pastry, meat products e.g. sausages and pies, chips. Alternatively choose lean meat or fish, boiled/jacket potatoes, pasta, boiled rice instead and as much fruit and vegetables as you like, as well as low fat dairy foods: semi skimmed milk, low fat yoghurt, cottage/lower fat cheeses.
- Again exercise is often helpful.



Examples of food with different GI values

High GI

Glucose
Maltose
Lucozade
Jelly beans
Cocopops
Cornflakes
Rice Krispies
Weetabix
Shredded Wheat
Brown/Wholemeal Bread
White Bread
French Stick
Brown/White Rice
Waffles
Bagel

Morning Coffee Water Biscuits Puffed Crispbreads Parsnips Baked Potatoes Chips* Pumpkin Swede

Broad Beans

Corn Chips*

Water Melon

Crumpet

Intermediate GI

Sucrose Honey Sports Drinks Fanta/Cola Shreddies Sustain Oatmeal Biscuits Shortbread* Arrowroot Pineapple Papaya Raisins Sultanas Squash Mars Bar* Muesli Bar* Taco Shells* Full Fat Ice Cream* Croissant* Beetroot **New Potatoes**

Pea Soup

Low GI

Fructose/Lactose All Bran/Muesli Porridge/Special K Sultana Bran Barley **Bulgar Wheat** Basmati Rice Noodles/Pasta (all types) Fruit Loaf Heavy Grain Bread (e.g. Granary/Multigrain) Pitta Bread/Rye Bread Chapatis Sponge Cake Banana Cake* Apple Muffin* Low-fat Ice Cream Milk/Yoghurt Fish Fingers Peanuts* Sausages* Crisps*/Popcorn Lentil/Tomato Soup Chocolate* Apple/Apricot/Banana/ Cherries/Cantaloupe Melon/Grapefruit/Grape /Kiwi/Mango/Orange/ Peach/Pear/Plum Apple Juice/Orange Juice Carrots/Peas/Sweetcorn Sweet Potato/Yam Baked Beans/Butter Chick Peas/Haricot Beans Kidney Beans

Sometimes despite your best efforts to maintain a healthy diet & weight, people with *Aspergillus* disease struggle to get good nutrition and lose weight. If this happens supplements may be needed and will be prescribed by your GP or dietician.



Lentils/Soya Beans

Precautions for handling compost and bark chippings

Composting often results in the growth of large numbers of fungi in the rotting material. One of the most important fungi involved in the composting process is *Aspergillus fumigatus*. *Aspergillus fumigatus* is the main cause of several medical problems varying from causing irritating allergy & asthma right up to and including serious invasive infections with consequent lung damage and severe disability that can be incurable.

There have been two recorded deaths in the UK over the last few years that may have been caused by people accidentally inhaling huge numbers of fungal spores from bags of compost that they opened not knowing the potential health hazards.

We would like to make people more aware of the dangers. Precautions include taking care when opening bags of compost as that seems to be a consistent theme, but also care can be needed when handling any heaps of rotting material. Take care not to inhale the clouds of spores that can be released when opening bags of compost, only open bags outdoors and preferably on a day when enough wind is blowing to prevent the spore clouds building up as you work.

Needless to say people who suffer from asthma & allergies should take more precautions.





Face masks

There have been a few rare cases of (apparently) completely healthy people accidentally breathing in huge numbers of spores - the latest was a healthy 40 year old man who opened bags of composted plant material which must have blown clouds of mould into his face . He became very ill within a day or two and died.

Clearly the best way to avoid health problems is to remove the source of the problem - in this case avoid situations where you are exposed to high numbers of spores. Unfortunately that is not always possible - the source might be part of your daily life or your work (e.g. if you are a gardener or agricultural worker).

Alternatives include:

- Adjusting your living or working practices to minimise exposure to mold spores
- Use protective barrier equipment to prevent spores being breathed in e.g. face masks
- Filter all of the air surrounding the vulnerable individual (only viable for quite small enclosed areas e.g. surgical operating theatres and required powerful expensive equipment)

Face masks represent the most cost effective solution if an individual must breathe in air that contains a lot of spores.



They are light and relatively cheap while not being too obtrusive to the user.

Which Face Mask to use?

There are a huge range of masks and filtration material available on the market - traditionally aimed at the industrial and medical protection markets but now increasingly available to the domestic user. Fortunately for simplicity the vast majority are useless at filtering out tiny fungal spores as they are too small to be stopped. A cheap paper mask sold at your local DIY store to prevent dust inhalation is far too coarse to filter out mould spores — consequently we can concentrate on filters that remove particles 2 microns in diameter and those are a little harder to come by.

Any filter that you intend for use to prevent exposure to fungal spores must be graded as a HEPA filter. There are three grades of HEPA filters namely N95, N99 and N100 and the numbers refer to the percent of particles 0.3micron in size that filter is capable of removing from air that passes through it.

An N95 filter will therefore remove 95% of all particles 0.3 micron in size from air that passes through it. Fungal spores are 2-3 microns in size so an N95 filter will remove far more than 95% of fungal spores from the air, though some will still get through. This standard is generally thought to be the best combination of efficiency and cost for the average home user - such as a gardener. Industrial users (e.g. workers



remediating mouldy homes or other premises) may be exposed to far more spores and may opt for the more efficient N99 or N100 filters at higher cost.

In the UK and Europe the standards referred to are FFP1 (not appropriate for this purpose), FFP2 and FFP3. FFP2 is equivalent to N95 and FFP3 offers higher protection. Masks generally cost £2-3 each and are intended for single use. More expensive masks are available which can be used more than once - see 3M for one possible supplier, also Amazon are used by many other suppliers (NB there is a list of suppliers at the end of this article)

These masks must be correctly fitted to work to their full potential so be sure to follow instructions carefully.

Industrial users are often advised to wear a full face mask including eye protection (to prevent eye irritation) and to use an additional filter to remove the chemical gases given off by moulds (VOC's), but this is mainly for people being heavily exposed to clouds of spores day after day.

NOTE: patients that use spectacles have reported that some facemasks are difficult to use for any length of time as they tend to 'steam up'. To avoid this, some models have a special valve that is designed to allow air out of the mask easily when exhaling.



UK

http://www.hse.gov.uk/respiratory-protectiveequipment/index.htm

USA

NIOSH-Approved N95 Disposable Particulate Respirators

NIOSH-Approved N99 Disposable Particulate Respirators

NIOSH N95 Certified Masks with FDA Approval



Fitting your facemask

Facemasks for the reduction of *Aspergillus* spores in the air that you breathe

Introduction

This information applies to fitting disposable FFP2 and FFP3 masks. The 3M 9320 mask is used here for demonstration purposes.

Things to consider prior to fitting:

If you wear glasses, you should remove them before fitting as they will interfere with achieving an effective seal.

Facial Hair – If you have a moustache/beard and it goes beyond the border of the mask then an effective seal will not be achieved. A half mask or powered respirator will be required.

Fitting instructions:

- 1. Open out the mask: lift straps & pull the flaps apart
- 2. Cup lower flap of mask under chin with one hand and slip straps over your head with the other.
- 3. Adjust straps so lower strap is below ears and upper strap is over crown of head.



- 4. Adjust top and bottom of mask for a comfortable fit.
- 5. Using index and middle fingers of both hands together, mould the nose clip over your nose and smooth onto your cheeks. Do not pinch the clip as this may prevent you getting an effective seal.
- 6. Check, using a mirror that your mask is on straight and flaps are not folded under. Adjust if necessary.

Additional important Information:

Your facemask should be the first item of Personal Protective Equipment (PPE) that is put on and the last item taken off. This is important because:

- 1. It will prevent you from being exposed to allergen material on the other PPE you are wearing as you take it off, and
- 2. It will prevent the inner surface of your mask becoming contaminated if you are going to re-use it.

NB: If you wear a cap or hat your face mask should be put on before the cap or hat.



UK suppliers offline

Patients have successfully sourced FFP2 facemasks from the following suppliers:

Graham's Machinery, Chester - 01244 376 764 (they told me they sell boxes of 10 masks)

SMH Products Ltd, St Helens - 01744 26660 (as well as 3M ones, sell another fold flat FFP3 mask by 'RESPAIR' in a box of 5)

Online sources

There are many – search Google or Amazon for 'ffp2 facemask'





Respiratory Physiotherapy



Provided by the Fungal Infection Trust



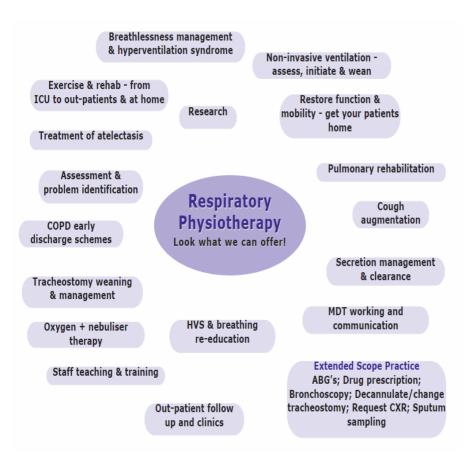
What do physiotherapists do?

- Physiotherapy helps restore movement and function when someone is affected by injury, illness or disability through movement and exercise, manual therapy, education and advice
- Physiotherapy takes a 'whole person' approach to health and wellbeing, which includes the patient's general lifestyle
- At the core is the patient's involvement in their own care, through education, awareness, empowerment and participation in their treatment

What is respiratory physiotherapy then?

 Frequently Respiratory physiotherapy or "chest physiotherapy" is used to mean using techniques to help clear mucus from the airways. However, there is much more that respiratory physiotherapy can offer:





- Physiotherapy may be helpful in helping patients produce sputum samples. These sputum samples can be extremely important in the management of Aspergillus-related diseases.
- Should you wish to access a video detailing one technique that may be useful in helping you cough up



sputum, it can be found online here: https://aspergillosis.org/loosen-and-clear-mucus/

- Simply put, try repeating this sequence a few times:
 - 4 deep breaths
 - 5 long, slow, gentle huffs
 - 3 short fast strong huffs
 - cough
- Exercise is often extremely effective at improving health but often people with lung or heart complaints worry about getting short of breath. A good rule of thumb is that it's ok to be breathless with exercise, but if you get speechless/ unable to talk you may be working too hard.



More Information and Support

The National Aspergillosis Centre runs a website for patients and carers that contains all the information we think you and your family will need. www.aspergillosis.org

The Aspergillus website contains a huge amount of reference material that the more expert reader might find useful www.aspergillus.org.uk

The patients charity the Aspergillosis Trust advocates and fundraises for aspergillosis patients and carers everywhere www.aspergillosistrust.org

Many people find that having a rare disease such as aspergillosis is very isolating and can promote emotional illness too, so it is well worth knowing that there are thousands of people just like you in our active Facebook support groups. We can also answer many of your questions. Aspergillosis Support

www.facebook.com/groups/aspergillussupport

We also run a monthly meeting in the first Friday of each month in the Altounyan Suite next to clinic. Come along at 12:30 for refreshments and chat informally to some fellow patients or to a member of staff, listen to informative talks. Everyone is welcome, finishes at 3pm (and you get a free car parking ticket for the day).

