

PCD Day 2020 Q&A Transcription:

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UPDATE ON FACEMASKS

It was widely acknowledged at our AGM that guidance around wearing facemasks is likely to evolve as more becomes known about Covid-19 and as governments update their advice.

A further conversation with some of the PCD specialists after the AGM confirmed that:

- People with PCD should definitely wear facemasks if visiting hospital or GP.
- Once adults with PCD have come out of shielding, they should endeavour to wear face masks in places where social distancing is difficult. If outdoors exercising alone, this is not necessary, though it may be wise to take one with you in case you find yourself requiring one.
- As more becomes known about the virus, there is increasing evidence that wearing a mask could be *protective* for the individual. Wearing a mask is certainly useful in helping cut down community spread.
- A homemade mask is better than nothing. If making a homemade one, 3 layers is best and ideally from manmade fibres. Universal fluid-protect masks are considered the best and may be bought from places such as Amazon and Boots.
- Please contact your PCD centre for specific and personalized advice. The vast majority of PCD centres will be unable to supply you with facemasks.

1) Can PCD patients take part in the Oxford Covid-19 Vaccine trial?

Dr Daniel Peckham: This would not be advisable as testing should involve healthy volunteers. However, once trials are complete and a vaccine is proven safe, then those with lung disease would be among the first to receive the vaccine.

2) Realistically, are we looking at shielding for PCD patients until we find a vaccine?

Dr Daniel Peckham: We need to start moving on and coming out of shielding but be very sensible. However, if we start to see an increased prevalence of Covid-19, then we'll need to move back into shielding. Being sensible means wearing masks in appropriate situations, observing distancing wherever possible and not putting yourself at risk. If you're going back to work, ask if it would be possible for you to work from home or check if your workplace has been assessed for compliance with Covid-19 rules. The risk, as has been seen with images of packed beaches, comes from other people. Coming out of shielding, we must continue to be very sensible in our actions and habits.

3) With regards to facemasks, what are the best ones to use and how do we obtain them?

Dr Mary Carroll: It's unclear where you can source the best facemask, however any facemask is better than nothing. I advocate people do wear facemasks. I would look to your PCD Service to help with supply of facemasks and would say surgical facemasks are the best. You need a mask that can clip to your nose and go over your ears and under your chin. Best to have a disposable single-use mask. If you make your own (lots of tips online!) remember that this also should be single use – pop it into a plastic bag and then take it home to put it in the washing.

4) Should schoolchildren be wearing facemasks?

Dr Woolf Walker: I would expect clearer guidance on this over the summer ahead of the wider return to school in September. It's a balance. Face masks are clearly helpful but, depending on their grade, may mainly offer protection to others, as oppose to the wearers themselves. The difficulty is that it may cause some stigmatisation if PCD children wear them and others don't. On a practical level, PCD patients have their runny noses and cough a lot which will soil the facemask over the course of a day, so close-at-hand spares may be required. It's possible that a decision on the wearing of facemasks in schools may be down to individual schools, rather than a universal policy. For schools who request all students where facemasks from September, I would certainly agree with this. For schools who don't

request students wear facemasks, I would hope to be able to offer more guidance prior to September on whether PCD patients who are students should still wear a facemask.

Further comments

Dr Simon Range:

(NB This response has been edited by Dr Range for clarity)

There are two reasons for wearing a facemask. The primary reason is for the protection of others, so you reduce droplet spread of infection by having a covering over your face. In that context what you are wearing isn't as important as the fact that you ARE wearing something. It is not necessary to wear a medical-grade face mask for this purpose. In general terms, more than one ply is better than single ply. Something that is man-made is better than cotton, with the most important factor being a tight weave. The second reason to wear a mask is to protect the wearer. There are 4 main grades of medical mask Surgical masks do a similar job to cloth masks in reducing the wearer spreading infection, with some additional protection for the wearer against breathing in larger droplet particles. FFP1, FFP2 (N95 in US), and FFP3 masks are more effective masks, which in addition to the above provide increasing protection against the wearer inhaling small particle aerosols. FFP3 giving the best protection. These masks are more expensive, uncomfortable to wear, and are more-effective if 'fit-tested'. Some masks have a one-way valve, so something can come out but not get in. This would be useless in terms of protecting others as the valve simply focuses what is coming out of the mask like a jet and could therefore infect the person being faced. It should also be noted that the way you use a mask is very important: Most are single use, and care should be taken when putting on and removing masks, as the outside of the mask may be contaminated. It is best practice to wash or sanitise your hands before and after taking masks off.

In summary, some sort of facemask when you are out and about to protect you and others would be advisable, especially when indoors.

Dr Daniel Peckham: The wearing of masks does send out a notice of caution to other people, especially if you are in busy more urban areas, who might then keep more of a distance. I think it's also really important to stress that people should enjoy their lives, especially if there are no other people near you. If you are in the country, you will not catch Covid-19 from sheep or cows, you will only catch it from other people! So, you shouldn't feel the need to wear a facemask at all times in all places.

5) What should the approach be to participating in sports e.g. gymnastics and at gyms for the PCD Community?

Dr Manjith Narayanan: We don't yet have clear evidence. The key is to be sensible. When gyms reopen, they will be Covid-19-assessed e.g. with distance between users. Science will determine when indoor spaces will reopen – they are currently seen as higher risks for community spread than shops and restaurants. When they do reopen, expect the same sorts of distancing rules as are being set up for shops and restaurants.

6) Is someone with Kartagener's Syndrome with mild Bronchiectasis and no regular treatment apart from daily airways clearance at greater risk from Covid-19?

Dr Simon Range: In short, no. The reason people with chronic diseases are shielded is because if they do catch Covid-19, the chance of it developing into a far greater problem for the patient is increased. Shielding represents a cautious approach which is appropriate while we don't yet have the accurate science and understanding of individual levels of risk to look at people and their conditions on a case by case basis.

7) If, as a PCD sufferer, you think you are showing early symptoms of Covid-19, what advice would you give to prevent worsening health?

Dr Simon Range: The symptoms of Covid-19 can range from nothing to being very severe. This can make it very hard for you differentiate between a flare-up from your own condition and Covid-19. You look at an individual's circumstances e.g. if that person has been shielding for the last three months, the chances of them developing Coronavirus is very low. We encourage everyone has a rescue package of antibiotics or whatever else they use to start using as you would normally, should you develop any symptoms. It would be wise to increase the frequency and depth of your chest clearance, maximize your fluid intake and take paracetamol if you have a temperature. Think about infection control and not infecting others. If things deteriorate, especially with an increasing level of breathlessness or persistent temperature, you should seek further medical advice.

8) How should someone displaying PCD symptoms be treated when they have a diagnosed glue ear?

Dr Manjith Narayanan: The key thing is the effect of the glue ear on the child, rather than the glue ear itself. For children with PCD, a grommet is unlikely to leave an eardrum that heals well. So, there has been an ENT reluctance to fit grommets for those with a background of PCD. We concentrate on the preventative aspect of glue ear alongside the effect of hearing aids. We know that nasal rinsing can help the middle part of the ear to be clear from fluids.

9) Are Doctors concerned about the reduction in social distancing in England to 'one metre plus' and the impact this may have on kids returning to school?

Dr Woolf Walker: The further you can stay apart, the safer you will be. Risk increases the closer you are to someone and the longer you stay in that close contact. That said, the data suggests the risk of Coronavirus to children is far less than the risk to adults. We should also be pragmatic about this going forward. Schools will return to some sort of normality and if we keep to the two-metre distancing, education will suffer, so there's lots of balancing to be considered and no clear-cut answer. My advice to schoolchildren is that if you can stay two metres apart, that would be preferable, but if you can only manage one metre distancing in your school, that should be fine. We do need to keep monitoring. So, if we find there's an increase in infections during the one metre plus ruling, then we would need to reflect and possibly increase the distancing.

10) Is the Northern event ending?

Lucy Dixon, PCD Chair: We've had to cancel all our events this year because of Coronavirus and we do have to think in the long run how we gather because of the risk of infections. So, it may be that we have to run virtual events until it's safe to get together again. I should stress that it's not just the Northern event which has been cancelled, all events have had to be cancelled in the current climate.

11) How can parents navigate the possibility of children being sent home from school for displaying Covid-19-like symptoms?

Dr Woolf Walker: I think it's really important for the school to have a clear understanding of what the baseline symptoms for that particular child with PCD is (which will vary from child to child). Some will have more of a cough than others. Care needs to be taken for the school not to confuse a PCD cough with Coronavirus. The key is that it's not just about how the child with PCD presents, because that is their baseline, it's a change in those symptoms which is the important factor. So, parents / carers need to take some responsibility noting any changes, as well as schools. Parents and PCD centres should also take some responsibility with children moving up to new classes where new teachers will be less aware of a child's baseline symptoms.

(On facemasks): I'm not sure that PCD Centres will have access to lots of facemasks to distribute to their PCD patients. I would suggest patients make their own in the first instance and if more become available, then we would let you know.

12) With Vestibular Dysfunction often being misdiagnosed or overlooked, will we see Vestibular Dysfunction added to the list of issues associated with PCD and will diagnostic centres and support groups raise awareness of the possibility that Vestibular Dysfunction can affect those with PCD?

Dr Daniel Peckham: I think things are developing. I think we are going to become much more aware and processes will standardise as we integrate and develop services moving forward. We are much more likely to really understand all the different aspects of PCD as we become larger and more united across Paediatrics and Adult Services and we also bring in experts from other fields outside of respiratory medicine as we have done successfully with the treatment of Cystic Fibrosis.

13) A physio who has PCD and who has also now contracted Coronavirus is also now suffering with Costochondritis (sharp chest pain). Is this likely to go away?

Dr Simon Range: We're not aware of Costochondritis being a particular part of the Coronavirus syndrome, but we are still learning much about the virus. I imagine it's a secondary effect from the coughing and the increased work of breathing in which case it should, in theory, settle down. What's important is to continue where possible with your daily chest clearance physiotherapy. If this is not possible due to pain you should contact your PCD Team.

Further comment from Lynne Schofield, Highly Specialist Physiotherapist: We're starting to see more breathing abnormalities with Covid-19 patients where they are using their respiratory muscles differently because they've become quite breathless with Coronavirus. This can make the chest work in a slightly different way which can then cause some aches and pains. Costochondritis can be quite common with these abnormal breathing patterns. So, it may be worth this patient being reviewed by a Respiratory Physio to take a look at their breathing pattern. We know that breathing patterns among PCD patients can be a little different if you have a really bunged-up nose. Keeping the nose clear can help with normalizing that.

14) If I've had a positive test for Coronavirus, can I get it again?

Dr Simon Range: We don't know with any certainty! It's likely that if you've had a positive test for Coronavirus and a positive antibody test, then you will have a degree of immunity. What we don't really know is how much immunity you will have and how long that will last for. For other Coronaviruses such as SARS, immunity has appeared to be fairly long-standing whereas with a common cold caused by other coronaviruses, immunity is relatively short-lived.

15) I have two children with x-linked RP Retinitis Pigmentosa with sino-respiratory infections on a known PCD gene. Will there be more research into this linked form of both conditions?

Prof Jane Lucas: We have a research programme looking at RP and PCD in Southampton, so if people contact me directly, I can put them in touch with the scientist leading on this. This is on-going work and we'd be happy to have you involved!

16) Are there any virtual groups where children can chat socially about their experiences and daily life with PCD?

Lucy Dixon, PCD Chair: At the moment no there aren't due to the safeguarding issues with having children in a chat room. But definitely going forward, we are really going to have a good look at how we can keep our PCD family better connected. We realise this is very important and we are thinking actively as to how we can achieve this.

17) Do the PCD Adult Service providers have any advice for those having to travel to work on public transport? (questioner commutes from Leicester to London)

Dr Mary Carroll: I think there's no doubt that public transport is tricky, especially when it's so crowded which might well explain the peaks in Coronavirus seen previously in London. I can't say this isn't a concern. I can only suggest you travel very early in the morning, but this still represents a concern.

Further comment

Dr Simon Range: If we could get them, this might be a case where wearing the highest grade FFP3 surgical facemask would be appropriate because that would give you protection. The challenge is that if you can source them, they cost approximately £15 each. Remember, they are also single use so you would need two to cover a return journey. I would also suggest some form of eyewear. You should wash your hands and not put your hands on your face. Plus, you should carry alcohol gel with you. There's no real benefit to wearing gloves if you are washing your hands well.

18) Is there research currently being undertaken regarding female fertility and if so, how can someone become involved?

Dr Daniel Peckham: I know there is research going on in London and I think this is an area which is going to gradually expand. I think the important thing is knowing and understanding the genetic mutations.

Further comments

Fiona Copeland, former PCD Chair: There is some research at Imperial university in London about rare diseases and fertility, so we've been encouraging them to include a PCD focus, although this research has centred more on male fertility.

Catherine, PCD Australia: I know someone in Australia (presumably a PCD patient) who has had two children through IVF but has been told she is unlikely to conceive naturally due to low egg-count and is expected to go in to early-onset menopause at age 32. So, I wonder if there is any link?

Fiona Copeland, former PCD Chair: A plus side about our PCD adult service is that we are going to be seeing more adult patients, so we'll be able to collect this data. Anecdotally, we know of some PCD patients who have had children naturally and some who had children through IVF. So, we should start to see much more evidence via the PCD services now we have everybody being cared for by their teams. Already, through our paediatric services we are learning how different children react to PCD. Dr Wolf Walker has done some work on the link between BMI and lung function in PCD children. Going forward as the adult services develop, we will start to see this sort of evidence and data in adults to know the approximate percentages of adults with PCD who have conceived naturally or through IVF.

19) What is the clinical view of the government shielding letters (which extend shielding in England until August 1st) being sent to advise parents of children with PCD?

Dr Woolf Walker: The government sent out letters automatically to everyone who had been shielding. Whilst we agree with the advice for adults continuing to shield, we don't advise this for children. So, from June 30th, we are comfortable with children no longer needing to shield. We are happy to give this different advice in line with that given to those with other respiratory illnesses because the evidence for risk to children is different to that of adult risk from Covid-19.

Further comments

Dr Manjith Narayanan: This advice also mirrors the Royal College of Paediatrics and Child Health Guidance in cases of respiratory disease.

Dr Priti Kenia: Some patients may receive the letters directly from the government depending on whether their GPs or PCD Centres have nationally registered them. There should also be individualised letters as appropriate coming from the PCD Centres confirming that children can be de-shielded.

Dr Woolf Walker: It may be that some PCD patients should continue to shield. Those patients will be contacted by their local PCD Centres.

Lucy Dixon, PCD Chair: Remember, for adults who are shielding there are different dates to end shielding depending on where you are. For example, in England it's August 1st whereas in Wales it's August 16th. So do make sure you check if you're an adult with PCD.

20) I participated in the 100k Genome Project two years ago but I am yet to receive any results. How can I obtain the results?

Prof Jane Lucas: The first thing to do is to return to the person / department that took the blood from you or whoever referred you to the 100k Genome Project. If the Project has easily identified genes for you in the 'clinical area' then that result should be available to you. What complicates this is that a lot of people in that clinical area haven't been identified and therefore have gone into a 'research area'. As a result, it's only if someone is doing research in that area of the 100k Genome Project that your mutations might be picked up. Across the UK, we've had several meetings of people who are doing research. In Southampton, for example, we're looking at all of our patients who didn't have anything picked up by the 100k Genome Project or who only had one mutation picked up and we're actively looking for others in the research areas. But this is going to take time as research is dependent on funding which is very limited.