



LAMPOST

LAM Action

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Summer 2008

Summer is here.....

Summer is here so am I trying to spend as much of it as possible in the garden. Seems like a lot of other people have been doing the same and so this edition of LAMPPost will be very short.

Those of you who were at the summer meeting (and it was great to see so many of you) will know that I stood down from the position of chair. It's been fabulous working for you all and we've seen some amazing progress in the last few years. I'm still going to remain part of the committee (you don't get rid of me that easily) but as I am now on the waiting list for a transplant I decided that it would be a good time to hand the role on. And can I just say that I am delighted the Gill Hollis will be taking over the reins. I've worked alongside Gill on the committee for a number of years now and know she will bring a whole host of skills and experience to the role. And it means I can prod her and say the chair really should write something for each LAMPPost.

Clare Lauwerys

Charity Event at Gateshead Metro Centre

Pete and Marie Hutchinson are organising a fundraising on behalf of LAM Action in the Gateshead Metro Centre (Blue Mall) on Monday 17th and Tuesday 18th November 2008. They are running a Charity Barrow in the blue sector selling seasonal homemade crafts and raising public awareness of LAM. Local LAM patients will be on hand over two days to staff the barrow and talk to the public who will have the chance to take away literature and souvenirs from LAM Action. Money raised will be donated to the work of our charity. If anyone (including families/friends) can either help at any time over the two days or who may be able to donate home made crafts for sale then please contact them on 07910825574 or e-mail details via the coordinator Jan Johnson. Unfortunately they cannot accept foodstuff for sale.

Travelling with LAM

Ever since Marie was diagnosed with LAM in 1990 we have travelled and taken foreign holidays. From the outset Marie made the decision not to fly and so our explorations were to take us in a European direction and by land and sea. In the early days Marie did not require oxygen as the condition had not progressed to that stage so travel was very much possible and over the years we embarked upon big multiple trips in our trusty estate cars from Newcastle upon Tyne to Austria, Switzerland, Slovenia, Finland, Sweden, Norway, Denmark, Holland and France. Often these trips would last up to 3 weeks to very remote areas including the Russian border areas on occasions. As long as Marie could rest along the way, we drove, camped and explored for many years. However time passed and eventually the LAM progressed to requiring oxygen, initially for a few hours per day then rising to 16 hours per day at present.

With the change in the regional oxygen delivery system in 2006 it became apparent that the new system could not allow for spontaneous travel if a supply was required and even planning well ahead in Britain using the Hoof system seemed a daunting prospect. As for foreign shores..... By now Marie had a supply of liquid oxygen at home with a Helios *plus* pack and a large concentrator supplied by Air Liquide, our local regional supplier, which we keep upstairs mainly for night time. Both were non starters for travel, the large concentrator cannot be lifted/carried and the liquid oxygen pack runs out after several hours. So in early 2007 we decided to bite the bullet and purchase a travel concentrator. There are several of these on the market and each individual will have different lifestyle needs if you are thinking of buying one, so do your research and companies will demonstrate at your home free of charge. The model we purchased was a 'Sequel Eclipse' from Pure O₂ based in Manchester,⁽¹⁾ and this had specific features we

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were looking for. i.e. can be carried or wheeled to car/hotel rooms, works from mains or car low voltage so can be used whilst driving and has it's own built in battery pack for using elsewhere. Supply is constant or pulsed. This allowed freedom again for Marie and is backed up by an initial two year guarantee and 24 hr replacement should it breakdown. To date it has covered holidays to Scotland, Wales, Holland and Mediterranean over several weeks, as well as overnight getaways on late bookings.

For 2008 we decided to extend our holiday portfolio even further afield and booked a Mediterranean cruise which coincided with my 50th birthday and this is the crux of my article. Initial research indicated we could use the concentrator in the cabin stateroom no problem although the company (Cunard)⁽²⁾ asked to have a quick visual inspection on arrival for health and safety of a portable appliance. Our chosen cruise was for two weeks leaving from Southampton on Queen Victoria during May and returning same place, thus avoiding flying. The car was left long stay at portside and Marie used the concentrator in the car on low voltage whilst we drove the 750 mile round trip. After booking, Cunard were absolutely brilliant and the company put us in touch with a local supplier called Bill Quantrill of OMEGA International Advanced Aeromed⁽³⁾ who supply Southampton cruise ships with oxygen. This allows even more freedom onboard and more importantly for all those shore excursions. Obviously you pay extra but the options were on this occasion; a supply of liquid oxygen for your cabin with a carry pack, a concentrator, a supply of small compressed oxygen cylinders with regulator set for variable pulse/constant flow as required. As we already had our travel concentrator Marie chose a supply of six small cylinders with backpack for her shore trips, which was partly chosen over the liquid oxygen option for budget reasons. Working between our concentrator and cylinders all eventualities were catered for. On arrival onboard we were met in our room by Bill Quantrill and the equipment was already delivered. He gave us an instructional demo then we were on our way.

As this was our first cruise holiday we did not really know what to expect but found the ship to be very user friendly for anyone with a disability or using wheelchair etc. Staff were helpful and friendly at all times and the shore excursions can be booked well in advance so that you can get trips to suite your needs. i.e. less walking, no climbing etc. Marie found her Oxygen supply to be perfectly adequate for excursions and managed good full days in Cadiz, Corsica, Rome, Sorrento/Pompeii, Malta, Gibraltar. We should have spent time in Tunisia also had they not crashed the ship in Malta's harbour!...but that's another story.⁽⁴⁾ The only comment we have with carrying a cylinder of course is that there is a trade-off between energy expended to carry and benefit gained from the Oxygen. We think it is in the holiday maker's favour and allowed Marie to bravely go where her LAM had not been before. Obviously pulling a concentrator around Pompeii for example is not possible. After this experience we can thoroughly recommend cruising as a way of travel for LAM patients and family/partners. We encountered no problems over a two week period apart from Marie being body searched at customs several times, as she tried to argue the case with open mouthed officials, as to why it would not be a good idea to put an Oxygen cylinder through the x-ray machine! All taken in good humour by both parties!

As a footnote we have used 'free-spirit.com'⁽⁵⁾ for holiday insurance for several years and they cover LAM no problem. Also it would appear cruise ships around Britain can be supplied with oxygen for your needs from local area suppliers at extra cost. Check this is the case with the cruise company for your exit port before you book and work costs into your budget. Our holiday was wonderful by the way, and the food...!

"Happy holidays".

This report reflects our own private experiences of getting around 'the system', others may wish to write in with their stories.

Pete Hutchinson.

References.

1. Pure O₂, The old Chapel, Manchester Road, Carrington Village, Manchester, M31 4BL, Tel:- 0870-7120202 / 0161-7762929. www.pocompany.co.uk
2. Cunard Line, Richmond House, Terminus Terrace, Southampton, SO14 3PN, Tel:- 0845-0710300. www.Cunard.co.uk
3. OMEGA International Advanced Aeromed, (Bill Quantrill) Tel:- 01273-308176
4. www.maltastar.com/pages/msrv/msfullart.asp?an=21112
5. Free-spirit travel insurance for pre-existing medical conditions. Customer services Tel:- 0845-2305000, (mon-fri. 8.00 – 18.00) www.free-spirit.com