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IAIN ARMSTRONG, PULMONARY HYPERTENSION ASSOCIATION UK CHAIRMAN

“Many of the people who live with the incurable lung condition Pulmonary Hypertension (PH) require supplementary oxygen as part of their treatment regime. I believe whatever the situation, whether it’s ensuring that you can maximise your own independence or taking a straightforward flight, no one ought to be saddled with a monetary yoke, not in our so called caring society.

Since its inception 10 years ago, the Pulmonary Hypertension Association UK (PHA-UK) has provided over £60,000 worth of grants to people living with PH to enable them to afford the ludicrously unfair charges levied by a significant number of airlines for the provision of supplemental oxygen whilst travelling by air. We could easily have doubled this amount if we had the financial strength to meet all the requests we’ve received.

Additionally and perhaps more significantly is the near £200,000 the charity has provided towards the costs of portable oxygen concentrators (POCs) that allow people with PH to carry on in their normal daily lives. It is incredible and, I believe, unacceptable that in the present NHS, individuals have had to fund their own ability to breathe.

Over the past two years we’ve mounted a concerted campaign, assisted and supported by our friends at the British Lung Foundation, to address the issues that face disabled passengers (estimated to be around 90,000 people across the UK) who require supplemental oxygen in flight. PHA-UK and its members are extremely grateful to the Equality & Human Rights Commission for their input and the 243 MP’s who have backed PHA-UK Trustee and Labour MP for Carmarthen West & South Pembrokeshire Nick Ainger’s call for an end to current practices operated by a large number of airlines towards disabled passengers who require supplemental oxygen in-flight via EDM 1444.

EDM 1444 *That this House recognises that patients with pulmonary hypertension, chronic obstructive pulmonary disease, muscular dystrophy and other conditions require supplemental oxygen when travelling by air; is dismayed that the vast majority of airlines operating in the UK currently charge passengers requiring supplemental oxygen on flights; applauds the work of the Pulmonary Hypertension Association, the British Lung Foundation and the Muscular Dystrophy Campaign to end the unfair financial impact of what is effectively a tax on the disabled; calls on all airlines flying from or through UK airports to allow passengers requiring in-flight supplemental oxygen to either bring personal oxygen equipment on board and use it, subject to necessary security checks, or to have supplemental oxygen provided for them by the airline, in both cases without charge; welcomes the recent decision by British Airways, Emirates and Cathay Pacific to drop all charges; notes that as of 1 May 2009 airlines in the United States of America will have to allow passengers requiring supplemental oxygen to be able to use their own portable oxygen concentrator free of charge; and urges all airlines operating in the UK to follow suit.*

The findings of our latest 'secret shopper' research exercise conducted by PHA-UK's members with 71 airlines underlines the urgent need for these practices to change:

- Two thirds of airlines would not allow our volunteer researchers to bring their own oxygen for use in- flight.
- Less than a quarter of airlines supply free supplemental oxygen.
- A quarter of airlines do not supply supplementary oxygen at all.
- Virtually every airline that provides supplemental oxygen to otherwise 'fit to fly' passengers and charges for it, levy's a different fee with prices ranging from £50 to £500 per trip, just to breathe.

I was particularly alarmed to learn of the widespread negative attitudes towards our disabled secret shoppers and the knowledge gaps of airline personnel. Sadly, all too often our researchers spent protracted periods of time 'on hold' and in some instances paying a premium rate for the privilege, speaking with an average of three different customer service staff and still not receiving the information they require. Alarmingly, in too many instances airlines were only prepared to share their supplemental oxygen policy, if our secret shopper had bought a ticket to fly first.

I believe disability rights are not about having different rights but equal rights and call upon all airlines that provide and charge for in-flight supplemental oxygen to follow the example of British Airways, Cathay Pacific, Thomson's and Emirates and drop these grossly unfair breathing taxes; for all airlines to allow passengers who require supplemental oxygen to be able to use their own supply and/or portable oxygen concentrator equipment in-flight and for the airline industry to urgently review and address the way they deal with disabled passengers especially, but not exclusively, people who require supplemental oxygen in-flight."



Iain Armstrong
Trustee and Chairman
Pulmonary Hypertension Association UK

WHY DOES AIR TRAVEL AFFECT PEOPLE WITH LUNG CONDITIONS?

Ninety thousand people in the UK currently need some form of supplemental oxygen due to lung conditions such as Pulmonary Hypertension (PH) and Chronic Obstructive Pulmonary Disease (COPD). People with such conditions are dependent on supplemental oxygen to improve delivery of oxygen and blood to the muscles and prolong life.

This requirement for additional oxygen is increased further during air travel due to the reduced air pressure in aircraft cabins – the air pressure in an aircraft cabin is lower than the air pressure at ground level and is like being at high altitude on a mountain (ie 6,000 to 8,000 feet). At such high altitudes blood oxygen levels fall in everyone and some people may feel a little breathless. In most people this has no health effect but for those people who already have low blood oxygen levels because of a lung condition this additional reduction in oxygen can cause increased breathlessness and discomfort.

People who can walk 100 metres on the level without needing oxygen, at a steady pace without feeling breathless or needing to stop, are not likely to be troubled by the reduced pressure in aircraft cabins. Those people living with lung conditions who cannot do this will need to investigate the options available to them during air travel with the airline they are travelling with and will need to get a certification from their GP that they are fit to fly.

There is no evidence to suggest the length of flight causes any extra risk in people with lung conditions such as PH and COPD – obviously longer flights may carry health risks for anyone, because of the health effects of long periods sitting without much exercise, and therefore all long haul air travellers should move about every hour or so to exercise their legs and reduce the chance of blood clots in the legs.

AIR TRAVEL – SUPPLEMENTAL OXYGEN OPTIONS FOR PEOPLE WITH LUNG CONDITIONS

Currently there are several options available to people with lung conditions during air travel, although availability and cost will vary dependent on the policies of the airline travelled with.

- Bring own portable oxygen cylinders – these are supplied on the NHS. However, there are limits placed on the size of portable cylinders that can be taken onto any airline and these generally only have around 2/3 hours worth of oxygen dependent on flow rate required and capacity of the cylinder.
- Oxygen supplied by the carrier – whilst quite a few airlines do give this option the cost per flight can be extremely high and as the PHA-UK secret shopper survey showed it can be very difficult to arrange. PHA-UK has contributed £60k of grants to its PH patient members who would otherwise not be able to afford to fly.
- Use own battery operated portable oxygen concentrator (POCs). These weigh on average about 5 to 25kg (dependent on the make) and provide concentrated oxygen from the air around the passenger and invariably can only be used if the passenger brings a pre-determined number of additional batteries. They provide about 8 to 10 hours of battery power and do work from a mains facility. These machines cost on average £3.5k to buy and haven't previously been available on the NHS. PHA-UK has provided £200,000 in grants to assist people with PH to purchase their own portable oxygen concentrators however because of the high costs and the charity's financial resources these grants are limited.

LEGAL REQUIREMENTS

The legal requirements vary across the world for the provision of supplemental oxygen on flights, for example:

- In the USA the Federal Aviation Administration (FAA) requires airlines to allow passengers to use portable oxygen concentrators from an approved list of 15 products
- The European Union states that airlines should transport medical equipment for passengers at no extra cost however many airlines interpret this as being in the baggage hold only.

This lack of standardised regulations across the airline industry makes air travel extremely difficult for people living with lung conditions.

PHA-UK 'SECRET SHOPPER' RESEARCHER REFLECTIONS

53 year old Jane Taylor from Berkshire was diagnosed with PH in 2006. “The information from airlines was very difficult to obtain, with only a few exceptions. Some of the Customer Service Representatives had no idea what I was talking about. I had people say they would get people to ring back but never did. The lack of knowledge by all was appalling. Even the special assistance teams lacked the information required. Most of them took longer than 20 minutes to find out the information”

55 year old Kathy Davis from Hampshire, who was diagnosed with PH in 2007, “There is a huge disparity between the airlines both in cost and the way they deal with potential disabled customers. Some airlines were very helpful; the people who answered the phone knew the answers to the questions or could transfer me immediately to the right person. Others were deliberately obstructive and would not give out any information until I had booked a flight and had the booking reference number.”

49 year old Bedfordshire mother of two Hazel Roberts has lived with PH for over three years. “I discovered that the variation in service is immense and getting the information from most of the airlines was quite difficult as in general you had to be passed to someone else, usually ‘medical support’ type people who only seemed to work certain, very limited hours or were on holiday, lunch break etc. Sometimes the person I was talking to didn’t know who to pass me to, on another occasion the airline put me on hold while they spoke to their head office, which happened to be in Sidney, Australia!”

60 year old Sonia Campbell from North London has diagnosed with PH in 2004, “I discovered that every airline had different policies/guidelines and prices. Some were fairly clear and others baffling. The final cost depending on journey could be high for a 2hour flight as for a 10hour flight. One required a passenger using oxygen to have someone flying with him/her. Another required you to buy an extra seat for the oxygen! I must add that the extra seat was at the price before added tax. Information given was based on the booking being made first which could cause problems. There were also restrictions as to how many oxygen using passengers can be on each flight. “

'Secret Shopper' Survey Results

SUMMARY OF RESULTS:

AIRLINE	CAN THE AIRLINE PROVIDE OXYGEN?	CAN I USE MY OWN OXYGEN?	CAN I USE MY OWN PORTABLE OXYGEN CONCENTRATOR?
<i>Adria Airways</i>	50EUR per sector	No	Yes*
<i>Aegean Airlines</i>	No	Yes	No
<i>Aeroflot</i>	No	No	No
<i>Aer Arann</i>	£72 per sector	No	No
<i>Aer Lingus</i>	£90 per sector	No	Yes*
<i>Air Berlin</i>	Yes - No charge	Yes	Yes*
<i>Air Canada</i>	\$150 CAD per sector	No	Yes*
<i>Air China</i>	Charge dependent on route and distance	Depends on carrier	Depends on carrier
<i>Air Europa</i>	No	Yes	Yes*
<i>Air France</i>	£180.50 per sector	No	Yes*
<i>Air India</i>	Information not available****	Information not available****	Information not available****
<i>Air Malta</i>	Yes - No charge	No	Yes
<i>Air Moldova</i>	Yes - No charge	No	Information not available****
<i>Air New Zealand</i>	Yes - depends on volume used	No	Yes**
<i>Air Southwest</i>	No	No	Yes**
<i>Alitalia</i>	Charge per segment + 2nd seat for O2	No	No
<i>American Airlines</i>	\$100 USD per sector	No	Yes*
<i>Atlantic Airline</i>	Information not available****	No	Yes*
<i>Aurigny</i>	No	Yes	Information not available****
<i>Austrian Airlines</i>	150EUR per sector	No	No
<i>BMI</i>	Yes - information on charge not available****	No	Information not available****
<i>British Airways</i>	Yes - No charge	No	Yes*
<i>Brussels Airlines</i>	175EUR per sector (4bottles + 125EUR)	No	Yes*
<i>Cathay Pacific</i>	Yes - No charge	No	Yes*
<i>Cimber Sterling</i>	No	Yes	Yes*
<i>CityJet</i>	Yes - No charge***	Yes***	Yes*
<i>Continental Airlines</i>	No	No	Yes*
<i>Cyprus Air</i>	85EUR per sector	No	Yes*
<i>Czech Airlines</i>	50EUR per sector	No	Yes*
<i>Delta Air Lines</i>	No	No	Yes*
<i>Eastern Airways</i>	No	Yes	Yes*
<i>Easyjet</i>	No	Yes	Yes*
<i>El Al Airlines</i>	£75 / \$150 per sector	Information not available****	Yes*
<i>Emirates</i>	Yes - No charge	No	Yes*
<i>Etihad Airways</i>	Yes - information on charge not available****	No	Yes*
<i>Finnair</i>	Information not available****	No	Information not available****
<i>First Choice</i>	Same policy as Thomson		
<i>Flybe</i>	No	Yes	Yes*
<i>flyglobespan</i>	No	Yes	Yes*
<i>Germanwings</i>	Yes - No charge	No	Yes*

<i>Gulf Air</i>	Yes - No charge	Yes	Yes*
<i>Iberia</i>	Yes - information on charge not available	No	Yes*
<i>Icelandair</i>	Yes - £66 per sector	No	Yes*
<i>Japan Airlines (JAL)</i>	10000 Yen / £66bottle	Yes	Yes*
<i>Jet2</i>	No	Yes	No
<i>KLM</i>	£125 per sector	No	Yes*
<i>Korean Air</i>	\$50 USD per bottle	No	Yes*
<i>LOT Polish Airlines</i>	£136 per sector	No	No
<i>Lufthansa</i>	300EUR Inter-continental 150EUR Continental	Yes	Yes*
<i>Malaysia Airlines</i>	£400 return	No	No
<i>Monarch</i>	£100 each way	Yes	Yes*
<i>Northwest Airlines</i>	No	No	Yes*
<i>Qantas</i>	Yes - £ depends on flow rate	No	No
<i>Qatar Airways</i>	Yes - No charge	No	No
<i>Royal Brunei</i>	No	Yes	Information not available****
<i>Royal Jordanian</i>	Yes – No charge	No	No
<i>Ryanair</i>	£100 per booking	No	Yes*
<i>Scandinavian Airlines - SAS</i>	Yes - 335 Euro Intercontinental 150 Euro other flights	Yes	Yes*
<i>Singapore Airlines</i>	Price depends on journey / proportion of extra seat	No	Yes*
<i>South African Airways - SAA</i>	\$150 USD per leg - 2L/4L charged at the same rate	No	Yes*
<i>Swiss International Air Lines</i>	Yes - 300francs or £183 per sector	No	Yes*
<i>TAP</i>	170EUR each way Europe 300EUR International	No	Yes*
<i>Thai Airways</i>	Information not available****	Information not available****	Information not available****
<i>Thomas Cook Airlines</i>	£100 each way on flights <5hrs	No	Yes*
<i>Thomson Airways</i>	Yes - No charge	Yes	Yes*
<i>TUIfly</i>	Same policy as Thomson		
<i>United Airlines</i>	\$125USD per sector	No	Yes*
<i>US Airways</i>	No	No	Yes*
<i>Virgin Atlantic</i>	Yes - No charge	No	Yes*
<i>Wideroe</i>	No	Yes	Yes*
<i>Wizz Air</i>	No	No	No

*airline has a list of approved models

**POC can be used subject to meeting size restrictions & must be switched off on takeoff and landing

***on some aircraft - check at reservation

****information couldn't be sourced at time of call(s) to airlines. Awaiting written confirmation of policy details from airline.

Methodology:

PHA-UK's researchers all live with Pulmonary Hypertension (PH) and were each provided with the verified contact details for the ticket reservation departments and a sample route for each of the airlines identified to fly from and to the United Kingdom. Fieldwork took place between the 1st of September and the 5th of October 2009.

ABOUT PULMONARY HYPERTENSION (PH)

- PH is a disease where the blood pressure in the arteries in the lungs elevates putting pressure on the heart, reducing the amount of oxygen that's able to reach the tissues of the body causing breathlessness & exhaustion. This can significantly impact on the patient's ability to lead a normal life. PH can often lead to heart failure. It can be a standalone condition or associated with other diseases.
- PH affects people of all ages including young children. It is twice as common in women as men and the commonest age at presentation is 40 - 50 years old.
- PH is often mistakenly diagnosed due to its similarities to asthma. People with PH experience a range of symptoms, the most common of which are breathlessness, dizziness, fainting, chest pain, palpitations and increased lethargy. These symptoms are described as "non-specific" which means it is quite difficult to diagnose
- With correct treatment and a faster diagnosis almost two thirds of PH patients will survive longer than 5 years, however if not treated, approximately half of PH patients die within two years
- There are currently approximately 4,000 people diagnosed as living with PH across the UK and it's estimated that there are a further 4,000 who are undiagnosed.
- There are 8 PH specialist centres in the UK, (4 in London with the remainder situated in Glasgow, Sheffield, Newcastle and Cambridgeshire) which provide expert diagnosis, treatment and management for PH patients on the NHS and are widely regarded as being the best in world.
- Although there is no cure, there are effective and relatively new treatments that can help people living with PH if they are diagnosed early in the disease progression.
- Heart-lung transplantation is a procedure offered to PH patients when all possible medical treatments have proved to be ineffective. The lungs can be transplanted without a new heart, but this type of transplant is not suitable for all patients. This treatment is limited by the availability of organs that are good enough to use. Sadly this means that some patients die whilst waiting for suitable organs.

ABOUT THE PULMONARY HYPERTENSION ASSOCIATION UK

The Pulmonary Hypertension Association UK (PHA-UK) charity number 1120756 provides support, understanding, and information for everyone whose life is touched by the incurable lung condition Pulmonary Hypertension (PH).

The Breathe Freely secret shopper airlines & oxygen research initiative is the second stage of a two year campaign mounted by the charity supported and assisted by the British Lung Foundation.

Now entering its tenth year, a concerted campaign by PHA-UK's 2000 members in 2008/9, hand in glove with clinicians at the PH specialist centres and their parliamentary supporters helped convince the National Institute for Health and Clinical Excellence (N.I.C.E) to withdraw draft guidelines that if implemented would have seen the withdrawal of a range of treatments that have no alternative and normally reserved for the sickest of patients with PH.

To find out more about PH and PHA-UK visit www.phassociation.uk.com

For details or comment on PH campaigns contact PHA-UK's Communications & Campaigns office: +44 (0)20 7272 3915/ media@phassociation.uk.com.

ABOUT THE BRITISH LUNG FOUNDATION

The **British Lung Foundation** is the only UK charity working for everyone affected by lung disease. The charity focuses its resources on providing support for people affected by lung disease today; and works in a variety of ways (including funding world-class research) to bring about positive change, to improve treatment, care and support for people affected by lung disease in the future. It provides information via the website www.lunguk.org and telephone helpline 08458 50 50 20.