

Participant Information Sheet/Consent Form

[Insert site name]

Title	Treatable Traits in Interstitial Lung Disease- Part 2 comparing management of Treatable Traits versus standard clinical care.
Short Title	TTRILD Part 2
Project Sponsor Coordinating Principal Investigator/	Medical research Future Fund Professor Yuben Moodley
Location <i>(where CPI/PI will recruit)</i>	<i>[Location]</i>

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project because you have a lung disease that is classed as an interstitial lung disease.

This study is comparing standard practice versus a specially designed Treatable Traits in Interstitial Lung Disease TTRILD program.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the tests and treatments involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local doctor.

Participation in this research is voluntary. If you don't wish to take part, you do not have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to have the tests and treatments that are described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Interstitial lung disease is not one single condition, but a group of different diseases affecting the lungs.

This project will investigate an innovative treatable-trait-based precision medicine approach (TTRILD) to improve the management of Interstitial Lung Disease (ILD).

It directly addresses consumer priorities,¹⁷ as encapsulated in their most frequently asked questions: ***‘What can make me feel better?’*** and ***‘How can I live longer’***

The first part of this study looked at the prevalence and management of treatable traits across Australia.

Treatable Traits (TT) are problems that you may experience with your lung disease. Some may be directly related while others are present alongside your ILD. The specific issues that we can identify, and treat are called treatable trait. In this study we will look at a specific group of traits These traits are as follows:

- Cough
- Hypoxaemia – reduced oxygen in your blood.
- Obstructive Sleep Apnoea
- Sarcopenia- loss of muscle mass and function
- Breathlessness
- Osteoporosis
- Anxiety
- Depression
- Fatigue
- Loss of appetite

The study aims to understand which TT are important and to assess whether targeted management of these specific traits versus standard treatment will improve patient outcomes.

This part of the study is to compare the effectiveness of a specially design Treatable Traits in Interstitial Lung Disease TTRILD program versus standard clinical care. The information that is gathered during the research project will be used to improve care for people with ILD.

TT are well described in airway disease (e.g. asthma), they have never previously been defined for ILD.

The TTRILD program we have designed is a world first and will assist in improved management and care for people with ILD.

In summary, this project will generate new knowledge of international significance for personalising the management of ILD and establish the evidence required to begin implementing this new approach in Australia.

The trial protocol has been developed and endorsed by the CRE-PF and the Pulmonary Fibrosis Australasian Clinical Trials network.

This research has been funded by Medical Research Future Fund (MRFF).

3 What does participation in this research involve?

To be eligible for this trial you will need to meet the inclusion criteria. Screening inclusion criteria will require a health history and several questions.

You will be asked to sign the consent for this study before any assessments or blood samples are taken.

You will be participating in a randomised controlled research project. The results are compared to see if one is better.

Your participation in the study will be 6 months after which time you will continue your regular ILD care.

The study will be conducted over a 1–2-year time frame. This is to cover any delays that may occur due to recruitment and scheduling.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study doctors or participants jumping to conclusions.

There are no additional costs associated with participating in this research project, nor will you be paid.

You will be reimbursed for any reasonable travel, parking, meals and other expenses associated with the research project visit.

It is desirable that your local doctor be advised of your decision to participate in this research project. If you have a local doctor, we strongly recommend that you inform them of your participation in this research project.

4 What do I have to do?

All participants will be required to attend 3 clinic appointments at 0, 3 and 6 months

Each participant will complete an assessment at enrolment which will include:

- Demographics
- Medical History
- Medications
- Physical assessment
- Previous Investigations

Investigations

- Blood tests including auto-immune screen
- Lung function tests
- DEXA scan – looks at bone density and muscle mass
- HRCT

Questionnaires to be completed at enrolment

- Leister Cough questionnaire - cough
- Stop bang questionnaire - OSA
- Dyspnoea-12 -breathlessness
- HADS Hospital Anxiety Depression Scale
- Anorexia Cachexia Scale
- Patient-Generated Subjective Global Assessment Short Form – nutritional status
- Perceived Stress Scale (PSS)
- KB-ILD, - QOL
- EQ-5D-5L
- Fatigue (FSS) - fatigue

You will ask to complete a cost diary for the duration of the study. This will be used to economically evaluate patient costs and health system costs for the TTRILD program versus standard care.

You will be allocated to either.

- Standard clinical care for ILD vs
- The TTRILD program

To try to make sure the groups are the same, each participant is put into a group by chance (random). The decision as to which group you will be allocated to will be done randomly by a computer.

Standard clinical care - the usually care that patients with ILD receive at hospital outpatients' clinics

TTRILD program - At each clinic appointment, you will be assessed by a nurse, physiotherapist, psychologist, and physician. At the end of the clinic the team will meet to discuss each patient and devise a plan to optimise the management of TTs for that individual. We will determine if expanding the multidimensional assessment of a patient will improve outcomes. This program will require a time commitment to attend sessions for physio and psychology.

In the TTRILD Program participants will have a personalised care plan.

Physiotherapy programs will be tailored to the individual. This will require a time commitment to take part in the program some of which will be done in a physio gym and some home-based exercises.

Dietician will consist of 3 appointments in the clinic and 2 phone calls at 2 and 4 weeks.

At each visit participants in the TTRILD program will be seen by a psychologist and a plan personalised for the individual.

Mindfulness Based Stress Reduction (MBSR) has been extensively tested in a range of chronic health conditions, generally finding reduced psychological distress, better health-related quality of life, and some improved physical outcomes (e.g., reduced fatigue) relative to control groups.

MBSR consists of 8 weekly group sessions that are 2.5 hours in duration (we would likely shorten it to 2 hours), as well as asking participants to practice what they learn daily for about 45 minutes.

It utilizes a range of therapeutic mindfulness practices, including sitting meditation, body scans, and light yoga, while also incorporating principles of cognitive-behavioural therapy.

If you are allocated to the Standard Clinical care, you will still have access to the allied health consults and programs. Referrals will be done through the usual standard care health referral system.

5 Other relevant information about the research project

The TTRILD program vs standard clinical care study will be conducted at Fiona Stanley Hospital in WA.

The trial aims to recruit 110 participants: 55 for the TTRILD Program and 55 for the standard clinical care program.

This part of the study is following on from part 1 which was to evaluate the prevalence and management of treatable traits across Australia. This was a series of questionnaires completed at 4 sites across Australia.

Dr Megan Harrison, respiratory physician will be collaborating on the study as a student, to complete a Doctor of Philosophy through the University of Sydney. Professor Tamera Corte is the student supervisor. Research data analysis completed by Dr Harrison for her PhD will be stored deidentified securely through the University for Sydney. When data analysis is complete, data will be returned and stored deidentified on the UWA REDCAP data base.

6 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with [\[Institution\]](#).

7 What are the possible benefits of taking part?

By taking part in this research, you have a 50% chance of being in the TTRILD program which will give you a multidisciplinary team-based care program personalised to your needs. This program will be innovative and aimed at improving health outcomes for people with ILD.

If you are selected for the Standard Clinical Care group, you will not be disadvantaged. You will still receive the standard care you would get in attending Fiona Stanley Hospital outpatient clinic.

Although you may not benefit directly from taking part in this study the information collected will help contribute to future improved care and health outcomes for people with ILD.

8 What are the possible risks and disadvantages of taking part?

Having a blood/tissue sample taken may cause some discomfort, bruising, minor infection or bleeding. If this happens, it can be easily treated.

This research project involves exposure to a very small amount of radiation. As part of everyday living, everyone is exposed to naturally occurring background radiation and receives a dose of about 2 millisieverts (mSv) each year. The effective dose from this research project is about 0.02 mSv. The dose from this research project is comparable to that received from many diagnostic medical x-ray and nuclear medicine procedures. At this dose level, no harmful effects of radiation have been demonstrated, as any effect is too small to measure. This risk is believed to be low and, theoretically, is approximately equivalent to a simple Xray. The research will include studies of inherited (genetic) factors. This is a blood or tissue sample that will be used to test DNA. There are important considerations for genetic testing that are listed below

- You will be informed of the results by the investigating doctor.
- This is not general health test.
- The results are based on current knowledge that may change in the future.
- This test will not predict all future health problems.
- You can change your mind about receiving the genetic test results at any time by contacting the investigating doctor.
- There are a number of different results from testing, and these can have implications for you and your family.
- The results may be of “unknown or uncertain significance” which means they cannot be understood based on current knowledge.
- There is a chance that some genetic tests could identify other medical conditions (or susceptibility to other medical conditions) as an incidental finding.
- The genetic tests may identify unexpected family relationships.
- The genetic tests may affect your ability to obtain some types of insurance (for example, life insurance).
- Further testing may be needed to finalise the result.
- The reason for testing and the potential benefits and limitations involved in the testing have been explained to you in a way you can understand.
- You have an opportunity to discuss the information, ask questions and have any concerns addressed and you are satisfied with the explanations and answers to your questions.
- Your results are confidential and will only be released with your consent or as required or permitted by law.

9 What will happen to my test samples?

Blood and any tissue samples taken from you will be used for this research project and with your consent used for future research into ILD. The purpose of the laboratory research is to understand more about TT in ILD.

Samples of your blood obtained for the purpose of this research project will be transferred to Institute Respiratory Health Biobank at Harry Perkins North QEII medical Centre Verdun Street Nedlands WA. Your blood/tissue will not be sold by IRH Biobank however IRH Biobank may charge study doctors a fee to recover some of the costs of storing and administering the tissue samples.

The research will use the latest laboratory tests to identify markers in the blood that will enable a scientifically based approach to predicting progression of ILD before there are changes in the lung function.

The samples for genetic testing will be transferred to the University of Tasmania. To be stored deidentified and secured confidentially. The samples will be kept for a period of 15 years. If you have a lung washout during the study as part of the routine standard care for your ILD we will ask you for a tissue sample. Your consent for a tissue sample during this procedure will be optional and a separate consent form will be signed

You will retain the right to have your samples destroyed at any time by contacting your study doctor. If you decide to have your samples destroyed, any data or analyses that were done before the request cannot be removed; however, no additional analysis will be done on your samples, and all your remaining samples will be destroyed. The central laboratory at the BIO Bank at SMHS is responsible for the destruction of all of your remaining samples at your request. Otherwise, your samples will be stored for use towards the above purposes.

If you decline consent for future research, your blood and genetic samples will be stored

10 Can I have other treatments during this research project?

Taking part in this study does not require any changes to your normal care and medications.

11 What if I withdraw from this research project?

If you decide to withdraw from the project, please notify a member of the research team before you withdraw.

If you do withdraw your consent during the research project, the study doctor and relevant study staff will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the sponsor up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

12 What happens when the research project ends?

At the end of the study your standard clinical care will continue at FSH.

A description of the study will be available at <http://www.clinicaltrials.gov>. This website will not include any information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

At the end of the study you may receive the study results including any publication(s) requested from the research team.

Part 2 How is the research project being conducted?

13 What will happen to information about me?

By signing the Consent Form, you consent to your study doctor and relevant research staff collecting and using personal information about you for the study. Any information obtained in connection with this study that can identify you will remain confidential. The information collected in this study will be identified by a code number. Only your study doctor and the study team will be able to link the code number to you personally. Your information will be included in the study database for analysis. Your information will only be used for the purpose of this study and it will only be disclosed with your permission, except as required by law.

Information about you may be obtained from your health records held at this and other health services for the purpose of this research. By signing the consent form, you agree to the research team accessing health records if they are relevant to your participation in this research project.

Authorised representatives may contact you to obtain follow-up information after study completion or requested by principal investigator, should your local hospital staff be unable to contact you using the contact details collected.

Your personal details and all study data will be held by the research organisation. All data collected will be held securely. All study-related documentation at the study sites will be maintained for 15 years following completion of the study. The documents will be archived securely as per (*insert site name*) data management policy. Only research staff associated with the study will have access to this material.

Electronic data will be stored in a password protected database on a secure password protected computer. This data will be kept deidentified on the UWA REDCAP server. Only research staff associated with the study will have access to the database.

Electronic data will be stored securely on the UWA server.

Your health records and any information obtained during the research project are subject to inspection for the purpose of verifying the procedures and the data. This review may be done by the relevant authorities, the institution relevant to this Participant Information Sheet, [*Name of institution*], or as required by law. By signing the Consent Form, you authorise release of, or access to, this confidential information to the relevant research personnel and regulatory authorities as noted above.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified,

Information about your participation in this research project may be recorded in your health records.

In accordance with relevant Australian and/or state privacy and other relevant laws, you have the right to request access to the information collected and stored by the research team about you. You also have the right to request that any information with which you disagree be corrected. Please contact the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

14 Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

15 Who is organising and funding the research?

This research project has been funded by the Medical Research Future Fund. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

16 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of South Metropolitan Health Service.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2023)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The trial protocol has been developed and endorsed by the CRE-PF and the Pulmonary Fibrosis Australasian Clinical Trials network. It will be registered at clinicaltrials.gov before commencing.

17 Further information and who to contact

The person you may need to contact will depend on the nature of your query.

If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor on [\[phone number\]](#) or any of the following people:

Clinical contact person

Name	[Name]
Position	[Position]
Telephone	[Phone number]
Email	[Email address]

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	[Name]
Position	[Position]
Telephone	[Phone number]
Email	[Email address]

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	South Metropolitan Health Service
HREC Executive Officer	Ethics Coordinator
Telephone	(08) 61522064
Email	SMHS.HREC@health.wa.gov.au.

Hospital Letter Head

Treatable Traits in Interstitial Lung Disease Study TTRILD Consent Form

Title Treatable Traits in Interstitial Lung Disease-
Part 2 comparing management of Treatable
Traits versus standard clinical care.

Short Title TTRILD Part 2

Project Sponsor Medical research Future Fund

**Coordinating Principal Investigator/
Principal Investigator** *Professor Yuben Moodley
Principal Investigator]*

Location *(where PI will recruit)* *Location*

Declaration by Participant

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

I give permission for my doctors, other health professionals, hospitals or laboratories outside this hospital to release information to [Name of Institution] concerning my condition and treatment for the purposes of this project. I understand that such information will remain confidential.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Study Doctor/Senior Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/
Senior Researcher[†] (please print) _____

Signature _____ Date _____

[†] A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Hospital Letter Head

Treatable traits in Interstitial Lung Disease - TTRILD

Consent for the collection of Blood samples

I consent to the storage and use of blood and tissue samples taken from me for use, as described in the relevant section of the Participant Information Sheet, please circle yes or no

- | | | |
|---|-----|----|
| • This specific research project. | Yes | No |
| • Other research that is closely related to this research project | Yes | No |
| • Any future research. | Yes | No |

I agree to the use of my tissue samples for genetic testing, as outlined in the relevant Section of the Participant Information Sheet.

Yes No

I wish to receive the results of genetic testing.

Yes No

Name of Participant (please print) _____

Signature _____ Date _____

Name of Study Doctor/
Senior Researcher[†] (please print) _____

Signature _____ Date _____

[†] A senior member of the research team must provide the explanation of and information concerning the research project.

Note: All parties signing the consent section must date their own signature.

Hospital Letter Head

Form for Withdrawal of Participation - Adult providing own consent

Title	Treatable Traits in Interstitial Lung Disease- Part 2 comparing management of Treatable Traits versus standard clinical care.
Short Title	TTRILD Part 2
Protocol Number	5.020231213
Project Sponsor	Medical research Future Fund or IRH
Coordinating Principal Investigator/	<i>[Coordinating Principal Investigator/</i>
Principal Investigator	<i>{Principal Investigator}</i>
Location (<i>where CPI/PI will recruit</i>)	<i>[Location]</i>

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with *[Institution]*.

Name of Participant (please print) _____	
Signature _____	Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Study Doctor/Senior Researcher will need to provide a description of the circumstances below.

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Declaration by Study Doctor/Senior Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher [†] (please print) _____	
Signature _____	Date _____

[†] A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Treatable trait overview booklet

Patient name:

Patient ID:

Date of registration:

For table please tick (✓) relevant column:

Treatable Trait	Present	Unknown	Absent	Page for further info
Aetiological				
Pulmonary inflammation				2
Connective Tissue Disease				3-4
Drug Exposure				5
Environmental exposures				6
Genetics				7
Pulmonary				
Progressive Pulmonary Fibrosis				8
Emphysema				9
Pulmonary Hypertension				10
Resting hypoxia				11
Exertional Hypoxia				12
Nocturnal Hypoxia				13
Obstructive Sleep Apnoea				14
Chronic Cough				15
Chronic Dyspnoea				16
Peripheral muscle dysfunction				17
Exercise Intolerance				18
Extra-pulmonary				
Sarcopenia				19
Frailty				20
Osteoporosis				21
Poor Appetite and Malnutrition				22
Anxiety and Depression				23
Fatigue				24
Behavioural				
Polypharmacy				25
Smoking				26
Physical Inactivity				27

1. Inflammation/ Immune dysregulation

Background:

- Can reflect the underlying aetiology, including autoimmune diseases or hypersensitivity pneumonitis (HP) [1]
- Identification not straightforward.
- When inflammation is identified, immunosuppressive medications are often utilised to improve patient health outcomes, including lung function, and quality of life [2]

Diagnosis:

Diagnostic Test:	Results	Present	Absent
HRCT Chest: Ground glass change, NSIP, OP [3]			
Bronchoalveolar lavage: Inflammation – lymphocytosis ($\geq 20\%$) +/- combination of neutrophilia/ eosinophilia [2,4]			
Histopathology: NSIP/ OP [5]			
MDT consensus: Inflammation			
MDT consensus: Benefit from immunosuppression			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Corticosteroids		
Other immunosuppression - Details		

2. Connective Tissue Disease

Background:

- ILD can develop in every CTD, ranging from limited disease with innate stability to fulminant and life-threatening disease.
- CTD-ILD is estimated to represent between 6-33% of all ILDs [6]

Diagnosis:

Diagnostic Test:	Results - notes	Present	Absent
Clinical features [5] <i>See figure 1</i>			
Radiological features (presence of a NSIP or OP pattern, evidence of serositis, or extra-thoracic manifestations of CTD) [3]			
Serology [5] <i>See figure 1</i>			
MDT consensus			

CTD	Prevalence of ILD	Clinical signs and symptoms	ILD manifestations	Non-ILD respiratory manifestations ⁵
SSc ⁶	Detectable: up to 75% Clinically significant: 25–45% ^{7,8}	Raynaud's phenomenon Sclerodactyly Digital ulcers/pits Telangiectasia Skin thickening GI involvement	Most common: NSIP Other: UIP, OP	PAH Pulmonary lymphoma Aspiration pneumonia
RA ⁹	Detectable: 30–60% Clinically evident: 10–30% ¹⁰	Polyarticular synovitis Rheumatoid skin nodules	Most common: UIP Other: NSIP, OP	Bronchiectasis, bronchiolitis Rheumatoid lung nodules Pleural disease ± effusion Respiratory muscle weakness
IIM ¹¹	30–50% ^{12,13} Up to 80% in anti-synthetase syndrome	Proximal symmetrical muscle weakness Gottron's sign Gottron's papules Heliotrope rash Shawl sign Mechanic's hands	Most common: NSIP Other: OP, UIP, AIP/DAD	
SLE ¹⁴	Detectable: up to 30% Clinically evident: 3–11% ¹⁵	Photosensitive and/or malar rash Oral ulcers Alopecia Serositis	Most common: NSIP Other: LIP, OP, UIP, FB, AIP/DAD	Pleuritis Diffuse alveolar haemorrhage Respiratory muscle weakness 'Shrinking lung syndrome'
SJS ¹⁶	10–30% ⁸	Sicca symptoms Enlarged parotid glands	Most common: NSIP Other: OP, LIP, UIP, FB	MALT lymphoma Amyloidosis Bronchiectasis
MCTD ¹⁷	20–85% ⁸	Swollen hands Synovitis Myositis Acrosclerosis Raynaud's phenomenon	Most common: NSIP Other: UIP, OP	Pleuritis Diffuse alveolar haemorrhage Respiratory muscle weakness Aspiration pneumonia

AIP, acute interstitial pneumonia; CTD, connective tissue disease; DAD diffuse alveolar damage; FB, follicular bronchiolitis; GI, gastrointestinal; IIM, idiopathic inflammatory myopathy; LIP, lymphocytic interstitial pneumonia; MALT, mucosa-associated lymphoid tissue; MCTD, mixed CTD; NSIP, non-specific interstitial pneumonia; OP, organizing pneumonia; PAH, pulmonary arterial hypertension; RA, rheumatoid arthritis; SJS, Sjögren's syndrome; SLE, systemic lupus erythematosus; SSc, systemic sclerosis; UIP, usual interstitial pneumonia.

Figure 1. Replicated from Jee et al, 2021.

Management:

Treatment	Treatment initiated	Notes on response
Rheumatology/ Immunology input [2,5,7]		
Corticosteroids		
Other immunosuppression		
Monitor for PPF and consider anti-fibrotic therapy		

3. Drug exposure

Background:

- Over 400 drugs have been identified as causative of pulmonary toxicity [8]
- Many common drugs being culpable including chemotherapeutics, methotrexate, amiodarone, and immune checkpoint inhibitors [8,9].
- 2 main mechanisms of injury are direct cytotoxic pulmonary injury and immune-mediated injury [9,10]. These can occur independently or in combination.

Diagnosis:

Diagnostic Test:	Causative drug(s)	Present	Absent
New drug (< 5 years)			
Drug identified with pulmonary toxicity (pneumotox)[8]			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Drug withdrawal [9,10].		
Corticosteroids [9].		
Other immunosuppression		

4. Environmental exposure

Background:

- Many environmental exposures are related to the development of ILD, and particularly HP [1,11].
- Prevalence of HP in high-risk groups is substantial with estimated prevalence in farmers at 1.2-12.9%, bird breeders at 3.7-10.4% and mushroom workers at 3.5-29% [1,12-19].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Targeted history: Presence of exposure – HP type [4,20]			
Targeted history: Presence of exposure – occupational [4,20]			

Management:

Treatment	Treatment initiated	Notes on response
Antigen avoidance [21,22]		
Corticosteroids [21,22].		
Other immunosuppression [21,22].		

5. Genetics

Background:

- Genetic variants account for approximately 30% of the risk of development of sporadic and familial IPF [23-26].
- Rare genetic variants can impact genes involved in telomere maintenance, resulting in shortened telomeres, premature cellular aging, and pulmonary fibrosis [27].
- Surfactant proteins are essential for lung function with genetic mutations causing disrupted alveolar stability.
- Common variants of the MUC5B gene including the promoter variant, a single-nucleotide polymorphism rs35705950 which encodes mucin, a key component in macrophage function and mucocilliary clearance, are associated with increased risk of IPF [25,28].

Diagnosis:

Diagnostic Test:	Details	Present	Absent
Telomere length (flow FISH) [29-32].			
Whole genome sequencing [29-31,33,34].			

Family tree:

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6. Progressive pulmonary fibrosis

Background:

- PPF refers to a non IPF progressive phenotype, despite optimal therapy [35,36].
- This has now been recognised across many ILD subtypes including CTD-ILD and chronic HP [35,37,38].
- ATS/ERS/JRS/ALAT guidelines, PPF involves two or more of:
 - (a) worsening respiratory symptoms
 - (b) physiological deterioration with absolute decline in FVC% predicted $\geq 5\%$ or decline in DLCO% predicted of $\geq 10\%$ or
 - (c) radiological progression over one year with no alternative explanation [39].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
ATS/ ERS/ JRS/ ALAT guidelines PPF Two or more of: (a) worsening respiratory symptoms (b) physiological deterioration with absolute decline in FVC% predicted $\geq 5\%$ or decline in DLCO% predicted of $\geq 10\%$ or (c) radiological progression over one year with no alternative explanation [39] [39]			
PPF – PBS criteria			

Management:

Treatment	Evidence	Treatment initiated	Notes on response
Antifibrotic – nintedanib [35,40].			

7. Emphysema

Background:

- Concomitant emphysema is common in ILD, with the prevalence in current or former smokers with fILD ranging from 8-67% [41].
- Combined pulmonary fibrosis and emphysema (CPFE) is the clinical syndrome of emphysema ≥ 10 -15% of total lung volume in the setting of fibrosis [41].
- CPFE results in a characteristic functional profile with preserved lung volumes, significantly impaired DLCO, exertional hypoxia and increased prevalence of pulmonary hypertension and lung cancer. [41-43].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
HRCT Chest – CPFE [41].			
Spirometry – obstruction (< LLN)			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Bronchodilator with obstructive spirometry [44-46]		
Multimodal monitoring with Radiology PFTs (DLCO) TTE (PH) [41,47,48].		

8. Pulmonary hypertension

Background:

- Prevalence ranging from 13-88% [49].
- Its presence confers worse survival [49].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
TTE - TR jet velocity of >2.8 m/s $\approx$ mPAP $\geq$ 35 mmHg [50-52].			
Right heart catheter (RHC) mPAP $\geq$ 20mmHg [50].			

Management:

Treatment	Treatment initiated (✓)	Notes on response
PAH specific treatments require PH speciality team/ service		
Consider Treprostinil [53,54]		
Consider PDE5i (Sildenafil) [55-59]		

9. Resting hypoxia

Background:

- Resting hypoxia is present in patients with severe disease and denotes a median survival of less than 1 year [60].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Baseline SaO2 $\leq 88\%$			
ABG PaO2 <60 mmHg with PH or <56mmHg [60-65].			

Management:

Treatment	Treatment initiated (✓)	Treatment details	Notes on response
Long term oxygen therapy [60-67].			

10. Exertional hypoxia

Background:

- 5-year cumulative incidence of 40.1% in ILD patients overall, with increasing prevalence with disease severity,
- Associated with reduced survival [60,68,69].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
6MWT trough Sats ≤ 88% [70-72]			
Repeat 6MWT on oxygen			

Management:

Treatment	Treatment initiated (✓)	Treatment details	Notes on response
Consider supplemental oxygen on exertion [73].			

11. Nocturnal Hypoxia

Background:

- Prevalence of 37% overall, increasing with disease severity [68].
- Mechanisms driving the pathogenesis of isolated nocturnal hypoxia, including reduced respiratory drive during sleep, particularly with rapid-eye-movement sleep muscle atonia, [68]
- Associated with poor HRQOL with impaired daytime function [74,75].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Overnight oximetry >10% of total sleep time with SpO2 <90% (TST90)			
Polysomnography			

Management:

Treatment	Treatment initiated (✓)	Treatment details	Notes on response
Consider supplemental oxygen overnight [76].			

12. Obstructive Sleep Apnoea

Background:

- Prevalence of 61% in ILD patients [77]
- Reduced lung volumes in ILD lead to upper airway instability and risk of OSA with resulting negative impacts on quality of life [78]

Diagnosis:

Diagnostic Test:	Results	Present	Absent
STOP-BANG questionnaire [79]			
Polysomnography [80].			

Management:

Treatment	Treatment initiated (✓)	Notes on response
CPAP [81]		
Consider nocturnal oxygen [82].		
Consider mandibular splint [82]		

13. Chronic Cough

Background:

- Cough is common - 84% of IPF patients have cough [83].
- Patients with cough are more likely to have disease progression and poorer outcomes [83].
- Underlying mechanisms for cough are complex and likely related to chemical or mechanical stimulation of cough receptors [83].

Diagnosis:

Diagnostic Test:	Result	Positive	Negative
Clinical history			
Leicester cough questionnaire score <17.68 [84].			

Management:

Treatment categories	Treatment	Treatment initiated	Notes on response
<i>Address co-contributing drivers</i>			
GORD	Treat if symptomatic - Lifestyle changes - Standard dose PPI#. Can wean after 4-8 weeks.[85]		
Post-nasal drip	Treat if suspected: - Intranasal antihistamines - Intranasal corticosteroids [86]		
Vocal cord dysfunction/ intermittent laryngeal obstruction	- Speech therapy [87,88] - Psychological counselling		
<i>Cough-specific treatments</i>			
Cough suppressive therapies	Speech pathology techniques [88,89]		
Consider neuromodulators	- Gabapentin - Baclofen		
Consider low-dose opioids [90,91].			

esomeprazole 40 mg, lansoprazole 30 mg, omeprazole 20 mg, pantoprazole 40 mg, or rabeprazole 20 mg.

14. Chronic dyspnoea

Background:

- Dyspnoea is one of the key symptoms of ILD, directly impacting on functional limitation and quality of life [7,92].
- Severity of dyspnoea at time of diagnosis is associated with poorer survival [93].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Clinical history			
Dyspnoea 12 score of			

Management:

Treatment categories	Treatment initiated (✓)	Notes on response
Increased airflow - Handheld fan [91]		
Outpatient pulmonary rehabilitation [94]		
Consider opioids [90,91,94].		

15. Peripheral muscle dysfunction

Background:

- Peripheral muscle dysfunction (PMD) can be seen in 20-46% of ILD patients [95].
- Hypoxia, deconditioning, systemic inflammation, and steroid use related to ILD all likely contribute [96].
- PMD contributes to exercise intolerance, reduced functional capacity, and poor quality of life.

Diagnosis:

Diagnostic Test:	Results	Present	Absent
1min STS < 20 repetitions [97]			

Management:

Treatment	Treatment initiated	Notes on response
Home based strength training		

16. Exercise intolerance

Background:

- Physical activity is greatly impacted in IPF patients compared to healthy age-matched controls [98].
- Exercise intolerance is associated with both decreased HRQOL and worse survival in patients with ILD [98-100].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
6MWT <350m [98-100]			

Management:

Treatment	Treatment initiated	Notes on response
Pulmonary rehabilitation [94].		

17. Sarcopenia

Background:

- Progressive and generalised skeletal muscle condition with accelerated loss of muscle mass and function [101].
- The reduction in physical activity in ILD patients results in muscle disuse and deconditioning leading to sarcopenia [102].
- Rates of sarcopenia in ILD vary across studies from 22.9 -39.3% of ILD patients [103-105].
- Sarcopenia is associated with increased ILD severity and mortality [106,107].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
<i>Function:</i> Isometric quadriceps force [106-108].			
<i>Mass:</i> DEXA - Low appendicular Lean Mass Index (z-score) [102,109].			

Management:

Specifics	Treatment details	Treatment initiated (✓)	Notes on response
Home based exercise prescription			
If borderline intake	High protein diet		
If poor intake	High protein diet + protein powder		

18. Frailty

Background:

- Frailty is a complex and multidimensional syndrome with reduction of physiological reserves that increase risk of adverse health outcomes [110].
- 21% of fibrotic ILDs considered frail [111]
- Frailty is an independent risk factor for early mortality, FVC% decline [111] and hospital admission [112].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Clinical frailty scale [111]			
1 min STS <20 repetitions [113]			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Pulmonary rehabilitation [114]		
Self-management and education [114].		

19. Osteoporosis

Background:

- Approximately one third of patients with IPF have been diagnosed with at least 1 vertebral fracture [115].
- Reduced bone mineral density is associated with significant decrease in FVC and diffusion capacity [115]

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Clinical history: low impact fracture (vertebral compression fracture, hip, wrist, humerus, rib, and pelvis.			
DEXA scan: T-score less than or equal to – 2.5			
<i>Additional:</i> Vit D level			
<i>Additional:</i> Calcium and phosphate level			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Dietary recommendations		
Supplements – calcium and vitamin D		
Consider Anti-resorptive therapy (with GP)		

20. Poor Appetite and Malnutrition

Background:

- Nutritional abnormalities including malnutrition are increased in ILD patients with reported rates varying between 9-55% [116-118].
- Malnutrition is likely due to multiple factors, including dyspnoea, increased metabolic rate and the side effect profile of antifibrotics and some immunosuppressive medications [40,116,119,120].
- Malnutrition is independently associated with decreased DLCO and reduced survival [118,120].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
<i>Poor appetite:</i> Anorexia Cachexia Scale Score ≤ 37 [121]			
<i>Malnutrition:</i> Patient-Generated Subjective Global Assessment Short Form ≥ 4 [122]			
<i>Malnutrition</i> BMI < 18.5 [123].			

Management:

Specifics	Treatment	Treatment initiated (✓)	Notes on response
With borderline intake	Small frequent meals and snacks [124-126].		
With poor intake	Small frequent meals and snacks + Nourishing drinks/ Oral nutritional supplements [124-126].		

21. Anxiety and depression

Background:

- Australian IPF cohort, anxiety and depression were 31% and 23% respectively [127]
- Associated with worsening symptoms, disease severity, numbers of comorbidities and worse quality of life [127,128].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
HADS ≥ 8 [127].			
PSS ≥ 14 [129]			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Mindfulness-Based Stress Reduction [130]		
GP referral for consideration of anti-depressants		

22. Fatigue

Background:

- One of the most common symptoms of ILD at time of presentation [131,132].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Clinical history			
Fatigue severity scale [133].			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Graded exercise program [91,134].		

23. Polypharmacy

Background:

- Defined by the World Health Organisation as the concurrent use of 5 or more regular medications, is most frequently seen in the elderly [135].
- 1 ILD cohort, polypharmacy seen in 51% of IPF patients and 63% of inflammatory ILD patients. [136]
- Increased risk for non-adherence, drug-related side effects, and drug interactions [136].

Diagnosis:

Diagnostic Test:	Medication list	Present	Absent
Medication list $\geq$ 5 regular meds [135].			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Medication rationalisation		

24. Smoking

Background:

- Causative in the development of smoking-related ILDs including respiratory bronchiolitis-ILD and desquamative interstitial pneumonia
- Important co-factor in the development of other ILDs such as IPF and RA-ILD [137].
- Active smoking confers poorer outcomes for survival in ILD [138].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Clinical history			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Quitline referral [139-141].		
Nicotine replacement therapy [139-141].		
Consider varenicline [139-141].		
Consider bupropion [139-141].		

25. Physical Inactivity

Background:

- Physical activity is reduced in patients with ILD compared to healthy controls [142].
- Breathlessness and exercise intolerance are associated with reduced physical activity [100].
- Physical inactivity is a strong risk factor for hospitalisation and all-cause mortality in ILD patients [142-144].

Diagnosis:

Diagnostic Test:	Results	Present	Absent
Clinical history			
Physical Inactivity Questionnaire [145]			

Management:

Treatment	Treatment initiated (✓)	Notes on response
Goal setting with pedometer		

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KB-ILD

1. In the last 2 weeks, I have been breathless climbing stairs or walking up an incline or hill.

1. Every time	2. Most times	3. Several Times	4. Some times	5. Occasionally	6. Rarely	7. Never
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2. In the last 2 weeks, because of my lung condition, my chest has felt tight.

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

3. In the last 2 weeks have you worried about the seriousness of your lung complaint?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
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4. In the last 2 weeks have you avoided doing things that make you breathless?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

5. In the last 2 weeks have you felt in control of your lung condition?

1. None of the time	2. Hardly any of the time	3. A little of the time	4. Some of the time	5. A good bit of the time	6. Most of the time	7. All of the time
---------------------	---------------------------	-------------------------	---------------------	---------------------------	---------------------	--------------------

6. In the last 2 weeks, has your lung complaint made you feel fed up or down in the dumps?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

7. In the last 2 weeks, I have felt the urge to breathe, also known as 'air hunger'.

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

8. In the last 2 weeks, my lung condition has made me feel anxious.

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

9. In the last 2 weeks, how often have you experienced 'wheeze' or whistling sounds from your chest?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

10. In the last 2 weeks, how much of the time have you felt your lung disease is getting worse?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

11. In the last 2 weeks has your lung condition interfered with your job or other daily tasks?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

12. In the last 2 weeks have you expected your lung complaint to get worse?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

13. In the last 2 weeks, how much has your lung condition limited you carrying things, for example, groceries?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

14. In the last 2 weeks, has your lung condition made you think more about the end of your life?

1. All of the time	2. Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. Hardly any of the time	7. None of the time
--------------------	---------------------	---------------------------	---------------------	-------------------------	---------------------------	---------------------

15. Are you financially worse off because of your lung condition?

1. A significant amount	2. A large amount	3. A considerable amount	4. A reasonable amount	5. A small amount	6. Hardly at all	7. Not at all
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APPENDIX 1: Leicester Cough Questionnaire. © 2001

This questionnaire is designed to assess the impact of cough on various aspects of your life. Read each question carefully and answer by CIRCLING the response that best applies to you. Please answer ALL questions, as honestly as you can.

1. In the last 2 weeks, have you had chest or stomach pains as a result of your cough?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

2. In the last 2 weeks, have you been bothered by sputum (phlegm) production when you cough?

- | | | | | | | |
|------------|------------|---------------|------------|--------------|--------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Every time | Most times | Several times | Some times | Occasionally | Rarely | Never |

3. In the last 2 weeks, have you been tired because of your cough?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

4. In the last 2 weeks, have you felt in control of your cough?

- | | | | | | | |
|------------------|------------------------|----------------------|------------------|------------------------|------------------|-----------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| None of the time | Hardly any of the time | A little of the time | Some of the time | A good bit of the time | Most of the time | All of the time |

5. How often during the last 2 weeks have you felt embarrassed by your coughing?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

6. In the last 2 weeks, my cough has made me feel anxious

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

7. In the last 2 weeks, my cough has interfered with my job, or other daily tasks

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

8. In the last 2 weeks, I felt that my cough interfered with the overall enjoyment of my life

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

9. In the last 2 weeks, exposure to paints or fumes has made me cough

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

10. In the last 2 weeks, has your cough disturbed your sleep?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

11. In the last 2 weeks, how many times a day have you had coughing bouts?

- | | | | | | | |
|--------------------------------|---------------------------|------------------------------|---------------------------|------------------------------|--------|------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time (continuously) | Most times during the day | Several times during the day | Some times during the day | Occasionally through the day | Rarely | None |

12. In the last 2 weeks, my cough has made me feel frustrated

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

13. In the last 2 weeks, my cough has made me feel fed up

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

14. In the last 2 weeks, have you suffered from a hoarse voice as a result of your cough?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

15. In the last 2 weeks, have you had a lot of energy?

- | | | | | | | |
|------------------|------------------------|----------------------|------------------|------------------------|------------------|-----------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| None of the time | Hardly any of the time | A little of the time | Some of the time | A good bit of the time | Most of the time | All of the time |

16. In the last 2 weeks, have you worried that your cough may indicate serious illness?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

17. In the last 2 weeks, have you been concerned that other people think something is wrong with you, because of your cough?

- | | | | | | | |
|-----------------|------------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

18. In the last 2 weeks, my cough has interrupted conversation or telephone calls

- | | | | | | | |
|------------|------------|------------------------|------------------|----------------------|------------------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Every time | Most times | A good bit of the time | Some of the time | A little of the time | Hardly any of the time | None of the time |

19. In the last 2 weeks, I feel that my cough has annoyed my partner, family or friends

- | | | | | | | |
|--------------------|-------------------------|----------------------------|-------------------------|---------------------------|--------|-------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| Every time I cough | Most times when I cough | Several times when I cough | Some times when I cough | Occasionally when I cough | Rarely | Never |

Thank you for completing this questionnaire.

Updated STOP-Bang Questionnaire

Snoring?

Yes No
☐ ☐ Do you **Snore Loudly** (loud enough to be heard through closed doors or your bed-partner elbows you for snoring at night)?

Tired?

Yes No
☐ ☐ Do you often feel **Tired, Fatigued, or Sleepy** during the daytime (such as falling asleep during driving)?

Observed?

Yes No
☐ ☐ Has anyone **Observed** you **Stop Breathing** or **Choking/Gasping** during your sleep?

Pressure?

Yes No
☐ ☐ Do you have or are being treated for **High Blood Pressure**?

Body Mass Index more than 35 kg/m²?

Yes No
☐ ☐

Age older than 50 years old?

Yes No
☐ ☐

Neck size large? (Measured around Adams apple)

Yes No
☐ ☐ For male, is your shirt collar 17 inches/43 cm or larger?
For female, is your shirt collar 16 inches/41 cm or larger?

Gender = Male?

Yes No
☐ ☐

Scoring Criteria:

For general population

Low risk of obstructive sleep apnoea (OSA): Yes to 0-2 questions

Intermediate risk of OSA: Yes to 3-4 questions

High risk of OSA: Yes to 5-8 questions

- or Yes to 2 or more of 4 STOP questions + male gender
- or Yes to 2 or more of 4 STOP questions + BMI > 35 kg/m²
- or Yes to 2 or more of 4 STOP questions + neck circumference
(17"/43cm in male, 16"/41cm in female)

Property of University Health Network, for further info: www.stopbang.ca

Modified from Chung F et al. Anesthesiology 2008; 108:812-21, Chung F et al Br J Anaesth 2012; 108:768–75, Chung F et al J Clin Sleep Med Sept 2014



Dyspnoea-12

This questionnaire is designed to help us learn more about how your breathing is troubling you.

Please read each item and then tick in the box that best matches your breathing **these days**.
If you do not experience an item tick the 'none' box. Please respond to all items.

Name: ID: Date: / /

Item	None	Mild	Moderate	Severe
1. My breath does not go in all the way				
2. My breathing requires more work				
3. I feel short of breath				
4. I have difficulty catching my breath				
5. I cannot get enough air				
6. My breathing is uncomfortable				
7. My breathing is exhausting				
8. My breathing makes me feel depressed				
9. My breathing makes me feel miserable				
10. My breathing is distressing				
11. My breathing makes me agitated				
12. My breathing is irritating				

Patient Name: _____ DOB: _____ Date: _____

Fatigue Severity Scale (FSS)

The Fatigue Severity Scale (FSS) is a method of evaluating the impact of fatigue on you. The FSS is a short questionnaire that requires you to rate your level of fatigue.

The FSS questionnaire contains nine statements that rate the severity of your fatigue symptoms. Read each statement and circle a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you.

- A low value (e.g., 1) indicates strong disagreement with the statement, whereas a high value (e.g., 7) indicates strong agreement.
- It is important that you circle a number (1 to 7) for every question.

FSS Questionnaire

During the past week, I have found that:	Disagree  Agree						
1. My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
2. Exercise brings on my fatigue.	1	2	3	4	5	6	7
3. I am easily fatigued.	1	2	3	4	5	6	7
4. Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
5. Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
6. My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
7. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
8. Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
9. Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7
Total Score:							

Scoring your results

Now that you have completed the questionnaire, it is time to score your results and evaluate your level of fatigue. It's simple: Add all the numbers you circled to get your score.

The fatigue Severity Scale key

A total score of less than 36 suggests that you may not be suffering from fatigue.

A total score of 36 or more suggests that you may need further evaluation by a physician.

Your next steps

This scale should not be used to make your own diagnosis.

If your score is 36 or more, please share this information with your physician. Be sure to describe all your symptoms as clearly as possible to aid in your diagnosis and treatment.



Scored Patient-Generated Subjective Global Assessment (PG-SGA)

History: Boxes 1 - 4 are designed to be completed by the patient.
[Boxes 1-4 are referred to as the PG-SGA Short Form (SF)]

1. Weight (See Worksheet 1)

In summary of my current and recent weight:

I currently weigh about ____ kg
I am about ____ cm tall

One month ago I weighed about ____ kg
Six months ago I weighed about ____ kg

During the past two weeks my weight has:

☐ decreased (1) ☐ not changed (0) ☐ increased (0)

Box 1

☐

Patient Identification Information

2. Food intake: As compared to my normal intake, I would rate my food intake during the past month as

- ☐ unchanged (0)
☐ more than usual (0)
☐ less than usual (1)

I am now taking

- ☐ *normal food* but less than normal amount (1)
☐ little solid food (2)
☐ only liquids (3)
☐ only nutritional supplements (3)
☐ very little of anything (4)
☐ only tube feedings or only nutrition by vein (0) **Box 2**

☐

3. Symptoms: I have had the following problems that have kept me from eating enough during the past two weeks (check all that apply)

- ☐ no problems eating (0)
☐ no appetite, just did not feel like eating (3)
☐ nausea (1)
☐ constipation (1)
☐ mouth sores (2)
☐ things taste funny or have no taste (1)
☐ problems swallowing (2)
☐ pain; where? (3) _____
☐ other (1) ** _____

Examples: depression, money, or dental problems **Box 3

☐

4. Activities and Function:

Over the past month, I would generally rate my activity as:

- ☐ normal with no limitations (0)
☐ not my normal self, but able to be up and about with fairly normal activities (1)
☐ not feeling up to most things, but in bed or chair less than half the day (2)
☐ able to do little activity and spend most of the day in bed or chair (3)
☐ pretty much bed ridden, rarely out of bed (3)

Box 4

☐

The remainder of this form is to be completed by your doctor, nurse, dietitian, or therapist. Thank you.

Additive Score of Boxes 1-4

☐ A

Scored Patient-Generated Subjective Global Assessment (PG-SGA)

Additive Score of Boxes 1-4 (See Side 1)

☐ A

Worksheet 1 – Scoring Weight Loss

To determine score, use 1-month weight data if available. Use 6-month data only if there is no 1-month weight data. Use points below to score weight change and add one extra point if patient has lost weight during the past 2 weeks. Enter total point score in Box 1 of PG-SGA.

Weight loss in 1 month	Points	Weight loss in 6 months
10% or greater	4	20% or greater
5-9.9%	3	10-19.9%
3-4.9%	2	6-9.9%
2-2.9%	1	2-5.9%
0-1.9%	0	0-1.9%

Numerical score from Worksheet 1 ☐

6. Worksheet 3 – Metabolic Demand

Score for metabolic stress is determined by a number of variables known to increase protein & caloric needs. Note: Score fever intensity or duration, whichever is greater. The score is additive so that a patient who has a fever of 38.8 °C (3 points) for < 72 hrs (1 point) and who is on 10 mg of prednisone chronically (2 points) would have an additive score for this section of 5 points.

Stress	none (0)	low (1)	moderate (2)	high (3)
Fever	no fever	> 37.2 and < 38.3	≥ 38.3 and < 38.8	≥ 38.8 °C
Fever duration	no fever	< 72 hours	72 hours	> 72 hours
Corticosteroids	no corticosteroids	low dose (< 10 mg prednisone equivalents/day)	moderate dose (≥ 10 and < 30 mg prednisone equivalents/day)	high dose (≥ 30 mg prednisone equivalents/day)

Numerical score from Worksheet 3 ☐ C

7. Worksheet 4 – Physical Exam

Exam includes a subjective evaluation of 3 aspects of body composition: fat, muscle, & fluid. Since this is subjective, each aspect of the exam is rated for degree. Muscle deficit/loss impacts point score more than fat deficit/loss. Definition of categories: 0 = no abnormality, 1+ = mild, 2+ = moderate, 3+ = severe. Rating in these categories is *not* additive but are used to clinically assess the degree of deficit (or presence of excess fluid).

Muscle Status

temples (temporalis muscle)	0	1+	2+	3+
clavicles (pectoralis & deltoids)	0	1+	2+	3+
shoulders (deltoids)	0	1+	2+	3+
intersosseous muscles	0	1+	2+	3+
scapula (latissimus dorsi, trapezius, deltoids)	0	1+	2+	3+
thigh (quadriceps)	0	1+	2+	3+
calf (gastrocnemius)	0	1+	2+	3+

Global muscle status rating

0 1+ 2+ 3+

Fat Stores

orbital fat pads	0	1+	2+	3+
triceps skin fold	0	1+	2+	3+
fat overlying lower ribs	0	1+	2+	3+

Global fat deficit rating

0 1+ 2+ 3+

Fluid Status

ankle edema	0	1+	2+	3+
sacral edema	0	1+	2+	3+
ascites	0	1+	2+	3+

Global fluid status rating

0 1+ 2+ 3+

Point score for the physical exam is determined by the overall subjective rating of the total body deficit.

No deficit	score = 0 points
Mild deficit	score = 1 point
Moderate deficit	score = 2 points
Severe deficit	score = 3 points

Again, muscle deficit/loss takes precedence over fat loss or fluid excess.

Numerical Score for Worksheet 4 ☐ D

Total PG-SGA Score (Total numerical score of A+B+C+D)

Clinician Signature

RD RN PA MD DO Other

Date

Global PG-SGA Category Rating (Stage A, Stage B or Stage C)

Worksheet 5 – PG-SGA Global Assessment Categories

Category	Stage A	Stage B	Stage C
Weight	Well-nourished No weight loss OR recent non-fluid wt gain OR recent OR Significant recent improvement	Moderate/suspected malnutrition ≤ 5% loss in 1 month (≤ 10% in 6 months) OR Progressive weight loss Definite decrease in intake	Severely malnourished > 5% loss in 1 month (> 10% in 6 months) OR Progressive weight loss Severe deficit in intake
Nutrient intake	No deficit OR Significant recent improvement	Presence of NIS (Box 3 of PG-SGA)	Presence of NIS (Box 3 of PG-SGA)
Functioning	No deficit OR Significant recent improvement	Moderate functional deficit OR Recent deterioration Evidence of mild to moderate loss of muscle mass &/or muscle tone on palpation &/or loss of SQ fat	Severe functional deficit OR Recent significant deterioration Obvious signs of malnutrition (e.g., severe loss muscle, fat, possible edema)
Physical Exam	No deficit OR chronic deficit but with recent clinical improvement		

Nutritional Triage Recommendations: Additive score is used to define specific nutritional interventions including patient & family education, symptom management including pharmacologic intervention, and appropriate nutrient intervention (food, nutritional supplements, enteral, or parenteral triage).

First line nutrition intervention includes optimal symptom management.

Triage based on PG-SGA point score

- 0-1 No intervention required at this time. Re-assessment on routine and regular basis during treatment.
- 2-3 Patient & family education by dietitian, nurse, or other clinician with pharmacologic intervention as indicated by symptom survey (Box 3) and lab values as appropriate.
- 4-8 Requires intervention by dietitian, in conjunction with nurse or physician as indicated by symptoms (Box 3).
- ≥ 9 Indicates a critical need for improved symptom management and/or nutrient intervention options.

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email: faithotterymdphd@gmail.com or info@pt-global.org

FAACT (Version 4)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Not at all	A little bit	Some- what	Quite a bit	Very much
<u>PHYSICAL WELL-BEING</u>						
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

		Not at all	A little bit	Some- what	Quite a bit	Very much
<u>SOCIAL/FAMILY WELL-BEING</u>						
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box ☐ and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

FAACT (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

FAACT (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
C6	I have a good appetite	0	1	2	3	4
ACT1	The amount I eat is sufficient to meet my needs.....	0	1	2	3	4
ACT2	I am worried about my weight	0	1	2	3	4
ACT3	Most food tastes unpleasant to me	0	1	2	3	4
ACT4	I am concerned about how thin I look.....	0	1	2	3	4
ACT6	My interest in food drops as soon as I try to eat	0	1	2	3	4
ACT7	I have difficulty eating rich or “heavy” foods.....	0	1	2	3	4
ACT9	My family or friends are pressuring me to eat	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
ACT10	When I eat, I seem to get full quickly	0	1	2	3	4
ACT11	I have pain in my stomach area.....	0	1	2	3	4
ACT13	My general health is improving	0	1	2	3	4

FAACT Scoring Guidelines (Version 4) – Page 1

- Instructions:*
1. Record answers in "item response" column. If missing, mark with an X
 2. Perform reversals as indicated, and sum individual items to obtain a score.
 3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.
 4. Add subscale scores to derive total scores (TOI, FACT-G & FAACT).
 5. **The higher the score, the better the QOL.**

Subscale	Item Code	Reverse item?	Item response	Item Score
PHYSICAL WELL-BEING (PWB)	GP1	4 -		=
	GP2	4 -		=
	GP3	4 -		=
	GP4	4 -		=
	GP5	4 -		=
	GP6	4 -		=
	GP7	4 -		=
Score range: 0-28				
				Sum individual item scores: _____
				Multiply by 7: _____
				Divide by number of items answered: _____ = PWB subscale score
SOCIAL/FAMILY WELL-BEING (SWB)	GS1	0 +		=
	GS2	0 +		=
	GS3	0 +		=
	GS4	0 +		=
	GS5	0 +		=
	GS6	0 +		=
	GS7	0 +		=
Score range: 0-28				
				Sum individual item scores: _____
				Multiply by 7: _____
				Divide by number of items answered: _____ = SWB subscale score
EMOTIONAL WELL-BEING (EWB)	GE1	4 -		=
	GE2	0 +		=
	GE3	4 -		=
	GE4	4 -		=
	GE5	4 -		=
	GE6	4 -		=
Score range: 0-24				
				Sum individual item scores: _____
				Multiply by 6: _____
				Divide by number of items answered: _____ = EWB subscale score
FUNCTIONAL WELL-BEING (FWB)	GF1	0 +		=
	GF2	0 +		=
	GF3	0 +		=
	GF4	0 +		=
	GF5	0 +		=
	GF6	0 +		=
	GF7	0 +		=
Score range: 0-28				
				Sum individual item scores: _____
				Multiply by 7: _____
				Divide by number of items answered: _____ = FWB subscale score

Perceived Stress Scale

A more precise measure of personal stress can be determined by using a variety of instruments that have been designed to help measure individual stress levels. The first of these is called the **Perceived Stress Scale**.

The Perceived Stress Scale (PSS) is a classic stress assessment instrument. The tool, while originally developed in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress. The questions in this scale ask about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way; rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

0 - never 1 - almost never 2 - sometimes 3 - fairly often 4 - very often

- _____ 1. In the last month, how often have you been upset because of something that happened unexpectedly?
- _____ 2. In the last month, how often have you felt that you were unable to control the important things in your life?
- _____ 3. In the last month, how often have you felt nervous and stressed?
- _____ 4. In the last month, how often have you felt confident about your ability to handle your personal problems?
- _____ 5. In the last month, how often have you felt that things were going your way?
- _____ 6. In the last month, how often have you found that you could not cope with all the things that you had to do?
- _____ 7. In the last month, how often have you been able to control irritations in your life?
- _____ 8. In the last month, how often have you felt that you were on top of things?
- _____ 9. In the last month, how often have you been angered because of things that happened that were outside of your control?
- _____ 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Figuring Your PSS Score

You can determine your PSS score by following these directions:

- First, reverse your scores for questions 4, 5, 7, and 8. On these 4 questions, change the scores like this:
 $0 = 4, 1 = 3, 2 = 2, 3 = 1, 4 = 0.$
- Now add up your scores for each item to get a total. **My total score is _____.**
- Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress.
 - ▶ Scores ranging from 0-13 would be considered low stress.
 - ▶ Scores ranging from 14-26 would be considered moderate stress.
 - ▶ Scores ranging from 27-40 would be considered high perceived stress.

The Perceived Stress Scale is interesting and important because your perception of what is happening in your life is most important. Consider the idea that two individuals could have the exact same events and experiences in their lives for the past month. Depending on their perception, total score could put one of those individuals in the low stress category and the total score could put the second person in the high stress category.

***Disclaimer:** The scores on the following self-assessment do not reflect any particular diagnosis or course of treatment. They are meant as a tool to help assess your level of stress. If you have any further concerns about your current well being, you may contact EAP and talk confidentially to one of our specialists.*

**State of New Hampshire
Employee Assistance Program**



Health Questionnaire (EQ-5D-5L)

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- ☐₁ I have no problems in walking about
- ☐₂ I have slight problems in walking about
- ☐₃ I have moderate problems in walking about
- ☐₄ I have severe problems in walking about
- ☐₅ I am unable to walk about

SELF-CARE

- ☐₁ I have no problems washing or dressing myself
- ☐₂ I have slight problems washing or dressing myself
- ☐₃ I have moderate problems washing or dressing myself
- ☐₄ I have severe problems washing or dressing myself
- ☐₅ I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- ☐₁ I have no problems doing my usual activities
- ☐₂ I have slight problems doing my usual activities
- ☐₃ I have moderate problems doing my usual activities
- ☐₄ I have severe problems doing my usual activities
- ☐₅ I am unable to do my usual activities

PAIN / DISCOMFORT

- ☐₁ I have no pain or discomfort
- ☐₂ I have slight pain or discomfort
- ☐₃ I have moderate pain or discomfort
- ☐₄ I have severe pain or discomfort
- ☐₅ I have extreme pain or discomfort

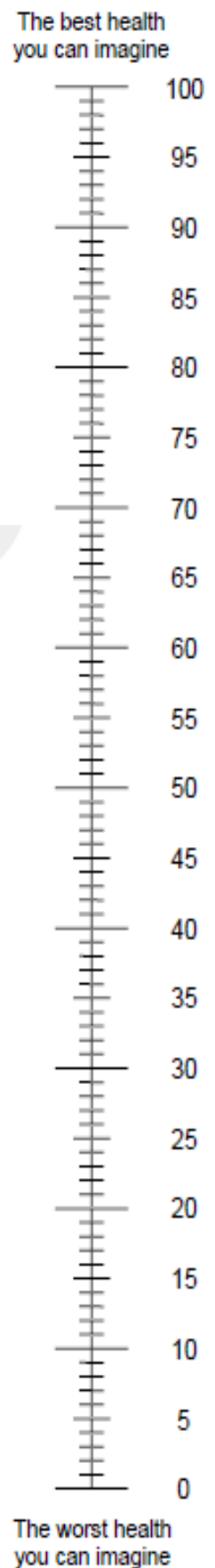
ANXIETY / DEPRESSION

- ☐₁ I am not anxious or depressed
- ☐₂ I am slightly anxious or depressed
- ☐₃ I am moderately anxious or depressed
- ☐₄ I am severely anxious or depressed
- ☐₅ I am extremely anxious or depressed

Health Questionnaire (EQ-5D-5L)

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is **TODAY**
- Now, please write the number you marked on the scale in the below.

YOUR HEALTH TODAY =



INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the **last 7 days**. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

1. During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

_____ **days per week**

☐

No vigorous physical activities



Skip to question 3

2. How much time did you usually spend doing **vigorous** physical activities on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐

Don't know/Not sure

Think about all the **moderate** activities that you did in the **last 7 days**. **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.

3. During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ **days per week**

☐

No moderate physical activities



Skip to question 5

4. How much time did you usually spend doing **moderate** physical activities on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

Think about the time you spent **walking** in the **last 7 days**. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

_____ **days per week**

☐ No walking → ***Skip to question 7***

6. How much time did you usually spend **walking** on one of those days?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

The last question is about the time you spent **sitting** on weekdays during the **last 7 days**. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

_____ **hours per day**

_____ **minutes per day**

☐ Don't know/Not sure

This is the end of the questionnaire, thank you for participating.

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D) _____ Anxiety (A) _____

0-7 = Normal

8-10 = Borderline abnormal (borderline case)

11-21 = Abnormal (case)

TTRILD Trial Cost Diary

Costs linked to my ILD

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Updates to your regular service usage

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Ethics

- [INSERT ETHICS INFORMATION HERE](#)

Need help?

For support, any questions or concerns please contact the TTRILD team:

(00) 0000 0000

AAAA.BBBB@cccc.edu.au

PART 1

Recording your basic information

In this first section you will record some basic information about yourself. This you will complete when you first get the *Cost Diary*.

Section A: Demographic information

A1. Please write your trial ID number

A2. What is your date of birth?

Please use the format DDMMYYYY

--	--	--	--	--	--	--	--

A3. What is your gender?

Male ☐

Female ☐

A4. What is your current postcode?

--	--	--	--	--

A5. What is your current relationship status?

Currently single, never married ☐

Currently married or de facto ☐

Currently separated, divorced or widowed ☐

A6. What is your race/ethnicity?

Oceanian (Papau, Maori, Melanesians, Micronesians, and Polynesians) ☐

Aboriginal/Torres Strait ☐

Caucasian ☐

Black ☐

North African and Middle Eastern ☐

Sub-Saharan African ☐

South-east Asian ☐

North-east Asian ☐

Southern and central Asian ☐

South American ☐

Central American/Caribbean ☐

The following questions are to provide information on the support you have within your home and if other people are dependent on you for support

Looking at
caring
responsibilities
and
productivity.
Fine to fill in
from clinical
history.

1

1

11

11

1

11

A diagram of a container with a piston. The container is partially filled with a dark substance, representing a small amount of gas. The piston is positioned at the top of the container, and a vertical line extends upwards from it, indicating the direction of expansion.

[illegible]

B2.If you have people who rely on you, e.g.: children at school or elderly relatives, please write in the boxes below the number of people who are dependent on you:

--	--

--	--

Section C: Current Employment Status

The following questions are about your current employment status, and the impact that your ILD may have/have had on your employment

C1. Which of the following best describes your current employment status?

important!

Employed full time - Go to C4 ☐

Employed part time - Go to C2 ☐

Self-employed - Go to C3 ☐

Unemployed, seeking full time paid employment - Go to C7 ☐

Unemployed, seeking part time paid employment - Go to C7 ☐

Unemployed, not seeking paid employment - Go to C7 ☐

Unpaid work only (e.g.: home management and/or volunteer work) - Go to C7 ☐

Student - Go to C7 ☐

Retired, not on a government pension (i.e.: self-funded retiree) - Go to C7 ☐

Retired, on a government pension - Go to C7 ☐

Other ☐

C2. For people employed PART-TIME, how many hours per week on average do you work part time? *PART-TIME please go to C4*

C3. For SELF EMPLOYED people, how many hours per week on average do you work?

C4. For those currently employed, what is your current occupation?

Manager ☐

Professional ☐

Technician or Trade Worker ☐

Community or Personal Service Worker ☐

Clerical and Administrative Workers ☐

Sales Worker ☐

Machinery Operator or Driver ☐

Labourer ☐

Other ☐

C5. Is your current paid employment at risk due to your ILD?

Yes - Go to C6 ☐

No - Go to Section D ☐

C6. Please indicate the main reasons your current paid employment is at risk due to ILD

Select ANY that apply

Not allowed flexible work hours/work conditions (e.g.: work from home) ☐

Not considered for promotion (perceived discrimination) ☐

Ran out of paid sick leave ☐

More suitable work not able to be found within the same organisation ☐

Asked to leave/sacked ☐

C7. For those NOT currently employed, has having an ILD made you leave your paid employment?

Yes - Go to C8 ☐

No - Go to Section D ☐

Not applicable - Go to Section D ☐

C8. In what year did you have to leave your paid employment?

--	--	--	--

C9. Please provide the main reasons you left your paid employment due to your ILD

Select ANY that apply

Not allowed flexible work hours/work conditions (e.g.: work from home) ☐

Not considered for promotion (perceived discrimination) ☐

Ran out of paid sick leave ☐

More suitable work not able to be found within the same organisation ☐

Asked to leave/sacked ☐

Section D: Employment Prior to ILD

The following questions are about your employment prior to the onset of your ILD symptoms

D1. Has the development of ILD caused you to change your employment status?

For example, from full time employment to part time.

Yes - Go to D2 ☐

No - Go to D6 ☐

D2. What year did you have to change your employment status due to ILD symptoms?

We appreciate this may include multiple changes over time. Please select a year that you think most accurately reflects the biggest impact to your employment status.

--	--	--	--

D3. Which of the following best describes your employment status before your first ILD symptoms?

Employed full time - Go to D6 ☐

Employed part time - Go to D4 ☐

Self-employed - Go to D5 ☐

Unemployed, seeking full time paid employment - Go to D6 ☐

Unemployed, seeking part time paid employment - Go to D6 ☐

Unemployed, not seeking paid employment - Go to D6 ☐

Unpaid work only (e.g.: home management and/or volunteer work) - Go to D6 ☐

Student - Go to D6 ☐

Retired, not on a government pension (i.e.: self-funded retiree) - Go to D6 ☐

Retired, on a government pension - Go to D6 ☐

D4. For those previously employed PART TIME - How many hours per week on average did you work part time before your first ILD symptoms?

--	--

D5. For those previously SELF EMPLOYED - How many hours per week on average did you work before your first ILD symptoms?

--	--	--

D6. Has the development of ILD caused you to change your occupation?

For example from "Labourer" to "Clerical"

Yes - Go to D7 ☐

No - Go to Section E ☐

D7. What year did you have to change your occupation due to your ILD?

--	--	--	--

D8. What was your occupation before your first ILD symptoms?

Manager ☐

Professional ☐

Technician or Trade Worker ☐

Community or Personal Service Worker ☐

Clerical and Administrative Workers ☐

Sales Worker ☐

Machinery Operator or Driver ☐

Labourer ☐

Other ☐

--

Section E: Education

E1. What is the highest level of education you have completed?

Can remove and collect in history

Did not go to school	☐
Year 8 or below	☐
Year 9 or equivalent	☐
Year 10 or equivalent	☐
Year 11 or equivalent	☐
Year 12 or equivalent	☐
Trade certificate	☐
Certificate II	☐
Associate diploma	☐
Advanced diploma	☐
Bachelor degree	☐
Postgraduate degree	☐

Section F: Income

F1. Have you received any of these government pensions or allowances in the past 12 months?

Select ANY that apply

- ABSTUDY/Austudy ☐
- Age Pension ☐
- Bereavement allowance ☐
- Carer Allowance ☐
- Carer Payment ☐
- Child Care Benefit ☐
- Child Care Rebate ☐
- Dad and Partner Pay ☐
- Disability Support Pension ☐
- Family Tax Benefit Part A ☐
- Family Tax Benefit Part B ☐
- Income Support Bonus ☐
- Jobs, Education and Training Childcare Fee Assistance ☐
- Low Income Supplement ☐
- Mobility Allowance ☐
- Newstart Allowance ☐
- Parental Leave Pay ☐
- Parenting Payment ☐
- Pensioner Education Supplement ☐
- Partner Allowance ☐
- Remote Area Allowance ☐
- Sickness Allowance ☐
- Single Income Family Supplement ☐
- Special Benefit ☐
- Widow Allowance ☐
- Widow B pension ☐
- Wife Pension ☐
- Youth Allowance ☐
- None, I do not receive any of these ☐

F2. Do you have a type of Concession or Health Care Card?

Select ALL that apply

Yes, Pensioner Concession Card ☐

Yes, Commonwealth Seniors Health Card ☐

Yes, Low Income Health Care Card ☐

Yes, DVA Gold card ☐

Yes, DVA White card ☐

Yes, DVA Orange card ☐

No, I do not have any of these ☐

Other ☐

F3. Which of the following is your current gross (before tax) personal income?

Nil income ☐

\$1 - \$199 per week (less than \$10,399 per year) ☐

\$200 - \$299 per week (\$10,400 – \$15,599 per year) ☐

\$300 - \$399 per week (\$15,600 - \$20,799 per year) ☐

\$400 - \$599 per week (\$20,800 - \$31,199 per year) ☐

\$600 - \$799 per week (\$31,200 - \$41,599 per year) ☐

\$800 - \$999 per week (\$41,600 – \$51,999 per year) ☐

\$1,000 - \$1,249 per week (\$52,000 – \$64,999 per year) ☐

\$1,250 - \$1,499 per week (\$65,000 - \$77,999 per year) ☐

\$1,500 - \$1,999 per week (\$78,000 - \$103,999 per year) ☐

\$2,000 or more per week (\$104,000 or more per year) ☐

Can collapse and
make them more
broad \$1-500
\$501-\$1000
> \$1000

(can be classified as
low, medium and high
income).

F4.

Which of the following is your current gross (before tax) combined household income?

Nil income

☐

\$1 - \$199 per week (less than \$10,399 per year)

☐

\$200 - \$299 per week (\$10,400 – \$15,599 per year)

☐

\$300 - \$399 per week (\$15,600 - \$20,799 per year)

☐

\$400 - \$599 per week (\$20,800 - \$31,199 per year)

☐

\$600 - \$799 per week (\$31,200 - \$41,599 per year)

☐

\$800 - \$999 per week (\$41,600 – \$51,999 per year)

☐

\$1,000 - \$1,249 per week (\$52,000 – \$64,999 per year)

☐

\$1,250 - \$1,499 per week (\$65,000 - \$77,999 per year)

☐

\$1,500 - \$1,999 per week (\$78,000 - \$103,999 per year)

☐

\$2,000 or more per week (\$104,000 or more per year)

☐

F5.

For those **CURRENTLY RETIRED** - At what age did you retire?

Section G: Personal Support

The following questions are about the assistance you may receive from people that you **DO NOT** pay for yourself (any assistance you do pay for will be covered in the Cost Diary). The assistance you receive is because of your GB and has started or increased due to your GB.

The last line in each category asks for an estimate of the number of hours of **additional support** you require but **do not** receive for that item. For the estimate, include additional hours you require but are not receiving whether they could be provided voluntarily or otherwise.

For example, you may be able to pay a gardener for 2 hours a week (reported in the Cost Diary) but you actually require 3 hours to keep the garden tidy. If you do **not** receive that additional hour because you can't afford to pay the gardener more and you have no volunteer to do it for you, then you would include that extra hour in the 'additional support you need but do not receive' line (even if you end up doing that hour yourself).

G1. Report the number of hours of assistance provided per week

Activities of daily living (e.g.: Personal care, meal preparation, physical access to or within the home):

can indicate benefit of
the intervention - less
cost due to less
assistance required

Partner/Spouse	
Other relative	
Friend	
Volunteer	
Non-charging organisation	
Estimate the number of hours of additional support (per week) you need but do NOT receive	

Home and garden (e.g.: Essential household tasks; repairs and maintenance; bills and household paperwork; maintenance outside and garden area):

Partner/Spouse	
Other relative	
Friend	
Volunteer	
Non-charging organisation	
Estimate the number of hours of additional support (per week) you need but do NOT receive	

Essential transport:

Partner/Spouse	
Other relative	
Friend	

Volunteer	
-----------	--

Non-charging organisation

Estimate the number of hours of additional support (per week) you need but do NOT receive

Child care:

Partner/Spouse

Other relative	
----------------	--

Friend	
--------	--

Volunteer	
-----------	--

Non-charging organisation

Estimate the number of hours of additional support (per week) you need but do NOT receive

Other:

Partner/Spouse	
----------------	--

Other relative	
----------------	--

Friend	
--------	--

Volunteer

Non-charging organisation

Estimate the number of hours of additional support (per week) you need but do NOT receive

G2. If you entered hours in the "Other" help required above, please describe the other item you receive or need assistance for.

[illegible]

Section H: Informal care

The following questions are to assess changes in the average yearly earnings of your support person (e.g.: partner, child, parent, friend) as a result of your ILD.

H1. Has someone (e.g.: partner, child, parent, friend) changed their employment situation or conditions to help you with your ILD?

Yes - Go to H2 ☐

No - Go to Section I

H2. Who changed their employment situation or conditions?

Partner
Child
Parent
Sibling
member
Friend
Other

Other

[illegible]

H3. What year did your support person change their employment conditions?

Please record the year of the change that has had the biggest impact.

--	--	--	--

H4. Please complete for your support person's change in employment:

Report average earnings per week rounded to the nearest \$10

Previously:

Average hours per week worked

--	--	--	--	--

Average earnings per week

--	--	--	--	--

Currently:

Average hours per week worked

--	--	--	--	--

Average earnings per week

--	--	--	--	--

H5. Please specify any other change in location or type of work for your support person

[illegible]

H6. Does this person receive a carer's payment or allowance from the government in relation to the care they provide you?

No - Go to Section I ☐

7

Yes, carer's payment - Go to Section I

Yes, carer's allowance - Go to Section I

Yes, other allowance - H7

Don't know - Go to Section I

H7. Please specify the 'other' carer's allowance

[illegible]

Section I: Insurance

The following questions ask about any health insurance you may have, and changes to this due to your ILD.

I1. Do you currently have Private Health Insurance?

Yes - Go to I2 ☐

```

graph TD
    Start([Start]) --> Q1{Q1}
    Q1 -- Yes --> Q2{Q2}
    Q1 -- No --> I3[No - Go to I3]
    Q2 -- Yes --> Q3{Q3}
    Q2 -- No --> I3
    Q3 -- Yes --> I3
    Q3 -- No --> I4[No - Go to I4]
    I3 --> End([End])
    I4 --> End

```

I2. For those with current Private Health Insurance - Please choose the level of cover you have:

Hospital only ☐

Extras only

Hospital and Extras	Room and Board	Physician's Fee	Other	Total
1	2	3	4	5
6	7	8	9	10
11	12	13	14	15
16	17	18	19	20
21	22	23	24	25
26	27	28	29	30
31	32	33	34	35
36	37	38	39	40
41	42	43	44	45
46	47	48	49	50
51	52	53	54	55
56	57	58	59	60
61	62	63	64	65
66	67	68	69	70
71	72	73	74	75
76	77	78	79	80
81	82	83	84	85
86	87	88	89	90
91	92	93	94	95
96	97	98	99	100

Other

Other

[illegible]

I3. Have you changed your private health insurance cover because of your ILD?

Yes - Go to I4 ☐

No - Go to I6	
---------------	--

I4. For those who have changed their private health insurance, why did you change your private health insurance cover?

Select ANY that apply

Can't afford premiums so stopped or decreased level of cover

Don't believe the benefit is worth the cost of the premiums

Don't believe I need it now ☐

Started cover so did not have to be on waiting list

Increased level of cover so receive benefits for more services

I5. Please choose the level of cover you used to have:

Hospital only ☐

Extras only	
-------------	--

Hospital and Extras

Other

Other

[illegible]

PART 2

Recording your initial details at the start of the *Cost Diary* period

Do this when you first get the *Cost Diary*.

This includes any major costs over the last 5 years, or any ongoing regular costs you may currently have linked to your ILD.

Section A: Cost Diary dates**A1.** Please state your *Cost Diary* start date:

<i>D</i>	<i>D</i>			/	<i>M</i>	<i>M</i>			/	<i>Y</i>	<i>Y</i>	<i>Y</i>	<i>Y</i>
										2	0	2	

A2. Please state your *Cost Diary* completion date – 6 months after start date:

<i>D</i>	<i>D</i>			/	<i>M</i>	<i>M</i>			/	<i>Y</i>	<i>Y</i>	<i>Y</i>	<i>Y</i>
										2	0	2	

A3. What is your date of birth?

<i>D</i>	<i>D</i>			/	<i>M</i>	<i>M</i>			/	<i>Y</i>	<i>Y</i>	<i>Y</i>	<i>Y</i>

Section B: Initial NDIS and My Aged Care package information**B1.** On your *Cost Diary* start date, were you on a *National Disability Insurance Scheme* (NDIS) or *My Aged Care* package?
 Yes, NDIS: ☐ Yes, *My Aged Care*: ☐ No (go to Section C): ☐
B2. What is your total annual package amount?

\$													

Section C: Gym or other membership packages**C1.** On your *Cost Diary* start date, did you have any gym or other memberships that you pay for on a per-time (not per-session) basis that helps your *ILD*?
 Yes: ☐ No (go to Section D: ☐
C2. What are your memberships, and how much do you pay for them?

Membership type		Cost			
1		\$ _____	every	☐ week ☐ fortnight	☐ month ☐ Year
2		\$ _____	every	☐ week ☐ fortnight	☐ month ☐ year
3		\$ _____	every	☐ week ☐ fortnight	☐ month ☐ year

Section D: Your regular services and appointments for your ILD

D1. Please record any regular service or appointment details you have for your ILD at your *Cost Diary* start date, and any transport that you use for services outside your home. These may include services such as house cleaning , gym visits, exercise physiology, pulmonary rehabilitation, physio appointments, etc. While you may miss sessions due to illness or vacations, they are a scheduled part of your routine, whether they occur several times a week or just once a month. Please record any transportation expenses that may be associated with each appointment where applicable.

☐ I do not have any regular services or appointments to record for my ILD

Type of service or appointment	Usual length of service or appointment	Service or appointment frequency	Is this service part of a package (from Section B) or membership (from Section D)?
1	h h : m m	week _____ times a fortnight month	☐ NDIS or <i>My Aged Care</i> funded ☐ Part of membership (D2 #____) ☐ Other payment source
2	h h : m m	week _____ times a fortnight month	☐ NDIS or <i>My Aged Care</i> funded ☐ Part of membership (D2 #____) ☐ Other payment source
3	h h : m m	week _____ times a fortnight month	☐ NDIS or <i>My Aged Care</i> funded ☐ Part of membership (D2 #____) ☐ Other payment source
4	h h : m m	week _____ times a fortnight month	☐ NDIS or <i>My Aged Care</i> funded ☐ Part of membership (D2 #____) ☐ Other payment source

Section E: Other Regular Transport

E1 Do you have any other regular transport costs for your ILD? For example, transport to work or the shops, where you need to take your car and park close because you can't use public transport, or needing to take a taxi as there is no suitable parking close to where you need to go?

☐ I do not have any other regular transport to record for my ILD

Transport type (N/A, private car, taxi, Uber, public transport)	Reason	Travel time	Approx distance (private car travel only)	Approx fare or parking cost	Travel frequency										
1		<table border="1"><tr><td></td><td></td><td>:</td><td></td><td></td></tr><tr><td><i>h</i></td><td><i>h</i></td><td></td><td><i>m</i></td><td><i>m</i></td></tr></table>			:			<i>h</i>	<i>h</i>		<i>m</i>	<i>m</i>	km	\$	☐ week _____ times a ☐ fortnight ☐ month
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		:													
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		:													
<i>h</i>	<i>h</i>		<i>m</i>	<i>m</i>											
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		:													
<i>h</i>	<i>h</i>		<i>m</i>	<i>m</i>											

Section F: Residential details impacted by your ILD over the last 5 years

F1. At the start of your *Cost Diary* period, do you live **full time** in a nursing home at least in part due to your ILD?

Yes: ☐No: ☐

F2. In the last 5 years have you had to **move residence** to somewhere more suitable for your ILD?

Yes: ☐No (*go to F3*): ☐

Please provide details on each move, including sale and purchase prices (if applicable), and an estimate of the total relocation cost (including any removalist costs, electricity reconnection, conveyancing fees, stamp duty etc)

	Purchase price of new house	Sale price of previous house	Approximate relocation costs
1	\$ OR ☐ N/A (I do not own my new home)	\$ OR ☐ N/A (I was not the owner)	\$
2	\$ OR ☐ N/A (I do not own my new home)	\$ OR ☐ N/A (I was not the owner)	\$
3	\$ OR ☐ N/A (I do not own my new home)	\$ OR ☐ N/A (I was not the owner)	\$

F3. In the last 5 years have you had to make any **alterations** to the **structure of your home** to better accommodate your ILD?

Examples include major structural renovations, through to installation of a wheel chair elevators, or ramps hand railings or other adjustments.

Yes: ☐No (*go to F4*): ☐

Please provide a description of the alterations to your house, and the total cost (including any labour costs for building or installation).

	Alteration description	Total cost
1		\$
2		\$
3		\$
4		\$

F4. Have you purchased or hired any **special equipment** for your ILD over the last 5 years?

Mobility, support items, medical equipment, oxygen concentrators/portable oxygen or similar equipment and replacement/ disposables associated with these, communication equipment, bathroom, kitchen, bedroom, general.

Yes: ☐ No (go to Part 3): ☐

Item description		Amount you paid	Tick if this item has been hired
1		\$	☐
2		\$	☐
3		\$	☐
4		\$	☐
5		\$	☐
6		\$	☐
7		\$	☐
8		\$	☐
9		\$	☐
10		\$	☐
11		\$	☐
12		\$	☐
13		\$	☐
14		\$	☐

PART 3

Recording your details during the trial *Cost Diary* period

In this section you will record your costs during the trial period. You may choose to do so at the intervals that we specify or continuously, whichever may be easier for you. If you decide to record at intervals you will need to record costs for the whole period.

PART 3

RECORDING YOUR COSTS: Medications and supplements relating to your ILD

This section is for all the medications and supplements you may purchase during the trial *Cost Diary* Period for symptom management and disease progression prevention and general health.

If you purchase some medications regularly and/or buy more than one packet at once, you may use the tally space provided to keep track of your total over the trial period, rather than having to create a new line each time.

Medications and supplements

Medication Name		Active ingredient strength	Packet or bottle size or volume	Tick for prescription medication	Number of packets purchased	
					Tally space	Total over the trial
1				☐		
2				☐		
3				☐		
4				☐		
5				☐		
6				☐		
7				☐		
8				☐		
9				☐		
10				☐		
11				☐		
12				☐		
13				☐		
14				☐		

Medication Name	Active ingredient strength	Packet or bottle size or volume	Tick for prescription medication	Number of packets purchased	
				Tally space	Total over the trial
15			☐		
16			☐		
17			☐		
18			☐		
19			☐		
20			☐		
21			☐		
22			☐		
23			☐		
24			☐		
25			☐		
26			☐		
27			☐		
28			☐		

Medications and supplements

Medication Name	Active ingredient strength	Packet or bottle size or volume	Tick for prescription medication	Number of packets purchased	
				Tally space	Total over the trial
29			☐		
30			☐		
31			☐		
32			☐		
33			☐		
34			☐		
35			☐		
36			☐		
37			☐		
38			☐		
39			☐		
40			☐		
41			☐		
42			☐		

PART 3

RECORDING YOUR COSTS: Item purchases and equipment hiring relating to your ILD

This section is for all items you purchase or hire for, or because of, your ILD during the trial *Cost Diary* period. Everything from purchasing/hiring a wheelchair, or oxygen equipment, through to equipment needed for physio sessions etc

Item purchases and equipment hiring relating to your ILD

Date		Item description	Amount you paid	Tick if this item has been hired
1			\$	☐
2			\$	☐
3			\$	☐
4			\$	☐
5			\$	☐
6			\$	☐
7			\$	☐
8			\$	☐
9			\$	☐
10			\$	☐
11			\$	☐
12			\$	☐
13			\$	☐
14			\$	☐
15			\$	☐
16			\$	☐

Date		Item description	Amount you paid	Tick if this item has been hired
17			\$	☐
18			\$	☐
19			\$	☐
20			\$	☐
21			\$	☐
22			\$	☐
23			\$	☐
24			\$	☐
25			\$	☐
26			\$	☐
27			\$	☐
28			\$	☐
29			\$	☐
30			\$	☐
31			\$	☐
32			\$	☐

Item purchases and equipment hiring relating to your ILD

Date		Item description	Amount you paid	Tick if this item has been hired
33			\$	☐
34			\$	☐
35			\$	☐
36			\$	☐
37			\$	☐
38			\$	☐
39			\$	☐
40			\$	☐
41			\$	☐
42			\$	☐
43			\$	☐
44			\$	☐
45			\$	☐
46			\$	☐
47			\$	☐
48			\$	☐

PART 3

RECORDING YOUR COSTS: Medical tests and scans

This section is for any tests or scans you may be required to undertake in the trial *Cost Diary* period for your ILD.

While the most common items would be blood tests and lung function tests, this section can include everything from liver function tests, through to CT and MRI scans.

Medical tests and scans

Date	Test or scan type	Have you included travel for this test elsewhere in the <i>Cost Diary</i> ?
1		No: ☐  Yes: ☐
2		No: ☐  Yes: ☐
3		No: ☐  Yes: ☐
4		No: ☐  Yes: ☐
5		No: ☐  Yes: ☐

	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Approx fare or parking cost
	To service: : km \$ ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$			1
	To service: : km \$ ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$			2
	To service: : km \$ ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$			3
	To service: : km \$ ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$			4
	To service: : km \$ ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$			5

PART 3

RECORDING YOUR COSTS: Temporary hospital and health care admissions

Hospital including emergency department attendances, rehab or respite admissions – including hospital in the home. Don't include full time nursing home care.

Temporary hospital and health care admissions

Accommodation type		Reason for admission	Dates	
1			Admission date: OR I was here at the start of the <i>Cost Diary</i> period: Discharge date: OR I have not been discharged: (at end of <i>Cost Diary</i> period)	
2			Admission date: Discharge date: OR I have not been discharged: (at end of <i>Cost Diary</i> period)	
3			Admission date: Discharge date: OR I have not been discharged: (at end of <i>Cost Diary</i> period)	
4			Admission date: Discharge date: OR I have not been discharged: (at end of <i>Cost Diary</i> period)	
5			Admission date: Discharge date: OR I have not been discharged: (at end of <i>Cost Diary</i> period)	

	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Approx fare or parking cost
	For admission: h h m m			

km \$

h

h

m

m

km \$

PART 3

RECORDING YOUR COSTS: Appointments and services

Please include all health(specialist, GP) or specialist nurse appointments related to your of your ILD. Do not include services such as physio, rehab or other allied health care services, support groups or support for household tasks here these should be included in Parts 1,2 and 5 in the appropriate sections.

Appointments and services

Date		Service type	Length of appointment	Type of appointment		
				Face-to-Face	Telehealth	
1			h h : m m			
2			h h : m m			
3			h h : m m			
4			h h : m m			
5			h h : m m			

	Did you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Approx fare or parking cost
	Yes ☐ No ☐	<i>To service:</i> : <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip <u>OR</u> <i>Return by:</i> : <i>h h</i> <i>m m</i> km \$	1		
	Yes ☐ No ☐	<i>To service:</i> <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip <u>OR</u> <i>Return by:</i> <i>h h</i> <i>m m</i> km \$	2		
	Yes ☐ No ☐	<i>To service:</i> : <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip <u>OR</u> <i>Return by:</i> : <i>h h</i> <i>m m</i> km \$	3		
	Yes ☐ No ☐	<i>To service:</i> <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip <u>OR</u> <i>Return by:</i> <i>h h</i> <i>m m</i> km \$	4		
	Yes ☐ No ☐	<i>To service:</i> : <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip <u>OR</u> <i>Return by:</i> : <i>h h</i> <i>m m</i> km \$	5		

Appointments and services

Date		Service type	Length of appointment	Type of appointment		
				Face-to-Face	Telehealth	
6			h h : m m			
7			h h : m m			
8			h h : m m			
9			h h : m m			
10			h h : m m			

	Did you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Approx fare or parking cost
	Yes ☐ No ☐	<i>To service:</i> : <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip OR <i>Return by:</i> : <i>h h</i> <i>m m</i> km \$	6		
	Yes ☐ No ☐	<i>To service:</i> <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip OR <i>Return by:</i> <i>h h</i> <i>m m</i> km \$	7		
	Yes ☐ No ☐	<i>To service:</i> : <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip OR <i>Return by:</i> : <i>h h</i> <i>m m</i> km \$	8		
	Yes ☐ No ☐	<i>To service:</i> <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip OR <i>Return by:</i> <i>h h</i> <i>m m</i> km \$	9		
	Yes ☐ No ☐	<i>To service:</i> : <i>h h</i> <i>m m</i> km \$ ☐ My return journey used the same transport type and route as my outbound trip OR <i>Return by:</i> : <i>h h</i> <i>m m</i> km \$	10		

PART 3

RECORDING YOUR COSTS: Other Transport

This is for other transport bits – eg item purchases, medications, one off trips to visit friends or go for coffee (this would be transport that you would have to take because of your ILD).

Other Transport

Date	Transport type (N/A, private car, taxi, Uber, public transport)	Reason	Travel time	Approx distance (private car travel only)	Approx fare or parking cost
1			h h : m m		

km

\$

PART 4

Impact on employment during the trial period

In this section you will keep track of how your ILD affects your work

Please only answer the following questions if you are currently employed (fulltime/part-time, casual/self-employed). If you have not worked, please go to Part 5.

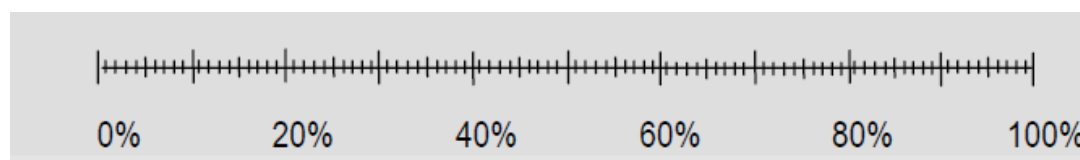
A.1

Have you stayed home for more than half the day because of ANY health problem (please insert date the date you stayed home)	Was this ILD related? (yes/no)	Did you go to work while suffering from ANY health problems? (please insert the date you worked)	Was this ILD related? (yes/no)

A.2 On these days when you went to work suffering from **ANY** health problems, what percentage of your time were you as productive as usual?

For example, if you were exactly as productive as usual please mark '100 %'.

Please indicate the percentage with a vertical line on the scale below.



A.3

Have you taken paid sick leave because of ANY health problem (please insert date)	Was this ILD related? (yes/no)	Have you taken sick leave because of ANY health problem (please insert date)	Was this ILD related? (yes/no)

PART 5

Finalising your details at the end of the trial period

In this last section you will update any details that may have changed in Part 2 over the trial period.

Section A: Updates to your NDIS or My Aged Care Package

A1. Have your NDIS or *My Aged Care* package details changed over the period of the *Cost Diary* (including starting a new package, or changes to existing package amounts)?

Yes ☐ No (Go to Section B): ☐

A2. What date did the change come into effect?

D *D*
M *M*
Y *Y* *Y* *Y*
 / /

A3. Which package were you on after this date?

NDIS: ☐
My Aged Care: ☐
None: ☐

A4. What is your new total annual package amount?

\$, .

Section B: Updates to your gym or other memberships for your ILD

B1. Have any of your gym or other memberships that you pay for on a per-time (not per-session) basis changed over the period of the *Cost Diary* (including starting a new membership, or changes to existing ones)?

Yes: ☐ No (Go to Section C): ☐

B2. What date did membership change come into effect, and how much do you pay?

Date of first or last payment		Membership type	Cost
1			\$ _____ every ☐ week ☐ month ☐ fortnight ☐ year
2			\$ _____ every ☐ week ☐ month ☐ fortnight ☐ year
3			\$ _____ every ☐ week ☐ month ☐ fortnight ☐ year
4			\$ _____ every ☐ week ☐ month ☐ fortnight ☐ year

Section C: Updates to your regular services or appointments for your ILD

C1. Since you started your *Cost Diary*, have you added any other regular services or appointments?

☐ I did not change any of my regular services or appointments for my ILD

Type of service or appointment	Date and type of change	Usual length of service or appointment	Service or appointment frequency	Is this service part of a package or membership?
1	Date ☐ removed ☐ added	: h h m m	☐ week ☐ fortnight ☐ month _____ times a	☐ NDIS or My Aged Care funded ☐ Part of a membership ☐ Neither
2	Date ☐ removed ☐ added	: h h m m	☐ week ☐ fortnight ☐ month _____ times a	☐ NDIS or My Aged Care funded ☐ Part of a membership ☐ Neither
3	Date ☐ removed ☐ added	: h h m m	☐ week ☐ fortnight ☐ month _____ times a	☐ NDIS or My Aged Care funded ☐ Part of a membership ☐ Neither
4	Date ☐ removed ☐ added	: h h m m	☐ week ☐ fortnight ☐ month _____ times a	☐ NDIS or My Aged Care funded ☐ Part of a membership ☐ Neither
5	Date ☐ removed ☐ added	: h h m m	☐ week ☐ fortnight ☐ month _____ times a	☐ NDIS or My Aged Care funded ☐ Part of a membership ☐ Neither

	Do you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Approx fare or parking cost
	Yes ☐ No ☐	To service: : km \$ h h m m ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$ h h m m			1
	Yes ☐ No ☐	To service: : km \$ h h m m ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$ h h m m			2
	Yes ☐ No ☐	To service: : km \$ h h m m ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$ h h m m			3
	Yes ☐ No ☐	To service: : km \$ h h m m ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$ h h m m			4
	Yes ☐ No ☐	To service: : km \$ h h m m ☐ My return journey uses the same transport type and route as my outbound trip OR Return by: : km \$ h h m m			5

Continued over...

Section D: Other Regular Transport

Have you started or stopped any other regular transport costs for your ILD since the start of the *Cost Diary*? For example, transport to work or the shops, where you need to take your car and park close because you can't use public transport, or needing to take a taxi as there is no suitable parking close to where you need to go?

☐ I did not change any of my regular transport for my ILD

Transport type (N/A, private car, taxi, Uber, public transport)	Reason	Date and type of change	Travel time	Approx distance (private car travel only)	Approx fare or parking cost	Travel frequency
1		Date removed added	h h : m m	km	\$	times a ☐ week ☐ fortnight ☐ month
2		Date removed added	h h : m m	km	\$	times a ☐ week ☐ fortnight ☐ month
3		Date removed added	h h : m m	km	\$	times a ☐ week ☐ fortnight ☐ month
4		Date removed added	h h : m m	km	\$	times a ☐ week ☐ fortnight ☐ month
5		Date removed added	h h : m m	km	\$	times a ☐ week ☐ fortnight ☐ month

Section E: Residential changes during the trial period

E1. Have you made any **alterations** to the **structure of your home** to better accommodate your ILD during the trial period?

Examples include major structural renovations, through to installation of a wheel chair elevators, or ramps hand railings or other adjustments.

Yes: ☐

No (go to E4): ☐

Please provide a description of the alterations to your house, and the total cost (including any labour costs for building or installation).

Alteration or purchase description		Total cost
1		\$
2		\$
3		\$

E2. Since the start of your *Cost Diary* period, have you moved to live **full time** in a nursing home?

Yes: ☐

No (Go to E3): ☐

What date did you move to the nursing home?

D D
M M
Y Y Y Y
 / /

E3. Since the start of the *Cost Diary* have you had to **move residence** to somewhere more suitable for your ILD?

Yes: ☐

No (go to Section F): ☐

Please provide details on each move, including sale and purchase prices (if applicable), and an estimate of the total relocation cost (including any removalist costs, electricity reconnection, conveyancing fees, stamp duty etc)

	Purchase price of new house	Sale price of previous house	Approximate relocation costs
1	\$ OR ☐ N/A (I do not own my new home)	\$ OR ☐ N/A (I was not the owner)	\$
2	\$ OR ☐ N/A (I do not own my new home)	\$ OR ☐ N/A (I was not the owner)	\$

Section F: Thank you!

Thank you for completing the *Cost Diary*.

Please check over each section to ensure you have recorded all costs. If you have any further questions or would like to clarify anything before returning your Cost Diary, please contact us on:

(00) 0000 0000

AAAA.BBBB@cccc.edu.au

Criteria	Questions	Score
Strength	How much is the difficulty to lift/carry 10 pounds (4.5 kilograms) weight?	0=no difficulty 1=some difficulty 2=a lot of difficulty
Assistance	How much is the difficulty to walk across a room and whether the use of aid or help is needed?	0=no difficulty 1=some difficulty 2=a lot of difficulty, use aids, or unable to do without personal help
Rise	How much is the difficulty to transfer from a chair or bed and whether the use of aid or help is needed?	0=no difficulty 1=some difficulty 2=a lot of difficulty, use aids, or unable to do without personal help
Climb	How much is the difficulty to climb a flight of 10 steps?	0=no difficulty 1=some difficulty 2=a lot of difficulty
Falls	How many falls are experienced for the past one year?	0=no falls 1=1–3 times falls 2=>3 times falls

Physiotherapy Exercise Program

Physiotherapy Department at Fiona Stanley Hospital runs exercise groups designed especially for people with Respiratory (Lung) Disease.

Time:

90-minute session
Most days per week

What to bring:

Wear comfortable shoes and bring a drink bottle, a small towel, and any puffers or GTN (if you have these)

Transport:

Assistance can be arranged for those with difficulties.

Warm up Stretches

The warmup phase of any exercise program is of utmost importance. It allows the blood flow to slowly increase to your muscles and therefore decrease the risk of muscle injury or soreness following exercise.

It is important to stretch each of the major muscle groups you intend to exercise. Do each stretch twice on each side of the body and hold for 10-15 seconds. Do not bounce when at full stretch.

Calf



Quads



Hamstring



Trunk



Chest



Arms



Endurance

This part of your exercise program is the one that takes the longest. Endurance exercise is the type of exercise that uses oxygen. Throughout this part of the exercise, you should work to a level that makes you feel moderate to somewhat-severely short of breath.

Walking

This is an essential part of your exercise program, helping to improve your function and mobility.

Course/Distance:

Time:

Intensity:



Hill Climbing



Step ups



Sit to stands



Wall squats

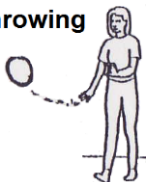


Additional Endurance Exercises:

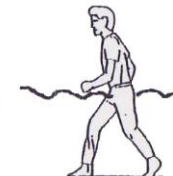
Cycling



Ball Throwing



Water Exercise



Tai Chi



Upper Limb Strengthening Exercise

This part of your exercise program focuses on strengthening your upper body and the muscles that assist with your breathing. They target each group of muscles individually.

Repeat each exercise ____ times.

Using a _____ kg weight

Biceps Curls



Triceps



Shoulder press



Punches



Shoulder Flexion



Shoulder abduction



Wall Pushups



Cool Down

This part of your exercise program is just as vital as the warmup in preventing muscle injury and soreness. As with the warmup, you should stretch each of the major muscle groups that you have been exercising.

Progression

It is important that your exercise program is completed in its entirety **at least 3 times** per week. Initially it will take at least one hour with frequent rests. Slowly increase your distance or number of repetitions and decrease the number and length of rests over a period of weeks. It will take perseverance and dedication over several weeks to achieve significant improvements.

Precautions

Do not Exercise.

- If you are unwell eg chest infection/flu
- Have pain of unknown origin
- Nausea or excessive shortness of breath
- Wait 1 hour after main meals.
- Avoid outdoor exercise in extremes of weather.
- Irregular or unusual fast heart beats

You should always discuss any new exercise program with your doctor before commencing.

Online resource: www.lungfoundation.com.au

Go to "Lung information" tab, "patient education material", and click on "Better living with COPD – a Patient Guide".

Am J Respir Crit Care Med Vol 159. pp 1666-1682, 1999

www.atsjournals.org

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Acknowledgement: Royal Perth Hospital, Swan Health Service, Bentley Health Service and Community Physiotherapy Service.



**Allied Health
Physiotherapy**

Fiona Stanley Hospital

**Physiotherapy
Pulmonary
Rehabilitation
Programs**

Contact Physiotherapist:

Phone: (08) 6152 _____

Please note, it is a requirement of enrolment that you contact us if you are unable to attend a session. Unfortunately, if we have not heard from you and you have missed three sessions, you will be discharged. Your doctor will be notified, and you will require another referral for the program.

Better Living with Exercise

YOUR PERSONAL GUIDE



This exercise guide belongs to:

Contact:



**Lung
Foundation
Australia**

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Introduction	1
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Acknowledgments

Lung Foundation Australia wishes to acknowledge the efforts of all those involved in the development of *Better Living with Exercise – Your Personal Guide*.

Clinical Advisory Team

- ♣ Ms Holly Landers, Program Coordinator Pulmonary & Cardiac Rehabilitation, Community Physiotherapy Services South Metropolitan Health Service, Perth
- ♣ Dr Julie Cooke (PhD), Senior Lecturer Anatomy & Physiology, Faculty of Health, University of Canberra
- ♣ Dr Narelle Cox (PhD), Research Fellow, Physiotherapy, La Trobe University, Melbourne
- ♣ Mrs Sara Slayman, Accredited Exercise Physiologist, AEP Health Group

Expert Reviewers

- ♣ Prof Jennifer Alison, Discipline of Physiotherapy, Faculty of Health Sciences, The University of Sydney
- ♣ Dr Lissa Spencer (PhD), Clinical Specialist Physiotherapist, Chronic Disease Rehabilitation, Royal Prince Alfred Hospital, Sydney

Patient Representatives

- ♣ John Poletti, COPD Patient Advocate Group, Victoria
- ♣ Michael Higgins, Lungs in Action Participant, Canberra

Congratulations on taking an active approach to managing your lung condition. *Better Living with Exercise - Your Personal Guide* was developed by Lung Foundation Australia to help you and your treating exercise professional develop the most suitable exercise program for you to improve your physical and social wellbeing.

Your exercise program will be prescribed based on your individual health status and the goals you want to achieve. You will not be asked to do anything that you are not comfortable with, and will be encouraged to take a key role in developing your program.

Better Living with Exercise - Your Personal Guide has been designed to be used from pulmonary rehabilitation, through to pulmonary maintenance exercise in conjunction with your exercise professional (for example; Accredited Exercise Physiologist or Physiotherapist). If you have not previously undertaken pulmonary rehabilitation, you may like to consider discussing the benefits of such a program with your lung specialist or GP.

Here are some outcomes that you may expect as a result of participating in pulmonary rehabilitation and improving your physical activity levels:

Reduction in

- ✦ Breathlessness
- ✦ Fatigue
- ✦ Level of symptoms relating to depression and anxiety
- ✦ Hospitalisations

Improvement in

- ✦ Physical capacity to perform everyday activities
- ✦ Quality of life
- ✦ Sense of control over lung condition

Better Living with Exercise - Your Personal Guide is only to be used once you have received medical clearance to exercise by your doctor.

Please note that this guide is designed to compliment existing educational resources developed by Lung Foundation Australia, such as *Better Living with COPD - A Patient Guide*. To view our suite of resources visit page 30-31 or contact Lung Foundation Australia's Information and Support Centre.

**Lung Foundation Australia's Information and Support Centre
can be contacted on freecall 1800 654 301.**

Exercise Safety

The safest and best way to learn how to exercise if you have a chronic lung condition is to take part in a pulmonary rehabilitation program.

To be safe during exercise make sure you:

- ✓ Have been clearly shown how to perform the exercises by an appropriately trained exercise professional before commencing.
 - ✓ Have taken your reliever inhalers before exercising if prescribed by your doctor to do so, and have them with you throughout.
 - ✓ Drink enough fluids.
 - ✓ Use recovery positions to reduce breathlessness.
 - ✓ Use pursed lip breathing.
 - ✓ Use your oxygen for exercise, if it has been prescribed by your doctor.
 - ✓ Are adequately warmed up before commencing.
 - ✓ Restart your exercise program at a lower intensity if you have not exercised for a while or you have been unwell.
-
- ✗ Avoid strenuous exercise if you have a fever, a flare-up of your condition or the common cold.
 - ✗ Do not exercise immediately after a big meal.
 - ✗ Do not exercise in extreme heat or cold.
 - ✗ Never turn your oxygen up higher than prescribed for exercising unless you have discussed this with your doctor.

**To locate your nearest pulmonary rehabilitation program
contact Lung Foundation Australia.**

- ✦ For further information on breathing techniques and managing breathlessness refer to chapter 12 of Better Living with COPD - A Patient Guide named breathlessness, breathing control and energy conservation.
- ✦ Before you exercise, please ensure you have checked that you do not have any symptoms of a flare up of your lung condition. Further information can be found in chapter 9 of Better Living with COPD - A Patient Guide named preventing and managing a flare up.

Danger signs



Stop exercising and call 000 if you experience any signs and symptoms of a heart attack.

The warning signs can be varied and may include discomfort and pain in the centre of your chest, along with discomfort to a number of areas in the upper body. You are encouraged to review Heart Foundation's resources on how to recognise a heart attack before exercising. (<https://www.heartfoundation.org.au/conditions/heart-attack>)



Stop and rest immediately if you experience any of the below:

- 🌿 Dizziness or feeling faint
- 🌿 Excessive wheezing
- 🌿 Extreme pain
- 🌿 Coughing up blood
- 🌿 Extreme shortness of breath
- 🌿 Blurred vision
- 🌿 Nausea
- 🌿 Feeling of palpitations or a racing heart
- 🌿 Chest pain

None of these danger signs are normal and should prompt you to seek medical attention.

In an emergency please do not hesitate to call 000.

- 🌿 If you also have diabetes, heart failure, angina or any other diseases that may affect your ability to exercise, discuss these with your health professional to ensure you know the danger signs related to your condition.
- 🌿 If uncertain about your current condition and safety to exercise please consult your doctor or health care professional.
- 🌿 Any exercises that cause pain in a muscle or joint should be discontinued, and reviewed by a medical practitioner.

Exercise Effectively

This section aims to cover important information that will help you and your treating exercise professional create a program that is safe and effective for your needs. A great way to design a program to help you safely achieve your goals is the FITT Principle.

- Frequency** refers to the number of times you will aim to exercise. *For example exercising 3-5 times per week.*
- Intensity** refers to how hard you work whilst exercising. *For example working hard enough to feel a breathlessness score of 3-4 on the Borg Dyspnoea Scale. (See table below).*
- Time** refers to the exercise duration or how long you exercise for. *For example 10 minutes of walking.*
- Type** refers to what kind of exercise you do. *For example walking, strength program, stretching.*

Modified Borg Dyspnoea Scale

0	NOTHING AT ALL	
0.5	VERY, VERY SLIGHT (just noticeable)	
1	VERY SLIGHT	
2	SLIGHT	
3	MODERATE	Exercise Training Zone
4	SOMEWHAT SEVERE	
5	SEVERE	
6		
7	VERY SEVERE	
8		
9	VERY, VERY SEVERE (almost maximal)	
10	MAXIMAL	

- In addition to the exercises described in this exercise guide, your exercise professional may prescribe you extra activities to meet your specific needs such as core/pelvic floor exercises, balance training etc.
- Get creative by thinking about other activities you enjoy that encourage you to be physically active.
 For example gardening, dancing, yoga or playing with grandchildren. Together with regular exercise, being physically active throughout the day is important for health and wellbeing.

Taking the FITT principles into consideration, the next step will be to start developing an exercise plan. Work with your exercise professional through the following four areas.

Warm Up

It is important to gradually warm up your heart and muscles. This part of your routine should make you only slightly out of breath, and include slow controlled movements targeting every area of the body you will be using. Examples may include, but are not limited to a slower paced walk, slow knee lifts, heel taps, trunk twists, shoulder shrugs/circles or ankle rotations. Alternatively, you can be creative and include tai chi, a balance routine or slow dance steps if you have experience in this area.

Aerobic Exercise

An aerobic program commonly involves walking as its main component, as this is the most relevant exercise for daily living. Other types of aerobic exercise may include cycling, riding an exercise bike or even using a rowing machine. Some people also find alternative exercises like exercising in water (for example walking through shallow water or swimming), tai chi, or dancing enjoyable. You could use these exercises to add variety to your program or if you have difficulties with walking.

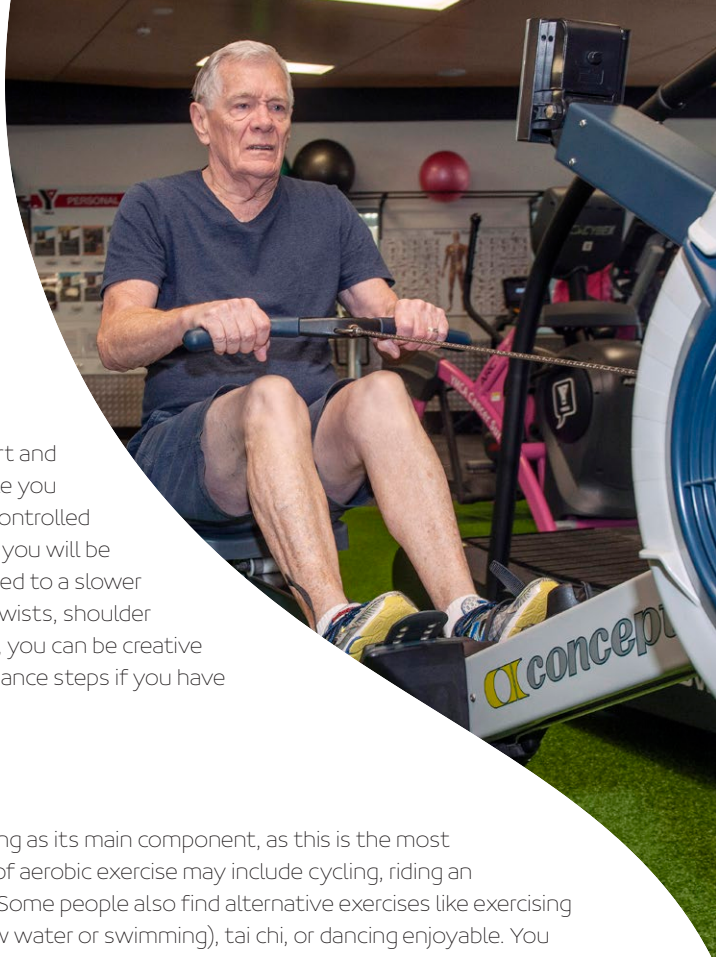
Strengthening

Including strengthening exercises in your routine will keep your muscles strong and prevent some of the effects of having a chronic lung condition. Strength training should include exercises for your arms, torso and legs. Strengthening exercises do not have to require special equipment. Improvements in strength can be achieved with simple body weight activities, such as standing up and sitting down from a chair, or by using easily available items such as a water bottle as a weight for arm exercises.

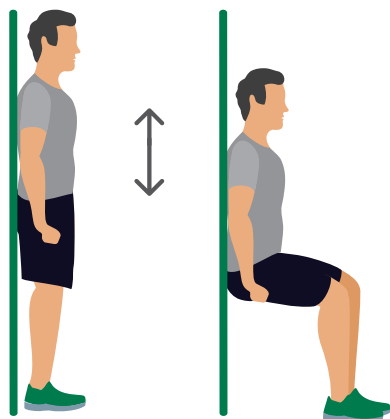
Stretching & Cool Down

Use this time to gradually lower your heart rate and breathing. This may include slow walking or marching on the spot followed by a number of stretches. Regular stretching as part of your exercise program will help to maintain your flexibility and reduce muscle soreness and stiffness.

It is important to discuss your interests with your prescribing exercise professional as some exercise options will not always be appropriate for your current condition. For example, water based activities can be a potential danger for those with some heart conditions, and clearance should therefore always be sought by your doctor.



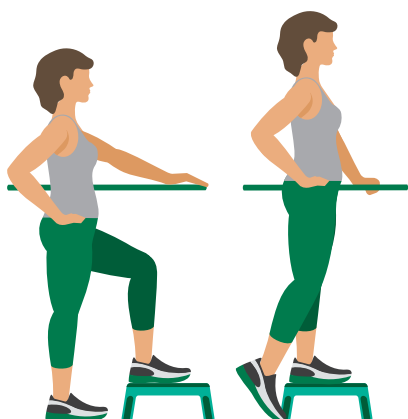
SQUATS



- ✦ Lean your back against a wall.
- ✦ Squat down until your thighs are parallel with floor.
- ✦ Slide up the wall to a standing position.
- ✦ Start with only sliding down a short way.
- ✦ Do not bend your knees beyond 90 degrees.

Comments & Considerations:

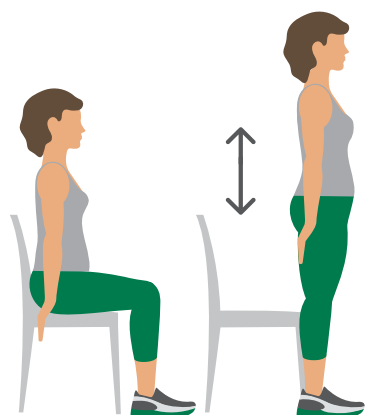
STEP UPS



- ✦ Stand in front of a step with hand support.
- ✦ Step up one foot at a time (like climbing stairs) making sure the entire foot is on the step.
- ✦ Return both feet to the ground.
- ✦ This activity can be either strength or an aerobic exercise.

Comments & Considerations:

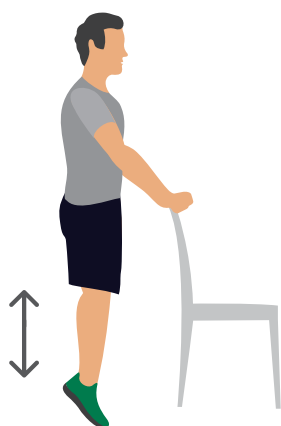
SIT-TO-STAND



- ✦ Sit on the edge of a chair with feet shoulder width apart.
- ✦ Stand upright.
- ✦ Sit back down.

Comments & Considerations:

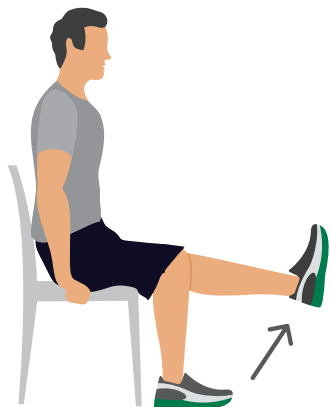
HEEL RAISES



- ✦ Find a solid supporting object such as a bench, wall or sturdy chair.
- ✦ Raise heels and rise onto toes.
- ✦ Lower heels back to floor.

Comments & Considerations:

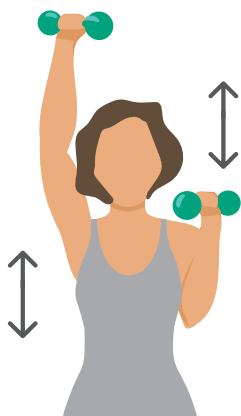
LEG EXTENSION



- ✿ Sit in a chair with knees bent at 90 degrees and feet on the floor.
- ✿ Slowly straighten one leg.
- ✿ Return to starting position.
- ✿ Repeat for other leg.

Comments & Considerations:

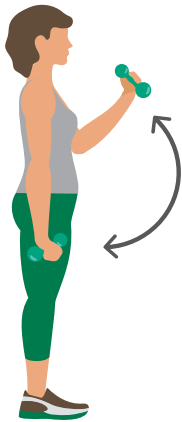
SHOULDER PRESS



- ✿ Hold a weight in each hand at shoulder height.
- ✿ With one arm, lift the weight straight up and down.
- ✿ Repeat the exercise with your other arm.
- ✿ This exercise can be completed either sitting or standing.

Comments & Considerations:

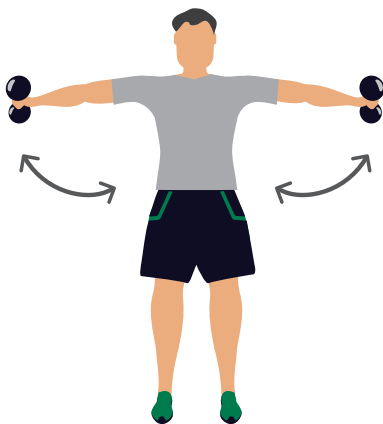
BICEP CURL



- ✿ Hold weight at your side, with elbows close to your body and palms facing forward.
- ✿ Curl arm towards your shoulder ensuring your elbows stay at your side throughout the movement.
- ✿ Slowly lower to the first position.
- ✿ Can be done with both arms together or alternating arms.

Comments & Considerations:

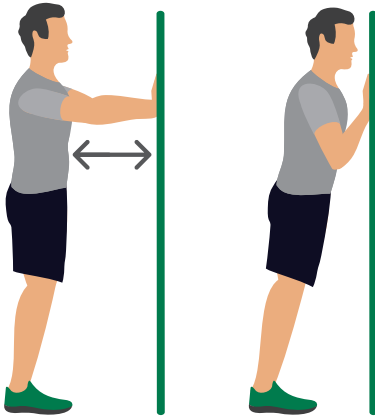
SIDE LATERAL RAISE



- ✿ Start with holding a weight in each hand at your side.
- ✿ Lift both arms out to the side, but not above your shoulders (move your arms as if you were “spreading your wings”).
- ✿ Keep palms and weight facing toward the floor throughout the movement.
- ✿ Keep your elbows slightly bent during the exercise.

Comments & Considerations:

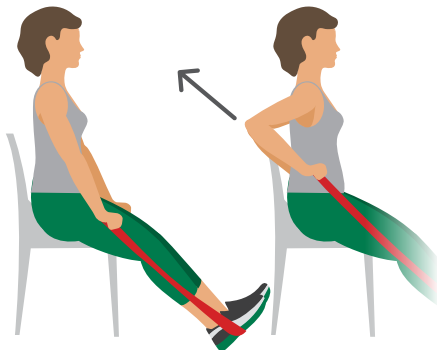
WALL PUSH UP



- ✿ Stand facing a wall with feet shoulder width apart.
- ✿ Leaning towards the wall place hands at shoulder height.
- ✿ From the start position, bend your elbows moving your body forward.
- ✿ Slowly push away from wall and return to the starting position.
- ✿ Ensure to keep body straight throughout.

Comments & Considerations:

SEATED ROW



- ✿ Sit upright with slightly bent knees and feet together.
- ✿ Anchor the band under your feet.
- ✿ Hold on with each hand, arms out straight by your side.
- ✿ Pull the tubing back leading with the elbows, keeping wrists straight and slightly squeezing the shoulder blades together.
- ✿ Do not rock back and forward.

Comments & Considerations:

SHOULDER STRETCH



- Place one arm across your body.
- Gently pull on your elbow with your opposite hand until a stretch is felt in the shoulder.

Hold for: _____ Repeat: _____

Comments & Considerations:

TRICEPS STRETCH



- Lift your arm so that your elbow is next to your ear.
- Place your hand between your shoulder blades.
- Gently push your elbow back with your other hand until you feel a stretch through back of the arm.

Hold for: _____ Repeat: _____

Comments & Considerations:

HAMSTRING STRETCH



- ✿ Sit on the edge of a chair or bed.
- ✿ Bend one leg, and straighten the other with toes pointed up.
- ✿ Lean forward slowly until you feel a stretch at the back of your thigh.

Hold for: _____ Repeat: _____

Comments & Considerations:

CALF STRETCH



- ✿ Place hands on a wall or a bench.
- ✿ Keep your body upright and bend your front knee.
- ✿ Straighten your back leg and keep your heel on the ground, with toes all facing forward.
- ✿ Slowly lean forwards until you feel a stretch in the back of your calf.

Hold for: _____ Repeat: _____

Comments & Considerations:

SIDE STRETCH



- ✦ Create a wide base of support with your feet apart.
- ✦ Reach one arm straight over your head.
- ✦ Lean into the direction of reach as far as it is comfortable and hold.

Hold for: _____ Repeat: _____

Comments & Considerations:

THIGH STRETCH



- ✦ Find a solid supporting object such as a bench, wall or sturdy chair.
- ✦ Pull your foot towards your buttock until a stretch is felt in the front of your thigh.
- ✦ Keep knees together.
- ✦ Tuck bottom under and push hips forward.

Hold for: _____ Repeat: _____

Comments & Considerations:

SIDE NECK STRETCH

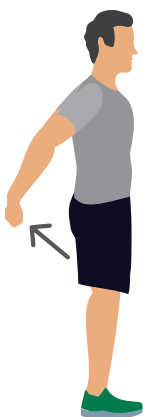


- ✦ Slowly tilt head towards one shoulder keeping chin slightly tucked under.
- ✦ Repeat toward other shoulder.

Hold for: _____ Repeat: _____

Comments & Considerations:

THORACIC STRETCH

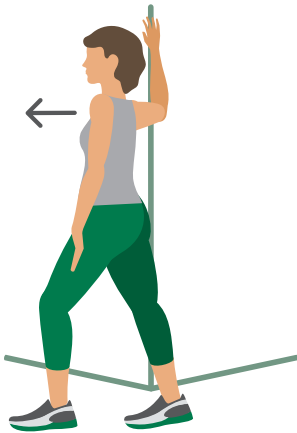


- ✦ Keeping shoulders down hold your hands behind your back with palms facing upwards.
- ✦ Move your hand away from your back until a stretch is felt.

Hold for: _____ Repeat: _____

Comments & Considerations:

CHEST STRETCH



- ✦ Stand in a corner or in a doorway with your elbow at shoulder level and your feet away from the corner or doorway.
- ✦ Lean forward until a comfortable stretch is felt across the chest.
- ✦ Take extra precaution if you have shoulder pain.

Hold for: _____ Repeat: _____

Comments & Considerations:

TRUNK ROTATION

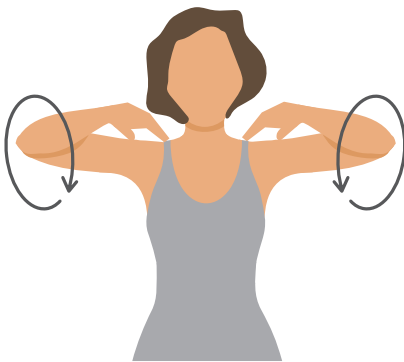


- ✦ Cross arms in front just below the chest.
- ✦ Gently rotate the trunk side to side as far as possible.
- ✦ Stretch should be felt in the middle and lower back.

Hold for: _____ Repeat: _____

Comments & Considerations:

SHOULDER ROTATION



- Place hands on your shoulder as shown.
- Slowly make forwards and backwards circles with your elbows.

Hold for: _____ Repeat: _____

Comments & Considerations:

NAME:

Description:

Comments & Considerations:

ADDITIONAL EXERCISES

NAME:

Description:

Comments & Considerations:

NAME:

Description:

Comments & Considerations:

Developing a plan to suit you

This section will help guide you and your exercise professional to some personal exercise goals that are tailored to help you better manage your lung condition. Setting goals helps you work out what you would like to achieve from your exercise program. Please follow the numbered steps in order.

1) What are your exercise options?

Think about what type of activities you could potentially do. Perhaps you have already developed a list of options in the previous chapter under type of exercise from the FITT principle. The exercise options you list here don't mean you have to commit to these, but it's important to have a look at all options for developing your immediate plan and as your program progresses. Here are some examples.

- ♣ Walking
- ♣ Exercise professional recommended exercises
- ♣ Gym/exercise facility

What are some of your options?

1. _____
2. _____
3. _____

2) What's important to you?

Think about the different reasons or motivators that have encouraged you to improve your physical health. These motivators could be factors that are important for you, or those around you. Such factors might be things like: playing with the grandchildren, or to have more independence.

In thinking about the reasons for improving your health and fitness with an exercise program, **identify the top 3 reasons that motivate you to make this change:**

1. _____
2. _____
3. _____

3) What's your SMART plan?

The next step is setting specific goals through the SMART goal setting principle. This helps you to develop goals that are structured, and improves your chance of achieving your goals. Here is an overview of the acronym SMART.

Specific: State clearly what it is that you need to do without any generalisations. For example; "At 10am I'll perform my prescribed home exercises everyday except Sunday for the month of August."

Measurable: Set criteria that will allow you to track progress. For example; "Use the logbook to tick the exercise day goals achieved."



Attractive: Outline why this goal is important to you, think about your motivators. For example; "To maintain independence or to set a good example for the family."

Realistic: Take a moment to reflect and consider if this goal is realistic to achieve? For example; "Is the time that I've set in my plan at a time I feel well enough to exercise, or does it conflict with any other commitments."

Time-framed: Set a start and end (review) date to ensure you can focus on achieving your goal. For example; "reassess log book and type of exercises with exercise professional at next appointment on xx/xx/xxxx"

Please write your SMART goal below:

4) What else needs to be considered?

It is also important to identify potential barriers that may impact on you achieving your goals. For example bad weather, motivation, exacerbations. Also consider what has stopped you from achieving your goals in the past and write any potential barriers below:

^

^

Now list some potential strategies that will help you overcome each barrier that you have listed, think about what has worked for you in the past and what are some new options to try:

^

^

My goal is

Date:

 Signed:

Exercise Log

Keep track of your daily exercise using the log below. Work with your exercise professional to design a program tailored to you, and schedule in regular reviews to support you as you progress. Each time you start your exercises below make sure you have reviewed the safety page, and you are well enough to commence.

		Day	MON / /	TUES / /	WED / /	THURS / /
Exercise Name	My Exercise Goals this week	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments
Aerobic eg: Walking	2 x 20 minutes	2 x 10mins (4) Hard today because of the wind				
Strength eg: Bicep Curl (7)	2 x 10 15kg	2 x 10 15kg (2) Becoming easy. Look at increasing weight.				
Stretch e.g.: Calf Stretch	20 seconds each leg	20 seconds (3)				

*Please use the *Modified Borg Dyspnoea Scale* found on page 4 to track your breathlessness.
For extra copies photocopy or download from www.lungfoundation.com.au



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*Please use the *Modified Borg Dyspnoea Scale* found on page 4 to track your breathlessness.
For extra copies photocopy or download from www.lungfoundation.com.au

Exercise Log

Exercise Name	My Exercise Goals this week	Day	MON / /	TUES / /	WED / /	THURS / /	FRI / /	SAT / /	SUN / /
		Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments

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		Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments

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		Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments	Details: Achievement, Breathlessness* Comments

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Resources and Support Services

Below is a list of some of the many resources developed by Lung Foundation Australia to support people with lung disease. Visit **www.lungfoundation.com.au** or **call 1800 654 301** to find out more.



Information and Support Centre

Our Information and Support Centre team provides guidance, information and support, and connects you to relevant support services. This free and confidential service is available Monday to Friday 8:00am - 4:30pm (AEST) (excl. public holidays). Please note this service does not offer medical or treatment advice. If you are interested in the information or services listed below call us on freecall 1800 654 301 (option 3) or email enquiries@lungfoundation.com.au.

Respiratory Care Nurse

The Respiratory Care Nurse telephone service is available for people living with Chronic Obstructive Pulmonary Disease (COPD) or bronchiectasis. Our skilled nurse can provide guidance on all aspects of your condition according to the management guidelines. Please contact our Information and Support Centre to make a booking with the Respiratory Care Nurse.

Lung Cancer Support Nurse

The Lung Cancer Support Nurse provides a telephone-based service for patients, their families and carers at any stage of their lung cancer journey. The Lung Cancer Support Nurse is a highly experienced oncology nurse who can provide evidence-based information regarding diagnosis, treatment, symptom management and well-being in addition to guidance about relevant support services. People living with lung cancer, their families and carers can contact our Information and Support Centre to make a booking with the Lung Cancer Support Nurse.



Lung Disease Resources

There are factsheets and information booklets available to help individuals find out more about their lung condition and how to self-manage effectively. These are freely available to download from our website: www.lungfoundation.com.au.



COPD The Basics Booklet

This booklet provides information for people who have recently been diagnosed with COPD. It provides information about COPD and what to expect living with this condition. Access this resource at www.lungfoundation.com.au



Better Living with COPD – A Patient Guide

This guide provides information about how to live well with a chronic lung condition. It offers practical advice about what people with COPD can do to improve their well-being. Access this resource at www.lungfoundation.com.au



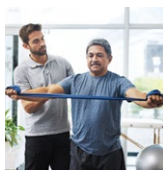
Home Oxygen

This booklet provides important information for those who have been prescribed home oxygen. The booklet discusses what oxygen is, who would benefit from it and practical tips for using oxygen. Access this resource at www.lungfoundation.com.au



Webinars

Our webinars are designed to increase your knowledge and gain the confidence you need to live well with your lung disease or lung cancer. Our webinars provide the opportunity for you to interact with speakers via an online presentation and live Q&A from the comfort of your own home, regardless of your location. Access the webinars at www.lungfoundation.com.au



Pulmonary Rehabilitation

Pulmonary rehabilitation is a six to eight week exercise and education program that teaches you the skills you need to exercise safely and manage your breathlessness. The exercise component focuses on increasing your physical function and is individualised to cover safety considerations and to ensure you are on-track to achieve your goals. The education component assists you in managing your condition, by providing knowledge in areas such as breathing techniques, using your medications and energy conservation.



Lungs in Action

Lungs in Action is a safe and enjoyable community-based exercise program designed to help people living with a chronic lung disease maintain the benefits achieved through pulmonary rehabilitation. It is also suitable for people with heart failure who often experience similar symptoms such as breathlessness, to those with chronic lung conditions.



C.O.P.E- COPD Online Patient Education Program

C.O.P.E - COPD Online Patient Education Program is available for free online. It provides the educational component of a pulmonary rehabilitation program to help those living with a lung disease. Access C.O.P.E at www.cope.lungfoundation.com.au



Peer Support

Lung Foundation Australia facilitates and supports a range of peer support programs for patients and carers affected by lung disease or lung cancer. These programs provide a safe space to provide mutual support and enables you to feel understood and heard when sharing your story. Contact our Information and Support Centre to find out about available peer support options.



Inspired Living

Inspired Living is Lung Foundation Australia's patient newsletter. The newsletter contains inspiring stories and valuable information about living well with a lung condition. Contact our Information and Support Centre for further information.



Love Your Lungs club

The 'Love Your Lungs' supporters club is a great way to show people with lung disease how much you care. By joining the club you are helping Lung Foundation Australia drive research, patient support, and health professional programs which help our community. The club is for everyone- patients, families and friends, so become a 'Love Your Lungs' member today. Contact our Information and Support Centre for further information.

Notes

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

How You Can Support Us



Leaving a Legacy

Naming Lung Foundation Australia in your Will is an act of generosity that proclaims your commitment to future generations of people impacted by lung disease and lung cancer. A gift in your Will does not have to be large for it to be valuable and give hope to others.



Give a regular gift

Understanding the causes and future treatment of lung disease and lung cancer requires a long-term approach. Regular donors give Lung Foundation Australia a reliable and sustainable stream of donations which help us plan well into the future. A donation of even \$5.00 per week goes a long way and allows great science to flourish.



Become a member

Lung Foundation Australia membership is not required to access any information or services offered by the organisation. However, your membership will provide us with much needed ongoing support, and in return you will join a community of health professionals, researchers and patients all striving to improve care for the seven million Australians living with lung disease and lung cancer.



Philanthropy and partnerships

We are proud to partner with philanthropists, companies, trusts and foundations to raise vital funds for lung disease and lung cancer research. We are outcomes focused and ensure your investment can be tracked against measurable goals, and we will keep you up to date on our progress.



Other ways to get involved

- Share your story
- Become a Lung Foundation Australia Ambassador
- Join workplace giving
- Participate in community fundraising



This handbook was printed on
EcoStar 100% recycled paper.

Congratulations on taking an active approach to managing your lung condition.

Better Living with Exercise - Your Personal Guide was developed by Lung Foundation Australia to help you and your treating exercise professional develop the most suitable exercise program for you to improve your physical and social wellbeing.



LUNG FOUNDATION AUSTRALIA

Level 2, 11 Finchley Street,
Milton QLD 4064

PO Box 1949, Milton QLD 4064
E: enquiries@lungfoundation.com.au

1800 654 301

www.lungfoundation.com.au





Treatable Traits in Interstitial Lung Disease Study

You are receiving this email as you may be eligible to be involved with an upcoming research project for interstitial lung disease (ILD) – Treatable traits in ILD (TTRILD).

This project is being undertaken to assess the prevalence of specific 'traits' that patients with ILD may experience. These include things such as lung inflammation or fibrosis, cough, low oxygen, other comorbidities, and difficulty with exercise. The primary goal of this project is to determine that if we identify and manage these specific factors, within a special multidisciplinary clinic, can we improve patient quality of life?

This project is a clinical trial where you will be randomly allocated into your normal ILD management clinic or a specific multidisciplinary clinic where you will (depending on your symptoms or concerns) be seen by a respiratory specialist +/- physiotherapist, dietician, or psychologist. This trial will include monitoring over a 3-6 month period. Both groups will receive their baseline level of care.

If you would like to learn more about this project please contact Sharon Maxwell, from our research team at Sharon.maxwell@health.wa.gov.au

Treatable Traits in Interstitial Lung Disease Study Team

South Metropolitan Health Service

Fiona Stanley Hospital

Harry Perkins South

5 Robin Warren Drive Murdoch WA 6150