

PR Network Meeting November 2022 Minutes

Long Covid and Pulmonary Rehabilitation: Reflections and Guidelines

- Date:** Tuesday 15th November 2022
- Time:** 1:00pm to 2:00pm AEDT
- Location:** Via Video or Teleconference only using Zoom details below
- Invitees:** All Pulmonary Rehabilitation Network Members
- Meeting Chair:** Professor Jennifer Alison (JA)
- LFA Reps:** Emma Halloran (EH)
- Video Recording:** <https://www.youtube.com/watch?v=Yy5l4PZkNJg>

Meeting Minutes

Welcome and acknowledgement to country

Jennifer Alison opened the meeting with an acknowledgement to country and a summary of the meeting agenda.

The PR Toolkit – Jennifer Alison

- Jenny provided a walkthrough of the Toolkit that has recently undergone a major review and re-design.
- The new Toolkit includes evidence for other patient cohorts as well as COPD including Lung Cancer, ILD, Bronchiectasis and Pulmonary Hypertension.
- The Toolkit is broken down into six sections including Getting Started, Patient Assessment, Exercise Training, Patient Education, Patient Re-Assessment and

Additional Resources. Each section has a resources sub-tab which contains downloadable resources.

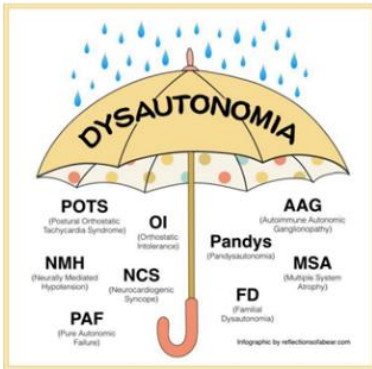
- The Patient Assessment section has an exercise capacity section which includes details on a variety of assessment options. The Quality-of-Life section includes suitable questionnaires for specific lung conditions including Pulmonary Hypertension, ILD and Lung Cancer.
- The Exercise Training section includes sections on endurance and strength training for Lower Limbs, Upper Limbs, as well as Flexibility and Balance exercises.
- The Patient Education Topics section includes downloadable resources on 13 different Education Topics.
- Jenny acknowledged [the panel of clinicians involved](#) in the clinical reviews, the Lung Foundation's support from Emma Halloran and the translators who volunteered their time to translate the entire site into Chinese.

View the Toolkit [HERE](#)

Long Covid – Jennifer Alison

- Jenny provided an update on the guidelines (specifically the WHO guidelines updated in Sept 2022) for supporting patients with post-COVID 19 syndrome (Long -COVID) (i.e. those whose symptoms persist for more than 12 weeks and are not explained by an alternative diagnosis).
- Symptoms can include, fatigue and weakness, anxiety/depression, brain fog (cognitive impairment and confusion), breathlessness/chest pain and tachycardia.
- There are some caveats around whether exercise rehabilitation can help with this group or not.
- Jenny provided some useful documents that have guidelines on caring for this cohort of patients including the [World Physiotherapy response to Covid-19](#), the [WHO clinical management of Covid-19](#) and the [NSW guidance for clinicians around the post Covid management](#).
- The World Health Organisation (WHO) provided updated guidelines in September 2022. They are using GRADE (Grading of Recommendations, Assessment, Development and Evaluation <https://www.gradeworkinggroup.org/>) to evaluate the strength of evidence for each recommendation. In adults with post COVID-19 condition exertional desaturation and cardiac impairment following COVID-19 should be ruled out and managed before consideration of physical exercise training. While orthostatic intolerance and post-exertional symptom exacerbation (PESE) are amenable to rehabilitation, their presence will require interventions to be modified in view of these diagnoses for rehabilitation to be safe. (Strong recommendation for)
- Interventions need to be modified for certain individuals. If there is a worry about pulmonary embolism then the patient can be sent for a CT pulmonary angiogram. There are some questionnaires to use for patients with Post-Exertional Symptom Exacerbation (PESE) including the DePaul Symptom Questionnaire.

- For patients experiencing PESE, the WHO recommends the exercise is titrated below the level of symptom exacerbation. Graded exercise training may be detrimental for this group.
- Dysautonomia is a term that has gained profile through Covid and can include Orthostatic intolerance and POTS (Postural Orthostatic Tachycardia Syndrome).



- The WHO recommends that for the clinical rehabilitation management of orthostatic intolerance in adults with post COVID-19 condition using a combination of education and skills training on self-management strategies and, **in the absence of PESE**, physical exercise training. Environmental modifications may be useful to support activities of daily living for people experiencing difficulties with upright positions or standing.
- For the clinical **rehabilitation management of fatigue in adults with post COVID-19** condition WHO suggest using a combination of education, skills training on energy conservation techniques such as pacing approaches and, in the absence of PESE, a cautious return to symptom titrated physical exercise training. The provision and training in the use of assistive products and environmental modifications may be considered for people experiencing levels of fatigue that limit instrumental activities of daily living. Psychological support may be offered to support coping with the symptom.
- For the clinical rehabilitation management **of breathing impairment in adults** with post COVID-19 condition WHO suggest using a combination of education and skills training on self-management strategies such as nasal breathing and pacing approaches and, in the absence of PESE, physical exercise training. Breathing control techniques could be offered to those presenting with a suboptimal breathing pattern, and psychological support may be useful to address contributing factors such as anxiety.
- In summary, we need to be careful with screening, not everyone will have PESE, orthostatic intolerance or POTS but need to check for these. There needs to be an individualised rehabilitation based on assessment and a continued monitoring of response.

View Jenny's slides [HERE](#).

A lived experience of managing patients with Long Covid - Janet Bondarenko and Mel Chong Alfred Health Melbourne

- The Alfred have been supporting patients with Long Covid symptoms throughout the Covid period.
- Patients are experiencing dysfunctional breathing, Fatigue and Postural Orthostatic Tachycardia (POTS).
- They are using additional assessment tools including the breathing Pattern Assessment Tool, The Fatigue Assessment Scale and Sit to Stand for patients with symptoms of POTS to assess heart rate.
- Fatigue is a big symptom with post COVID patients. Exercise intensity is adjusted depending on the severity of fatigue and they are monitored for post exertional malaise before progressing exercise. Patients with severe fatigue may not be suitable for exercise rehabilitation.
- There are training modifications for patients with POTS to avoid symptom triggers. Patients start with low level horizontal exercises or recumbent exercises. Swimming can be beneficial for this group as they are horizontal, and the water pressure may help.
- The mean age of the people seen is 56 years. 58% female. More people participate with Home-based programs with only one third attending the centre. On baseline assessment a third were desaturating below 90% but patients seem to have a well-preserved exercise capacity. There were some significant improvements in symptoms such as fatigue and mastery as a result of rehabilitation.
- Mel provided some case studies of three patients who had completed Pulmonary Rehabilitation at the Alfred.
- **Patient A** 50-year-old male with Long Covid who had had a long stay in ICU as a result of Covid. Prior to Covid he was fit and could run 7-10 km regularly. He was screen in November and commenced rehabilitation in January 2022. He attended a tele-rehab program run on Zoom that ran twice a week. He completed 13 sessions. In the first session he achieved two sets of 15 minutes cycling on an exercise bike. He could manage a two-minute jog with a 5-minute walking interval. By the final session he could manage 30 minutes on a bike without stopping and run for longer amounts of time without stopping. On discharge there was a reduction in breathlessness, fatigue and an increase in emotional function and mastery.
- **Patient B** 47-year-old female. Increased SOB on exertion and had elevated fatigue. She attended centre-based rehabilitation and attended 14 out of 16 sessions. On her baseline assessment she managed two ten-minute sessions on the treadmill and could use 1kg for strength training. She experienced increase chest tightness and two intervals of acute chest pain. They developed a modified program and aimed to keep her breathlessness rating down to <3. They introduced some breathing exercises and commenced Pectoral stretches. As the end of the program, her assessment showed no change in her exercise capacity. There was improvement in breathlessness, fatigue, emotional function and mastery.

- **Patient C** 55-year-old female. Admitted to Home-based program. Towards the end of her program, she was able to achieve an interval jog of 30 minutes daily and weights ranged from 2.8-7.3kg. Her outcomes showed improvements in her levels of fatigue, emotional function and mastery.

View Mel and Janet's slides [HERE](#)

A lived experience of managing patients with Long Covid – Zoe Coleman Liverpool Hospital NSW

- Zoe provided an overview of the patients that had been referred to her service.
- In the SWSLHD area there have been 460,127 Covid Cases and 5% of these experienced Long Covid symptoms.
- The Liverpool LGA saw 31 (out of a total of 94) referrals into PR from 1/1/22 to 31/10/22.
- 10 of the 31 patients have been assessed and 8 required enrolment in a PR program (4 males and 4 females). 5 of the patients had been hospitalised (3 in ICU) and 2 were ward-based only.
- 7 patients attended F2F group exercise program and 1 attended a telehealth program.
- Initial Assessment Objective Measures:

	Hospitalised patients (5)	Non-hospitalised patients (3)
6MWT	Mean 324m (175 - 490m) 2/5 desaturating 88%	Mean 505m (450 - 535m) 3/3 normal HR response 1/3 desaturating SpO2 85%
5 x STS	Mean 17.1 seconds	Mean 11.3 seconds
CAT	Mean 18.6 (medium impact)	Mean 26 (high impact)
DASS21	D: 10.6 (moderate) A: 10.6 (moderate) S: 14.6 (normal)	D: 19 (moderate) A: 17 (severe) S: 19 (moderate)
PFTS:	4/5 had reduced FEV1 and FVC (% pred)	1 x Normal PFTs 1 x reduced DLCO (50%) 1 x reduced FEV1 and FVC

- Zoe provided a case study of one patient, Mrs C who was a 46-year-old female. Her main issues were a return to work due to fatigue.
- Her outcomes showed a decrease in exercise capacity mid-way and end program:
 - ▶ Initial 6MWT: 450m, no desaturation, normal HR response
 - ▶ Mid program 6MWT: 428m
 - ▶ End program 6MWT: 447m
 - ▶ 3 months post program: 529m

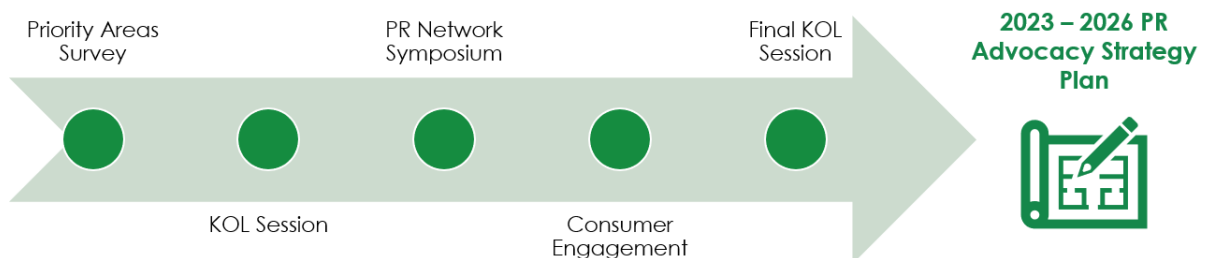
- Three months after the program, the patients exercise capacity had returned. Zoe was not sure if her reduction in exercise capacity had been due to post-exertional symptom exacerbation.
- In summary, Zoe would recommend being mindful of post-exertional symptom exacerbation and actively screening for it. Need to take into consideration the impact of psychosocial factors such as a return to work and workers compensation. Peer support has been extremely valuable for this group of patients, and it is important to take a flexible approach when supporting this group of patients.

View Zoe's slides [HERE](#).

Lung Foundation Update – Emma Halloran

The 2023 to 2026 National Pulmonary Rehabilitation Strategy:

- Emma introduced LFA's plans to develop a three-year advocacy action plan for pulmonary rehabilitation.
- A Key Opinion Leader session will be held on the 17th November to discuss the long standing an emerging priority for pulmonary rehabilitation. The session will discuss the why, what and how of our advocacy approach and the viability of another MBS application based on evidence and experience.
- A symposium will be held in Q 2 of 2023 with the broader PR Network to capture your feedback on the advocacy plan developed. More details of the session will follow on in 2023.
- Consumers will be engaged throughout the process to ensure we get to the heart of the matter.
- A short survey was posted on the chat to capture the Network's feedback on the priorities. This survey is now closed.



Jenny informed the group of the formal release of the COPD Blueprint on World COPD Day (16th November) which was developed by LFA with the support of a range of clinicians, consumers, researchers from across Australia. [View the Blueprint HERE](#).

Peer Support (LFA) – Sahba Dehghani

- Sahba provided information on the Peer Support program at LFA.
- Peer support is offered in three different modes including Face-to-Face, Online and One-On-One sessions.

- The online groups are more disease specific to enable consumers to speak to people with a similar lived experience to themselves. They have a Long Covid group for people within this recovery process.
- The One-On-One Peer Connect Program is facilitated via telephone and is a more specific matching service. Consumers are matched by age, condition, medication or treatment options.
- There is strong evidence for the benefits of peer support. Consumers are able to better self-manage their condition and feel more connected to their peers.
- If you would like to refer your patients to the Peer Support program, you can refer them through two channels:
 1. Get them to call 1800 654 301 (option 3)
 2. Complete an expression of Interest form:

<https://lungfoundation.com.au/patients-carers/support-services/peer-support/>

- There are many Peer Support groups that work in conjunction with Pulmonary Rehabilitation programs as it is a great way to offer continued support to patients.
- You can contact Sahba directly on sahbad@lungfoundation.com.au

View Sahba's slides [HERE](#).

Strong Lungs – Annemarie Lee

- The Strong Lungs website is a segway from the Bronchiectasis Toolbox developed specifically for the Aboriginal population. It launched in December 2021.
- The site contains a variety of videos including general health information and specific information such as physiotherapy or smoking cessation. The site also contains a series of relatable patient stories. All the videos come in English and a number of different local languages. The videos were developed within various local Aboriginal communities in the Northern Territory and have been adapted to suit each local community.
- There are also a series of patient handouts with information such as airway clearance techniques.
- More videos will be added to the site over the next few years. Annemarie would welcome feedback on any suggested topics.

View the Strong Lungs site [HERE](#).

Meeting Close

- This is the last meeting of 2022. Emma will be in contact in Feb/March next year with more information on the symposium and 2023 Network meetings.
- If you would like to join the PR Community of Practice, please register [HERE](#).

- If you have any suggestions of the format or content of future PR Network meetings please email either jennifer.alison@sydney.edu.au or emmah@lungfoundation.com.au.

Questions

Q: What are your thoughts of using heart rate to monitor exertion levels for patients presenting with PESE or PEMS compared to BORG?

A: Janet Bondarenko: I have found RPE easier to use for most patients to monitor their symptoms, but do use HR monitoring for some patients in the community

A: Zoe Colman: I would also recommend using RPE (and consider if pulmonary rehabilitation is the most appropriate setting for rehab, if breathlessness and/or desaturation isn't a primary issue). I would also suggest using caution when utilising heart rate to monitor exertion levels. This is helpful for true PESE/PEMS, however if used inappropriately/unnecessarily it may cause significant self-limiting and anxiety in patients which could otherwise be minimised or avoided.

Q: Are these Long Covid patients being seen within the general pulmonary rehab cohort or as a separate group?

A: Janet Bondarenko: We see long COVID patients in our usual PR cohort

A: Zoe Colman: We also see long COVID patients in our usual PR cohort, though try and put them in the same classes as other long COVID patients for the benefit of peer support if possible.

Q: How is everyone doing with management of referrals into PR at the moment? Dealing with the backlog of chronic disease patients from COVID, then having referrers use PR as a resource for management of Long COVID just isn't currently feasible from a staffing / funding perspective at the moment with the additional screening of referrals and often longer-term rehab requirements of Long COVID so patients tending to be seen in our community rehab programs (where the psychological and OT aspects of their care can be better addressed)

A: Janet Bondarenko: We prioritize anyone with underlying respiratory disease, and those who are functionally limited in regard to returning to work/study.

A: Zoe Colman: Agree that this is a significant challenge. Similarly, to Janet, we prioritise any patients that are functionally limited regarding RTW/study and have ongoing respiratory symptoms (breathlessness, desaturation, sometimes just fatigue) +/- an underlying respiratory disease. If an alternative setting is more suitable (private EP/PT, community rehab etc) we refer them on. I also won't see patients unless they are > 12 weeks post-acute illness.

Q: For home-based or clinic-based pulmonary rehab for someone post long COVID, and is on home oxygen 24/7, is their oxygen titration meant to be increased, decreased or remain as is?

A: Zoe Colman: All long COVID patients I've seen have already been weaned off home oxygen (possibly a result of not accepting referral for them until they're > 12 weeks post-acute illness).

A: Jenny Alison: Sometimes worth asking for a reassessment of oxygen needs to be sure oxygen still needed 24/7.

Q: If a patient with COPD on O2, and is now experiencing long COVID, would you titrate their O2 to SpO2 88-92% to reduce the risk of T2RF? Or titrate to their perceived level of dyspnoea?

A: Janet: I would titrate O2 to their usual levels 88-92. Their dyspnoea is likely multi-factorial, and additional O2 may not relieve symptoms.

A; Zoe: I agree with Janet.

Q: Do long Covid patients attend the usual PR education schedule or is it just exercise-based program +/- covid specific education?

A: I focus on individualised education for these patients, those with underlying/pre-existing respiratory disease may benefit from usual PR education depending on their individual situation and main impairments at the time of their enrolment.

A: Jenny Alison: Patients often find the WHO self-management pamphlet useful. We give it to all our post-COVID patients.
(<https://www.who.int/europe/publications/i/item/WHO-EURO-2021-855-40590-59892>)