



## *Living With Alpha-1*



A lifestyle guide for people diagnosed  
as having the genetic condition  
Alpha-1 Antitrypsin Deficiency

**It is very important for Alphas to do everything possible to protect their lungs and liver and to maintain overall good health. Your medical specialist can give you advice on how to do this. Always take note of this advice.**

The advice is generally addressed to full-blown Alphas (PiZZ) but there is a growing appreciation that so called “carriers” (PiMZ) also have increased risk. In this booklet, we will refer to an Alpha as somebody who is PiZZ, PiSZ or PiMZ.

Each Alpha is different. Your condition, your symptoms and how your body reacts to stress and irritants are almost certainly quite specific to you. Learn from your body. Become the expert on yourself.

### **Risk Factors – for Your Liver**

Chief among the substances known to cause liver damage is alcohol. Excess alcohol consumption is by far the most common cause of toxic chemical damage to the liver in our society as a whole. Other agents that are inhaled, swallowed, or absorbed through the skin can also cause damage to the liver. Among these are solvents, toxic alkaloids, pollutants, dietary supplements, and prescription and over-the-counter drugs.



Many medications have been implicated as a potential cause of liver damage. The widely used pain medication paracetamol is one such drug. Paracetamol is generally safe when taken as prescribed. However, when taken in excessive doses, either all at once or over a period of time, it can cause severe damage to the liver. If you drink alcohol then you should at least halve the recommended dosage of paracetamol.

### **Risk Factors – In the Home**

Aside from tobacco smoke, other potentially harmful substances encountered in the home environment include

- Fumes
- Aerosols
- Mould and mildew
- Some Household cleaners
- Fireplace smoke

Some people who are sensitive to substances such as cleaning products, soaps, deodorants, and cosmetics may experience respiratory difficulties with exposure to some items. People with Alpha-1 or those with known or suspected allergies may experience difficulty breathing when exposed to pet hairs, mould, mildew, pollen, or other airborne particles. Persistent exposure by sensitive individuals to any of these elements may lead to long-term respiratory problems. Open windows and increase ventilation when you are in areas where fumes may accumulate or install extractor fans. Remember to inspect fans and clean them routinely.

### **Risk Factors - Smoking**

First among the controllable risk factors associated with development of lung disease in Alpha-1 is exposure to cigarette smoke. Whether from personal use or secondhand exposure, cigarette smoke has been undeniably shown to exert the greatest risk.



For the smoker, inhaling cigarette smoke is known to accelerate the destructive processes in the lungs and for someone with Alpha-1 Antitrypsin Deficiency (AATD or A1AD) the damage done to the air-sacs in the lungs leads to emphysema. But it is not only the risk to the smoker that is of concern. Secondhand smoke can also cause considerable damage to the lungs of Alphas who do not smoke themselves.

In addition, children of smokers appear to have a much higher incidence of asthma than children of non-smokers. If your child is an Alpha, the risk of developing lung disease in later life will be greatly increased by exposure to secondhand smoke.

The chemicals created from burning tobacco destroy Alpha-1 Antitrypsin (AAT). A single cigarette destroys all the Alpha-1 Antitrypsin in the lungs. Because each cigarette smoked results in a repeated episode of irritation and inflammation, this process may therefore account for a significant portion of the lung disease seen even in the general population.

Among individuals with normal AAT levels, this damaging process generally occurs gradually. The symptoms of lung disease in these individuals, if they occur, tend to develop during their 50s or 60s. Alphas, with their reduced AAT levels, may develop these symptoms as early as in their 30s.

Although cigarette smoking is recognised as a controllable risk factor, it is clear that, in many cases, it is not an easily avoidable one. Some Alphas live with smokers who are unwilling to quit. It is important to understand that dealing with a cigarette addiction, as with any addiction, may be very difficult. Successful change takes knowledge, help from others, and a long-term commitment to health.

## **Aerosols**

*Many aerosols including deodorants, hair sprays, perfumes, air fresheners and spray disinfectants can cause breathing issues to some lung affected Alphas. Try switching to roll-on deodorants, pump sprays, solid air fresheners, and other non-toxic alternatives.*



## **Household cleaning products, ammonia-based products, spirit-based products, oven cleaners, bleach, spray furniture polish, paint sprays, and mildew remover sprays.**

Use cautiously as these products pose a threat to your liver, as well as your lungs.

- *Seek less toxic or more natural alternatives as much as possible. For example, baking soda or a solution of vinegar and water serve quite well as household cleaning products.*
- *Use commercially available pre-moistened dusting/polishing cloths or a cloth slightly dampened with water.*
- *Be aware of the nature of chemicals that come in contact with your skin, these can be absorbed through the skin and affect your liver.*

## **Dust and dirt can accumulate quickly and cause difficulty in breathing.**

- *Avoid dusty situations*
- *When cleaning areas where dust and dirt routinely accumulate, use a damp rag or mop to reduce airborne particles. Remember, many household appliances collect dust and other irritants and should be cleaned regularly.*

## **Risk Factors – Outdoors**

Here you have less control over fumes and other irritants that other people put into the air. The general advice is to think ahead and remove yourself from the polluted area as soon as possible.

Watch bonfires and fireworks from a safe distance, for you this may be more than others may consider safe. Be careful with barbecues especially when they are being ignited using solid or liquid firelighters.

Heed any air quality warnings, especially in the hot summer months. If ozone levels are high, try not to venture outside for too long.

Avoid contact with anyone who has a cold or flu.

## **Health – Exercise**

Exercise can improve your mental outlook as well as your physical health. An exercise routine is critical for all Alphas, even those with minimal or no symptoms. A pulmonary rehabilitation exercise programme is recommended for Alphas with lung problems. These programmes include exercise, breathing retraining, education, dietary advice, and when necessary, help to stop smoking.

## **Health – Hygiene**

Studies have repeatedly confirmed hand washing is the best first-line defence against the spread of infection. Good hand-washing technique is not related to using an expensive antibacterial soap. The chief benefit of hand washing comes from the friction of rubbing your hands together and thorough rinsing.



Alphas who use nebulisers, inhalers and masks should pay particular attention to keeping the apparatus clean. Advice on how to do this will be written in the manufacturer's user guide.

Oral hygiene is especially important for users of inhalers and nebulisers. The active drugs and sometimes the propellants can irritate the gums, tongue or throat. Rinsing the mouth with water can stop this but if a problem persists then seek medical advice.

## **Health - Diet**

A healthy diet is an important part of optimising short term and long term health for Alphas. Eating a balanced diet provides us with the range of nutrients our bodies need and also helps maintain a healthy weight. Being a healthy weight (categorised as a BMI of between 20 and 25) can help reduce the risk of developing other conditions such as heart disease and diabetes but can also help your Alpha-1. Being underweight can increase risk of developing infections (including those of the respiratory system). Being overweight can put increased pressure on vital organs (including the liver and lungs) and therefore make them work harder. If you are concerned about your weight, speak to your GP who may refer you to a Dietician.

An important aspect of a balanced diet is dietary fats. There are different types of fats found in the diet and the balance of these is essential for achieving good health. Cakes, biscuits, takeaways, butter, cream, meat fat and poultry skin are examples of foods that are high in **saturated fats**. These fats increase the levels of cholesterol in the blood which collect on the inside of blood vessels and restrict blood flow to and from major organs. These foods should be kept as occasional treats. There are two main fats that are classed as good fats:

**Monounsaturated fats** can be found in olive oil, rapeseed oil and margarines made from these oils. They actually help to lower cholesterol levels in the blood and should replace butter, lard and dripping.

**Omega 3** fats help to protect the body by making the blood less likely to clot and can be found mainly in oily fish (salmon, mackerel, trout, sardines, pilchards, fresh tuna) but are also found in smaller quantities in other foods. As part of a healthy diet it is recommended that we should aim to eat one portion of oily fish per week in order to help protect our heart. It is worth

remembering that *all fats are high in calories*, even the good ones. Olive/rapeseed oil and margarines based on these oils need to be used sparingly for those who are wishing to reduce their weight.

Vitamins and minerals are essential nutrients that have many roles within the body. They help tissue function and structure, vision, bone strength, circulation, nerve transmission, metabolism and help prevent oxidative damage. A large proportion of vitamins and minerals can be found in fruit and vegetables. Eating five portions of fruit and vegetables each day helps ensure that we get sufficient quantities and variety of vitamins and minerals.



Examples of a portion are:

- One medium piece of fruit (e.g. apple, orange banana)
- Two smaller fruits (e.g. kiwi fruit, satsuma)
- A handful of berries or dried fruit
- A serving spoon of vegetables
- A bowl of salad
- One glass of fruit juice (150mls)

There is no need for vitamin and mineral supplements if you have a well balanced diet and reach your five a day for fruit and vegetables. High doses of certain vitamins and minerals can sometimes be dangerous.

## **Health – Help your Doctor**

If your doctor is not already aware that you are an Alpha then tell them immediately about your condition.

Since lung infections can be very serious for an Alpha they must be treated at the first signs. Even if the infection is caused by a virus there may be complications from bacteria and this can be treated by antibiotics.

A yearly flu vaccination is recommended for individuals who are at increased risk of complications from the flu; these include Alphas of any age. Additionally, it may be prudent for individuals living in the same household to have a yearly vaccination.

Ask your GP if he/she recommends a 5-yearly vaccination against pneumococcal viruses.



For more information please visit:  
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