

Questions You Could Ask Your Respiratory Specialist

Background

Lung disease can occur in patients with Alpha-1 antitrypsin deficiency due to a lack of circulating antitrypsin which would normally protect lungs from inflammation and disease. Several respiratory diseases have been reported in Alpha-1 patients including: emphysema and chronic bronchitis (often referred to as Chronic Obstructive Pulmonary Disease - COPD); tracheobronchomalacia (TBM); bronchiectasis; bacterial and fungal disease; and lung cancer.

Lung Disease Questions

- ❖ Do I have COPD?
 - What type of COPD do I have e.g. emphysema, chronic bronchitis, other?
- ❖ Is my COPD mild, moderate or severe?
- ❖ Can I stop or slow the progression of my emphysema?
- ❖ Is COPD reversible?
- ❖ Do I have asthma?
- ❖ Do I have bronchiectasis?
- ❖ Do I have tracheomalacia or tracheobronchomalacia?

Questions about Tests

- ❖ What tests do I need to confirm any lung diseases / to monitor my lungs / disease progression (e.g. low-dose or high dose chest CT, MRI, spirometry, sputum)?
- ❖ How will I track the progression of my lung disease over time?
 - How often should I have these tests?
- ❖ When and why would I have a bronchoscopy?
- ❖ If I have COPD, how often and how would you check for lung cancer - which I believe is a risk associated with COPD?
- ❖ Should I have a sleep study?

Treatment

- ❖ Would I benefit from a daily inhaler e.g. short-acting and/or long-acting bronchodilator; steroid inhaler or combination inhaler?
- ❖ What procedures are available to manage my airway / lung symptoms or disease?
- ❖ Am I a candidate for a bullectomy, bronchial rheoplasty or endobronchial valves?
- ❖ What are the best strategies to manage my symptoms e.g. daily coughing up sputum, fatigue, sleep disruption?
- ❖ Should I be on weekly low-dose antibiotics?
 - Should I keep emergency antibiotic and/or steroids on hand to use if needed as part of this plan?
- ❖ Am I a candidate for augmentation therapy?
- ❖ Does the PBS/ cover any lung treatments for Alpha-1?
- ❖ Do I need supplementary oxygen?
 - When would I be considered for supplementary oxygen?
 - In regard to home oxygen, what government assistance is available / forms need to be completed?
 - Can I travel with supplementary oxygen?

- ❖ What clinical trials for lungs / Alpha-1 are in Australia for which I might be eligible?
- ❖ Should I be doing daily airway clearance? If so, what devices / treatment do you recommend e.g. should I be using a positive airway pressure device (PEP) or nebulising saline and if so what strength?
 - Is 6% hypertonic saline available on prescription from the local public hospital, for nebulising?
- ❖ Will biologics help me? If yes, how and where would they be administered e.g. home / doctor's rooms?
- ❖ What should I do if I am coughing up blood or have a sudden bleed from my mouth?
- ❖ What treatment can I have for severe lung disease if I am struggling to breath and having panic attacks?
- ❖ Based on my sleep study results would I benefit from a CPAP or BIPAP machine?
- ❖ Should I have a COPD ACTION PLAN? [COPD Action Plan - Lung Foundation Australia](#)

Lifestyle

- ❖ Should any foods be eaten or avoided?
- ❖ What daily activities / exercise should I be doing?
- ❖ Should I be attending pulmonary rehabilitation?
 - Where can I access pulmonary rehabilitation?
- ❖ Should I have a referral to a pulmonary physiotherapist?
- ❖ Would any supplements help symptom management or limit disease progression?
 - Are there any foods or supplements that I should avoid?
- ❖ What else can I consider to maximise my lung and airway health e.g. in addition to minimising exposure to irritants?
- ❖ Are there environmental or occupational exposures I should avoid (e.g. pollution/ careers with high exposure to pollutants, seasonal risks)?
- ❖ What vaccination programs should I participate in (e.g. COVID, RSA, pneumonia, influenza/flu)?
- ❖ Would I be eligible for disability/ home care support funding - and if so, can you assist my application to access this?

Lung Transplant

- ❖ Do I need a double lung transplant?
- ❖ When would I be considered for a double lung transplant?
- ❖ How long would I be on the transplant list?
- ❖ Where / at what hospital would I have the transplant?
- ❖ What medication will I be on before transplant?
- ❖ What medication will I be on after transplant and for how long?
- ❖ How long would I be in hospital following the transplant?
- ❖ What food / supplements / medication do I need / need to avoid post-transplant?
- ❖ What is my life expectancy?

Information and support

Alpha-1 Organisation Australia. Email contactus.a1oa@gmail.com

Lifeline Australia 13 11 14.