

Q&A with John Wort, Chair of the UK Pulmonary Hypertension Physicians Group and Iain Armstrong, Chair of the PHA UK

23rd March 2020

Iain: Good morning John. I know you're one of the leading doctors at the Brompton Hospital and have been working in PH for many years. I know these are very strange times, but could you give our listeners some background as to why we're specifically speaking to you as a national perspective on the PH service?

John: I'm the Clinical Lead for pulmonary hypertension at the Royal Brompton Hospital, one of the designated centres, and I'm also chair of the national PH Committee. These are difficult times which have led us to co-ordinate our actions as the national service to help patients with pulmonary hypertension during this difficult time.

Iain: Just so people get to know you a little bit, how long have you worked in PH specifically?

John: Since 2006. After having done a PhD in pulmonary hypertension I was persuaded that this was the way to go and so I've been a consultant in PH since 2006.

Iain: I know that the government have some good advice. We've put some guidance on our website – what are your thoughts on that, do you think it's good advice?

John: I think the advice is very good actually. It's not an ideal situation at all but they give some very clear advice about how to self-isolate, and what to do if you're on your own in a home or you share your house with other people, how to manage your day-to-day time, how to avoid unnecessary contact but still live and do things. There's also advice about how to stay healthy – it's very important for instance that people still find ways to exercise, do hobbies that they enjoy and to eat healthily. They also tell you how to get your food and give advice for people who might be caring for you and living with you to make sure that they know what they need to do. For instance, washing their hands a lot, keeping a certain distance.

But it's not like being in prison – it's not nice to have to do all this but it's still not like being in prison and so I'd say look at this website which is linked from the PHA UK website and there's some very good information. Furthermore, I was very impressed with their links to advice about exercising but also Every Mind Matters, which gives advice about how to cope with staying at home in terms of mental welfare and tips on anxiety. I know there are also some very good links to that on the PHA UK website and on Anxiety UK's website including links to exercise.

Iain: I know that physiotherapist Carol Keen has given some good advice for keeping as physically fit and well as you can at home during this difficult time. It's one thing being physically fit to fight a bug but as you rightly mention, the mental and emotional wellbeing is vitally important.

John: Absolutely, it's vital that we all look after ourselves especially our patients and there's some very good information out there on how to cope with this situation.

Iain: I think that information is relevant to friends and family as well as PH patients themselves.

John: Absolutely and they'll be worried all the time that they're going to give this virus and there's some very good information on how to protect patients but also how to cope with the anxiety that is going to be associated with looking after people who have PH.

Iain: If somebody is at home with PH and was to develop signs such as a high temperature or sore throat, is the advice still the same for those people as for everyone else?

John: Yes, the advice is that if you think you might be developing coronavirus you should use the 111 NHS England line or look at their online advice and take that advice. That's your first port of call and then once you've done that, there's lots of information on the PHA UK website and on the websites of the PH services. Clinical nurse specialists will of course be there to answer questions as well, but I think it's very important to use the NHS 111 links first.

Iain: I think that is crucial because while there are the nurse specialists and doctors at the centres, what we've got to avoid is suddenly swamping them with lots of calls and they would then be redirecting you back to the places we've mentioned. Not forgetting their own GP service as well, that's where it's going to need to be managed. It's about protecting the specialist centres because they will already be very busy anyway.

Can we concentrate now on the national service and how people with PH can be reassured during this period of time?

John: The first thing to say is please do not think that we will be abandoning you. We will have to change the way we work over the next few months but we're talking to each other to try and develop a new way of working for the next three or four months. This will inevitably mean that we won't see patients in clinics face-to-face but we are all developing telephone and video conferencing to get over that and in fact we hope we might be able to do that in a more frequent way because people will be more worried about the current situation.

We won't be able to do as many investigations – that might come as a relief to many people. For instance, if our current patients feel a bit more breathless and are admitted for a host of investigations, we might have to limit what we can do and think about the most likely thing that might be wrong and try and work with that empirically. That means using all the expertise that we've been talking about for many years. A lot of the time we know what the situation is and we do the tests to confirm them but I think we are going to have to go with our clinical expertise in a lot of cases and then treat accordingly. There will still be situations where that isn't possible and we will need to see patients, and we will still be able to do that. We're just going to have to cut it back to patients who we think really need it, but that will still be available.

Iain: In this period of time, are the centres themselves talking to each other and working together?

John: We're having weekly telephone conferences to determine how we're going to manage this situation and we're talking, taking advice and coming up with some documents to show to the government about how we think we should deliver this service nationally during the period of the COVID infection. Over and above that we've had emails, texts and WhatsApp and there's traffic

going back and forth daily. As you said earlier, things are changing daily in terms of the government advice so we're reacting to that daily and we're adjusting what we need to do. So it is a very dynamic process but we are very much reacting and thinking how we can best treat our patients and manage this situation.

Iain: What about people who have recently been referred to a specialist centre?

John: One of the things we've been looking at is using our expertise and information given to us by referring doctors, I think we can be pretty sure about the diagnosis in many cases and we do the test to prove it. So I think we've all agreed that we do not need to do all the tests necessarily – we use the ones that we think are the minimum that we need to make the most likely diagnosis and we will treat accordingly. I think the bottom line is if we think during this period someone really needs treatment, we will find a way of giving the treatment. We're screening all the referrals, we're prioritising them, we're saying if it looks like someone we need to get on treatment, we will get them on treatment regardless of the coronavirus. It might not be exactly the same way as we would do it in calmer times, but we will get them on treatment, and we won't just hope that everything is okay in three or four months' time.

Iain: So it's about doing things in a different way. We have a brilliant service in the UK for PH with lots of collaborative working across the service with people in different centres so people will be reassured, and this is probably the biggest test for that service. We've grown in the last 25 years from nothing to where we are now so that's a point of reassurance don't you think?

John: Absolutely – I was on a call last week and we were talking about what would happen if people in the service got sick and it got to a point where we couldn't run the service very well and patients needed to be seen? Straight away everyone said, 'we'll look after them', so even if one service gets hit hard, and I hope that doesn't happen, there will be another service that will take it up. Just because you might be associated with a particular service doesn't mean that another service won't be able to help you if everyone in your service comes down with coronavirus.

Iain: The evidence is strong that if we can flatten this curve, we can avoid lots of the same people getting it at the same time.

There are lots of stories around about the coronavirus, some are scary, and some are not. How can you point people to the best advice?

John: There is a lot of scaremongering and there's just a lot of information out there. One thing I would say straight away is limit the time you look online and listen to the news about coronavirus because it makes people very anxious. Again, there's advice about how to manage all this bad news that's coming in and it's really important not to keep checking. Maybe limit it to specific times when you check on how things are doing but also use the official sites – the PHA UK, government and PH service websites all have excellent up-to-date information. I wouldn't go onto Google because you'll find something absolutely awful and it will scare you and it's not necessarily true.

Iain: That's really helpful. We may come back to you in a few weeks if that's okay?

John: I'd love to do that – I'll look forward to it.

