# DON'T FORGET TO BREATHE

A guide for patients with Chronic Obstructive Pulmonary Disease (COPD) and their Carers.



By Sue Ward • Carole Donnelly • Carol D Cooper-Taylor • Phyl Cooper-Taylor

Click on any of the links below to jump straight to that section.

# **Table of Contents**

Copyright vi
Dedicationvii
Forewordix
Prefacex
About the Authorsxi
About the Contributorsxii
Major Contributorsxii
Other Contributorsxiii
Acknowledgementsxiv
SECTION 1
The Journey to Diagnosis
Meet the COPDers1
Jean & Bob1
Debra & Judy1
The journey begins1
SECTION 2
Getting Your Diagnosis
Your GP Visit
Tests
Lung Function Tests
Peak Flow5
Spirometry6
Other Tests
Stages of COPD7
What is COPD?
Emphysema
Chronic Asthma9
Chronic Bronchitis9
Alpha-1 Antitrypsin Deficiency9
SECTION 3

Understanding Your Breathing
Normal Breathing
Muscles Used In Breathing
How Breathing Changes with COPD11
SECTION 4
Living with COPD – Medication
Medication
Inhalers
Relievers
Preventers
Other Medication
How to Use Your Inhaler
Metered Dose Inhalers
Turbuhalers
Accuhaler21
Handihaler
SECTION 5
Living With COPD - Pulmonary Rehabilitation
What is Pulmonary Rehabilitation?23
Who Benefits From Pulmonary Rehab?23
How to Get a Referral to a Pulmonary Rehab Programme24
The BODE score and Other Questionnaires
What's in a Pulmonary Rehab Programme?25
Pulmonary Rehab 1: Physical Exercise25
Modified Borg Scale
Why Exercise? What are the benefits?
Types of exercise27
A) Cardiovascular Endurance (Aerobic exercise)
Walking28
Cycling28
Rowing29
Swimming / aqua jogging or aqua aerobics29
B) Strength Training

Squats	30
Press ups	30
Calf raises	
Dumbells	
C) Other types of exercise	
Warm up	
Balance exercises	
Cool down and stretches	
Types of Pulmonary Rehab Programmes	33
Continued Exercise	
Pulmonary Rehab 2: Breathing Retraining	
Abdominal breathing - how to do it	
Breathing during exercise	
Recovery Breathing and Positioning	
Clearing Sputum	39
Active Cycle of Breathing Technique (ACBT)	40
Postural drainage	
PEP therapy	
Pulmonary Rehab 3: Education	
A) Breathing	
B) Medications	
C) What is COPD? Respiratory Anatomy	
D) Occupational therapy	43
E) Social Welfare	43
F) Dietician	43
G) Continence	43
H) Anxiety management	43
I) End-of-life care options	
SECTION 6	45
Living With COPD – Smoking, Home, Travel and Other Stuff	45
Smoking Cessation	45
Help to Stop Smoking	45
A Healthy Home	

Dealing with Exacerbat	tions		7
Travel			)
Diet			2
Tips for maintaining	a healthy weight with COPD		1
Nasal Rinsing			5
Practical Tips			5
Practical planning			5
Prioritising energy e	xpenditure		5
The breathlessness	moment	56	5
Breathing control			7
Bedtime choices			7
Life control			7
House Work			3
Cooking			3
SECTION 7			)
Your Healthcare Team ar	nd Their Role in Managing Your	COPD	)
Counsellor / Mental He	ealth Team		)
Dietician			)
General Practitioner		61	L
New Zealand Asthma I	oundation	61	L
New Zealand Heart an	d Lung Transplant Service		2
Occupational Therapis	t		2
Pharmacist			3
Physiotherapist			3
Practice Nurse			ļ
Pulmonary Rehabilitat	ion Nurse		5
Respiratory Nurse Spe	cialist		5
Respiratory Consultan	t		5
Respiratory Physiologi	st / Technologist / Scientist		7
Social Worker			7
SECTION 8			3
Complementary Therapie	25		3
Aromatherapy		68	3

Aromatherapy Treatments for COPD	68
Acupuncture	72
Medical Herbalist	73
Reflexology	75
SECTION 8	77
Caring for the Carers	77
SECTION 9	79
Palliative Care / End of Life Care	79
What is palliative care?	80
Key Principles of Palliative Care	80
What Are Hospices?	81
What symptoms can palliative care help to manage?	82
Who should be referred for palliative care?	83
Advanced care planning	83
SECTION 9	85
Glossary	85
SECTION 10	93
Resources	93
Books	93
Organisations	93
Social Media	93
Web Sites	93

# Copyright

This work is created under the following creative commons license.

If you are interested in using this work as the basis of a different country specific version, please get in touch with us.

### Attribution-NonCommercial-NoDerivs 3.0 Unported (CC BY-NC-ND 3.0)

You are free:

• to Share — to copy, distribute and transmit the work

Under the following conditions:

- **Attribution** You must attribute the work in the manner specified by the author or licensor (but not in any way that suggests that they endorse you or your use of the work).
- Non-commercial You may not use this work for commercial purposes.
- **No Derivative Works** You may not alter, transform, or build upon this work.

With the understanding that:

- **Waiver** Any of the above conditions can be waived if you get permission from the copyright holder.
- **Public Domain** Where the work or any of its elements is in the public domain under applicable law, that status is in no way affected by the license.
- **Other Rights** In no way are any of the following rights affected by the license:
  - Your fair dealing or fair use rights, or other applicable copyright exceptions and limitations;
  - The author's moral rights;
  - Rights other persons may have either in the work itself or in how the work is used, such as publicity or privacy rights.

See http://creativecommons.org/licenses/by-nc-nd/3.0/ for the full license.

# Dedication

To all COPDers and their carers everywhere, and to the healthcare professionals who care for them.

We hope this book will be helpful and enlightening.

Your living is determined not so much by what life brings to you as by the attitude you bring to life;

Not so much by what happens to you as by the way your mind looks at what happens.

Kahil Gibran

# Foreword

It is a great privilege to have been asked to provide the foreword for this book.

Chronic obstructive pulmonary disease (COPD), also known as chronic obstructive lung disease (COLD), or chronic obstructive respiratory (CORD), is a major economic health burden throughout the world in terms of both direct health costs and lost productivity.

It is rated as the sixth commonest cause of death worldwide, and in New Zealand it is the fourth commonest cause of death. It ranks high amongst the major causes of disability and profoundly affects the quality of life of its sufferers.

Estimates are that it affects 200,000 New Zealanders and up 15% of adults over the age of 45 years may have COPD: many of these people will not be aware that this is the case.

Whilst there is a plethora of information available on COPD, much of it is dispersed in small noncohesive fragments and scattered through various resources. Much of the information available (e.g. on the Internet) is not relevant to our situation in New Zealand.

This book brings together a wealth of well researched information from various sources and presents it in a cohesive and ordered manner which is applicable to New Zealand.

I have had a small personal part to play in helping Carol along her journey with COPD. I can testify that she has experienced many of the issues covered in this booklet and it reflects much of what she has learned and personally experienced. She was keen to share her experiences with other COPD sufferers, and with input from Sue and Carole, and help from Phyl (amongst others), she has achieved it: "Don't Forget to Breathe".

I am sure that readers of this book, sufferers of COPD, and other health professionals will find much helpful and practical information to help them deal with the various issues that afflict sufferers with COPD.

Dr Rob Armstrong Respiratory Consultant, Hawke's Bay Hospital FRCP, FRACP

# Preface

Carol Cooper-Taylor was on her third go on Sue Ward's and Carole Donnelly's pulmonary rehabilitation course when it struck her that all the information she was being presented with should be in a book for all people like her to read. Not a book written by healthcare professionals for patients but one written as a partnership between patient, carer and the healthcare team.

So after one of the course talks, out came the question, "How do you feel about writing a book?" Thankfully the question met with enthusiasm; the idea became reality and two years of hard work began.

The book is titled after a phrase that is often heard in pulmonary rehab sessions "Don't forget to breathe".

# **About the Authors**

#### Sue Ward - Respiratory Rehabilitation Nurse

RN, BA (Hons) Palliative Care, PGCert COPD, PGCert Asthma, PGCert Pulmonary Rehabilitation



Sue is the Respiratory Rehabilitation Nurse at Hawke's Bay Hospital, New Zealand. Having trained as a registered nurse in Oxford in the UK, she has worked with people with respiratory disease in a variety of settings; community, acute respiratory units, emergency departments, and paediatric units. She now facilitates the pulmonary rehabilitation programme for people in Hawke's Bay. Her area of special interest is enabling people to be able to live with their COPD, rather than their COPD ruling their lives.

Sue@DontForgetToBreathe.org.nz

#### **Carole Donnelly - Senior Respiratory Physiotherapist**

BSc (Hons) Physiotherapy



Carole is a Senior Respiratory Physiotherapist at Hawke's Bay Hospital, New Zealand. She trained and worked in Newcastle upon Tyne in the UK, and has worked with people with Chronic Respiratory Disease for many years. She now works within the pulmonary rehabilitation programme in Hawke's Bay and also has a respiratory outpatient caseload. She enjoys helping people with COPD realise their potential and find the strength and confidence to make real changes to their lives.

Carole@DontForgetToBreathe.org.nz

#### **Carol D Cooper-Taylor – Patient**

MPhil, BEd (Hons), CertEd, Cert Online Education & Training



Carol's career has spanned teaching, nursing, nurse education, ICT, eLearning and education management. It has also taken her half way round the world from the UK to New Zealand. For this book however she has her "patient" hat on. Diagnosed with asthma in early adulthood her condition has declined with time and she now does battle with COPD on a daily basis. She says "battle" as she is determined she will not give in to it.

Carol@DontForgetToBreathe.org.nz

#### **Phyl Cooper-Taylor – Carer**



Phyl started her working life working in computers, back when punch cards were cutting edge. On retirement she was managing 300 staff in the industrial cleaning sector. She is Carol's partner of 20 years and is her carer. For Phyl the hardest part is that "COPD never goes away, the challenge is to make the best of it." **Phyl@DontForgetToBreathe.org.nz** 

# About the Contributors

### **Major Contributors**

### Michelle Rodda – Nurse

BN, RCompN, PG Dip Respiratory Medicine, PC Cert Palliative Care



Michelle was born and grew up in Hawke's Bay. During her OE in the UK she worked as a nurse is various acute settings. Finding respiratory was the area she loved the most she worked as a senior ward sister of a respiratory unit with non-invasive ventilation (CPAP). On her return to NZ she worked as a nurse specialist in respiratory at Hawke's Bay Hospital for two years. She now works as a Registered Nurse within the hospice between the in-patient unit and the community. She is currently studying for a Post Graduate Diploma in Palliative Care and plans to undertake a Masters in Clinical Nursing next year.

#### Deborah Taylor - Charge Clinical Respiratory Physiologist

HNC in Medical Physics and Physiological Measurement, Post Grad Cert in Medical Technology, CRFS (Certified Respiratory Function Scientist)



Deborah has been employed as a Clinical Physiologist since 1981. Originally from the UK she spent 6 years in South Africa then moved with her family to New Zealand in 1993 to take up a position at Napier Hospital. She is currently Charge Clinical Respiratory Physiologist at Hawke's Bay Hospital and maintains a focus on her interaction and care of patients requiring Pulmonary Function tests to consistently achieve high quality results. Married with two adult children she enjoys life in New Zealand and particularly Hawke's Bay.

### Kylie H Vannaman – GP MD



Kylie is a U.S. board-certified Family Medicine Physician who has a special interest in asthma / COPD, integrative medicine and nutrition. As a passionate learner / teacher, one of the things she finds most rewarding in primary care is helping patients to better understand their conditions and encouraging self-care. She is honoured to be a part of this book and hopes that it may serve as a catalyst for patients and their families to live their lives to the fullest!

### **Other Contributors**

Cathy Caldwell, Reflexologist www.reflexology.org.nz

Francie Dulieu, NZRN, MA(Appl) Nursing, BN, Dip Aromatherapy(NZ), Int Cert Aromatherapy(USA)

Fy Dunford MHSc (C/R), MPNZ, Grad. Dip Phys.

Karen Waimana, Reflexologist www.reflexology.org.nz

# Acknowledgements

We would like to thank the many people involved in proofing this book and making suggestions for improvements. You have all made the book so much better.

In particular we would like to mention:

Larissa Hamlin Brenda and Tony Jackson Jenny Mansfield John Purdie

# SECTION 1 The Journey to Diagnosis

### Meet the COPDers

This book is about real people with Chronic Obstructive Pulmonary Disease or COPD for short. To help tell their stories we have created fictional characters who will pop up throughout the book. They are based on the experiences of many people we have met and cared for but they are not real people. They do though, represent the real questions, concerns, ups and downs experienced by COPDers and their carers everywhere.

### Jean & Bob

Jean, a lady of 62, works part time as a dinner lady in a school, although she finds that keeping on working is becoming harder and harder. Her husband, Bob, is fit and well, working full-time in a council facility. They have three daughters and four grandchildren.



### Debra & Judy

Debra, a 60 year old woman, lives with Judy her partner of 30 years. Debra has a son and Judy a daughter, both of whom live overseas. They have four grandchildren. Debra was a librarian, but reluctantly took early retirement when she could no longer cope. Judy is also retired.



### The journey begins

Every person's journey will be different so it is not possible to say it starts like this and ends like this.

Jean's journey, for example, started with a visit to her GP when a cold would not clear up. Diagnosed with a chest infection, she was given 7 days of Amoxil (an antibiotic) and 5 days Prednisone (a steroid). She thought she made a good recovery, but felt she never quite regained her strength. She "plodded along" over the next six months never really feeling right.

Debra's journey probably began as a child. She enjoyed sport but was unable to run over long distances like the other kids. As a young adult she spent a number of years with an unresolved cough and felt rather helpless being shunted from one doctor to another, from one test to another whilst

they mulled over whether she was asthmatic or not. The decision finally came down on the side of asthma and years of trying different inhalers followed.

With both of our COPDers there was a recognition that there was something not quite right with their health which resulted in a visit to their GP.

Commonly, symptoms include:

- Shortness of breath, such as getting breathless doing normal activities or not being able to do as much as you could previously without getting out of breath,
- Wheezing, a whistling or rattling breathing sound,
- **Tight chest**, a feeling that the chest has become inelastic,
- Chronic cough, with excessive mucous/phlegm production,
- **Recurrent colds** that often lead to respiratory infections and that take longer than normal to clear up.



If you have any of the symptoms listed above your first point of call should be your GP or Practice Nurse.

# SECTION 2 Getting Your Diagnosis

So you have some of the symptoms we discussed at the end of Section 1 and you book an appointment with your GP.

Both Debra's journey and Jean's show that there is no one way that a person will present to their GP with COPD. Symptoms are often subtle and do not add up to much taken individually. Your GP will be looking for trends over time. This is why having a relationship with your GP and practice nurse is so important.

### Your GP Visit

During your appointment your GP will "take your history" by asking questions that revolve around what brought you in to see your GP on this particular day:

• What are your symptoms?

These might be shortness of breath, cough, sputum production, recurrent chest infections, wheezing or the sensation of chest tightness.



• Does your shortness of breath worsen with your daily activities? Do you wake up suddenly short of breath at night (paroxysmal nocturnal dyspnoea)?

How severe these are can be used to track if symptoms are getting better or worse. Waking up suddenly at night short of breath can be caused by several conditions that affect the heart and lungs, not just COPD.

• When did the symptoms start? Do they come and go? What makes them worse/better? Your symptoms may indicate COPD or something else.

Asthma generally starts in early life and symptoms vary daily, often disappearing completely between attacks.

If symptoms did not start until adulthood and developed gradually, COPD is more likely, but there is certainly a lot of overlap.

Severe forms of scarring of the smaller airways (bronchiolitis) can occur in young, non-smokers and is sometimes associated with rheumatoid arthritis. Symptoms mimic COPD.

If someone has recently had fevers, chills or body aches, they may have acute influenza, bronchitis or pneumonia.

Often people cannot recall when their symptoms started as they've been so gradual, however, sometimes there will be, like Jean, a sense of "I never really felt quite right after that bout of bronchitis I had a few years ago"...

#### • Do you smoke or have you in the past?

If a person is over the age of 50, has a history of tobacco smoking and/or exposure to other lung irritants (second-hand smoke, chemicals, fumes or other work-related or hobby exposures), the risk of COPD is greater.

• What other medical issues do you have? Does anything run in your family / whanau? If there is a history of heart disease or congestive heart failure, the symptoms could be cardiac related.

Allergies, eczema and asthma are common together.

#### • Have you been exposed to tuberculosis?

Some of the symptoms of TB (tuberculosis) can mimic COPD including persistent cough, thick sputum and difficulty breathing.

Your GP will then usually examine you or may do this at the same time as asking questions.

- Temperature, pulse, breaths per minute and blood pressure will be checked.
- Oxygen-saturation (pulse oximetry) may also be checked by using a nonpainful little clip on your finger.<sup>1</sup>
- Eyes, nose, throat and ears will be examined for any sign of infection.
- Chest will be examined to listen to heart and lungs.
  - Wheeze can result from tightened small airways found in asthma, bronchitis, bronchiolitis and COPD.
  - Coarse breath sounds can indicate an infection or fluid in the lungs depending on where and how severe.
  - Crackles, usually at the bases of the lungs generally represents fluid in the lungs either from infection or fluid overload from an overworked heart. Crackles can also be caused when the tiny air sacs (alveoli) at the far ends of the airways are collapsed shut due to shallow breathing, chronic lung damage or infection.
- Neck
  - If there is some degree of heart failure, the jugular veins that run up each side of the neck can become larger due to fluid backing up from the heart.
- Abdomen
  - Assess whether the abdominal or rib muscles are being used to help breathe (normally the diaphragm is strong enough to do it on its own).



<sup>&</sup>lt;sup>1</sup> Image Credit: http://en.wikipedia.org/wiki/File:FingertipPulseOximeter-MD300C1NoLogo.jpg

- Check for any hernias or fluid in the abdomen that might be pushing up on the lungs making it more difficult to breathe.
- Hands / legs / feet
  - Check for any swelling, especially in the feet and lower legs, which could mean the heart is pumping harder or suffering from some degree of heart failure.

### Tests

Once your history has been taken and your examination is complete, there may be a variety of tests that need to be done. These will be either requested urgently on the day or over the following weeks to determine the cause of your symptoms. Some tests are done to confirm a diagnosis of COPD and some are done to rule out other possibilities.

Initial tests may include:

- An ECG (Electrocardiogram) and a **blood test** may be ordered to rule out a heart attack or acute congestive heart failure.
- A **chest x-ray** may be needed to determine whether there is an active lung infection or fluid in the lungs that may represent heart failure.

### Lung Function Tests

Once your acute symptoms are stable, i.e. your chest infection or other episode has settled down, further testing will help determine whether COPD is the cause of your symptoms. Spirometry (see page <u>6</u>) is the most important initial test in diagnosing COPD, but is not very accurate during an acute illness, which means you may need to return to see your GP about 6 weeks after you recover from an acute illness before having this testing done. Even if you recover and feel well again it is very important to keep your follow up appointment if your GP asked for one. Not keeping a follow up appointment may mean your COPD goes on undiagnosed and makes it harder for your GP to treat you appropriately.

### **Peak Flow**

Your doctor or nurse may recommend that you monitor your peak flow (maximum peak of blowing out) with a small device, called a peak flow meter that you can use at home. This shows how tight your airways are at any given time. It often takes a bit of practice to get the hang of this test, but is painless and otherwise fairly easy to operate. <sup>2</sup>



<sup>&</sup>lt;sup>2</sup> Image Credit: http://en.wikipedia.org/wiki/Peak\_expiratory\_flow

This kind of monitor can be useful to help differentiate between whether your symptoms are caused by asthma or COPD. In asthma, you will tend to notice that your peak flow readings fluctuate throughout the day, whereas in COPD the readings stay fairly constant.

### Spirometry

Similar to a peak flow test, spirometry involves blowing into a handheld mouthpiece, but takes a bit more practice. Your practice nurse or respiratory technician will lead you through this and demonstrate the correct technique.

Spirometry testing is often done both before and after the use of a short-acting bronchodilator (such as salbutamol).<sup>3</sup>

The standard spirometry process is to breathe in as far as you can (take a maximal deep inspiration) followed by breathing

out as fast and as hard as you can (maximum forced exhalation). Several measurements can be read from this blow:

• FVC – Forced Vital Capacity

The total volume of air that you can forcibly exhale in one breath.

- **FEV1 Forced Expiratory Volume in One Second** The volume of air that you are able to exhale in the first second of forced expiration.
- FEV1 / FVC

The ratio of FEV1 to FVC expressed as a fraction (previously this was expressed as a percentage).

The values of FEV1 and FVC are measured in litres and are also expressed as a percentage of the predicted values for the person being tested.

People with normal lungs can exhale most of the air in their lungs in one second. When lungs are obstructed (as in COPD), it takes longer to blow all the air out.

In COPD the three measurements (FVC, FEV1 and FEV1/FVC) are decreased. However in early COPD the FVC may often be normal.

COPD is diagnosed when you have a FEV1/FVC ratio of less than 70% and an FEV1 of less than 80% of expected (based on age, gender, height and ethnicity). Your GP or Respiratory Specialist will talk to you about your results if you have this test.

Spirometry testing is very **useful in both diagnosis and monitoring** of COPD and should be done at regular intervals (but not during acute illness) for those suspected of and living with COPD to help guide treatment.



<sup>&</sup>lt;sup>3</sup> Image credit: http://en.wikipedia.org/wiki/Spirometry

### **Other Tests**

Other tests may be used to help rule out other causes of breathing difficulties such as:

- A chest x-ray or CT scan to look for infection or other abnormalities
- An ECG or echocardiogram to check for heart problems, or
- Allergy testing.

Sometimes people can have overlapping diagnoses that lead to breathing problems and you may be sent to the Respiratory Specialist for other tests such as:

- Lung diffusion testing which involves breathing in a gas for an enhanced version of spirometry.
- **Bronchoscopy** a tiny tube and camera are inserted into the airways to look for abnormalities.
- V/Q scan a nuclear isotope scan that compares ventilation of the lung versus perfusion (blood flow through the lung).
- Sleep study.
- Specialized blood tests.

Although people are often treated before COPD is confirmed, accurate diagnosis is important as some treatment options are only fully funded in New Zealand if specific criteria (spirometry measures) are met. Thus it is important that you help your GP and healthcare team by keeping your appointments for any tests that are organised for you.

### Stages of COPD

You may be told by your GP or Specialist that you are COPD Stage 1-4. These stages help to classify COPD based on the level of airflow obstruction found on spirometry and are classified by GOLD (The Global Initiative for Chronic Obstructive Lung Disease).<sup>4</sup>

Stage 0	At risk	FEV1/FCV<0.70	FEV1 > 80% normal
Stage I	Mild COPD	FEV1/FVC<0.70	FEV1 ≥ 80% normal
Stage II	Moderate COPD	FEV1/FVC<0.70	FEV1 50-79% normal
Stage III	Severe COPD	FEV1/FVC<0.70	FEV1 30-49% normal
Stage IV	Very Severe COPD	FEV1/FVC<0.70	FEV1 <30% normal, or <50% normal with chronic respiratory failure present

<sup>&</sup>lt;sup>4</sup> The Global Initiative for Chronic Obstructive Lung Disease (GOLD ) is a collaboration between the National Institutes of Health and the World Health Organization, which helps to classify COPD

**Please note** this sort of classification is meant to help people to understand their disease better and to help doctors make better treatment recommendations, but it is NOT a predictor of a person's quality of life or life expectancy! For example, someone who is considered Stage III or Severe COPD may be much more active and fit than a person in Stage I or Mild COPD based on many other factors such as physical fitness, smoking status, weight and co-existing medical conditions.

### What is COPD?

Once you have your diagnosis of COPD don't think you are on your own. In 2004 the World Health Organisation estimated that 64 million people worldwide had COPD <sup>5</sup>. Here, in New Zealand, COPD affects an estimated 200,000 people or 15% of the adult population over the age of 45 years <sup>6</sup>.

One of your first questions is probably, "What is COPD?" COPD is an umbrella term for the diseases emphysema, chronic bronchitis and chronic asthma. A person with COPD has one or more of these diseases. All of these are diseases where the airways are partially blocked and the lungs are damaged making it difficult to breath.



### **Emphysema**

In Emphysema, inflammation of the air sacs (alveoli) causes them to lose their elasticity. The walls of the individual air sacs break down and air sacs join up together forming one large space rather than the normal "bunch of grapes" appearance. With one large structure there is less surface area for gas exchange resulting in low levels of oxygen in the blood (hypoxaemia) and the tissues of the body (hypoxia).



<sup>&</sup>lt;sup>5</sup> http://www.who.int/mediacentre/factsheets/fs315/en/index.html

<sup>&</sup>lt;sup>6</sup> http://www.asthmafoundation.org.nz/copd\_in\_new\_zealand.php

### **Chronic Asthma**

In asthma narrowing of the flow of air is due to inflammation which causes thickening of the walls of the airways. Unlike normal asthma where the narrowing of the airways is reversible with medication, in long standing chronic asthma, this inflammation can lead to scarring and the airways become remodelled, making them less able to return to normal functionality.



### **Chronic Bronchitis**

With Chronic Bronchitis the large and medium sized airways (bronchi) are inflamed and produce a lot of mucous. This leads to coughing and difficulty getting air in and out of the lungs.

### Alpha-1 Antitrypsin Deficiency

Alpha-1 Antitrypsin Deficiency (Alpha-1) is the most common known genetic risk factor for emphysema. For this reason, it is often referred to as "genetic COPD." Alpha-1 can cause both lung and liver disease though lung disease is the most common. Up to 3% of all people diagnosed with COPD may have Alpha-1.

Alpha-1 is often misdiagnosed as asthma or smoking-related COPD. Alpha-1 cannot be diagnosed definitively based on a patient's medical history Nor physical examination and diagnosis is made by a simple blood test.

In 2003, the American Thoracic Society (ATS) and the European Respiratory Society (ERS) jointly released the ATS/ERS Consensus Document, providing new standard guidelines for testing those with the following at-risk factors:

- Symptomatic adults with emphysema, COPD, or asthma that can't be completely treated with bronchodilators.
- Individuals with no symptoms (asymptomatic) but with persistent obstruction on pulmonary function tests who have identifiable risk factors such as cigarette smoking, occupational exposure, etc.

Your GP should be able to arrange this blood test if appropriate.



Further information can be found at http://alpha-1foundation.org

# SECTION 3 Understanding Your Breathing

### **Normal Breathing**

It is important to understand how breathing is "supposed" to work in healthy lungs in order to appreciate how it affects people with COPD.

People usually breathe without thinking about it. When you breathe in, air goes in via your nose or mouth, down the back of your throat, down the windpipe (trachea), splits into the two large airways (bronchi), into the smaller airways to the air sacs (alveoli) where oxygen in the air is passed into the bloodstream. Carbon dioxide is passed from the bloodstream into the air in your lungs. The air then travels the reverse pathway as you breathe out.



If you have access to the Internet this video will help explain how breathing works:

Meet The Lungs http://bit.ly/MeetTheLungs

## Muscles Used In Breathing

Air doesn't pass in and out on its own; muscles in the chest ensure this happens. The main muscles of breathing are the diaphragm and the intercostal muscles. The other muscles which can play a part are known as the accessory muscles.



### The Diaphragm

This muscle is responsible for approximately 60 - 80 % of the air that enters the lungs during quiet (resting) breathing.

The diaphragm is a dome shaped layer of muscle that separates the chest cavity from the abdominal cavity. The diaphragm is a bit like the heart muscle in that it does not tire, contracting and relaxing without 'effort'.



This is a great 3D view of the diaphragm working:

http://bit.ly/Diaphragm3D

#### The Intercostal Muscles

This group of muscles are found between the ribs and form the chest wall. They help to lift the rib cage up and out during breathing in to allow the lungs to expand. They work harder when we need to exert ourselves to help allow more air into the lungs.

#### **Accessory Muscles**

On exertion, when extra oxygen is required, other muscles of the neck, spine and abdomen are also used. They are only used when we are exercising quite hard or during fight / flight responses and they tire quickly.

#### What Happens When You Breathe In (Inhalation)

As you breathe in, or inhale, the diaphragm tightens (contracts) and moves downward. The intercostal muscles also contract pulling your rib cage upwards and outwards. Both of these muscle activities cause an increase in the space in your chest cavity (thorax). This results in a lower air pressure and the lungs expand to fill the space. As your lungs expand, air is pulled in through your nose or mouth to equalise the pressure.

#### What Happens When You Breathe Out (Exhalation)

Exhaling is, obviously, the opposite: The diaphragm relaxes, moves upwards to its relaxed curved state, and the air pressure in the chest cavity (thorax) therefore increases (because there is now less air space). The lungs deflate and air passes out of your mouth and nose. It is important to remember that there are no muscles working when we breathe out normally. Exhalation is a completely passive action.

### How Breathing Changes with COPD

Due to the physical changes to the lungs with COPD (as discussed in the earlier chapter), the mechanics of breathing (how breathing works) can change quite dramatically.

**Airflow obstruction and inflammation** causes increased resistance to the movement of air in and out of the lungs. This means it is harder to breathe in and out. People without COPD can get an understanding of what this feels like by breathing through a straw for a while. It is not pleasant!

**Over-inflation** (hyperinflation) is another major cause of breathlessness. Air becomes 'trapped' in the lungs (not expelled fully with each breath out). When you are unable to breathe out fully, it makes it much harder to take the next breath in. This can lead to a shortened, 'flattened' diaphragm which is then at a mechanical disadvantage, and is unable to work as efficiently as normal. To

compensate the intercostal muscles (those between the ribs) have to work harder and they use much more energy than the diaphragm. Breathing out is no longer a passive process and thus uses a lot more energy.

Accessory Muscles need to assist with the breath in in some situations, and this uses even more energy.

**Clearing Sputum** from their lungs is also a problem that some people experience, or they just produce huge volumes of sputum which makes it difficult to clear. This can also cause more difficulty with breathing. We talk about methods for <u>Clearing Sputum</u> on page <u>39</u>.

All of the above means that people with COPD tend to adopt a shallow 'upper chest' breathing pattern, and they are unable to fully expel all the air with each breath out. The intercostal muscles and accessory muscles work overtime and demand a lot of oxygen to do so and the end result leaves you feeling tired and breathless.

As people with COPD tend to use more energy just to breathe it can mean that other previously simple tasks can become extremely difficult due to breathlessness and tiredness. They can then begin to start avoiding doing exercise or heavy tasks because the feeling of breathlessness is unpleasant or frightening. In turn this leads to a reduction in fitness, and then further breathlessness on exertion.



All this can seem quite depressing; it may feel that there is no way back. However with the help of healthcare professionals within a pulmonary rehabilitation programme, improvements can be gained in breathing whilst at rest and with exertion. If you have recognised the symptoms in the diagram above ensure you discuss with your doctor or nurse about attending pulmonary rehabilitation.

<sup>&</sup>lt;sup>7</sup> Adapted from Global Initiative for Chronic Obstructive Lung Disease (GOLD). *Global Strategy for the Diagnosis, Management and Prevention of COPD*, 2010. Available at: http://www.goldcopd.org.

# SECTION 4 Living with COPD – Medication

After being diagnosed with COPD your life will change. If you smoke you will be advised to stop and we will talk more about that later. Undoubtedly your GP or respiratory consultant will prescribe some medication and exercise (yes, exercise) will become a regular part of your life.

Firstly we will look at the treatment aspects of your care - medication. Pulmonary rehabilitation follows in the next section.

### Medication

### **Inhalers**

Medications for COPD are mainly taken by means of inhalers. Oral medications are also available but inhalers are preferred as they ensure the smallest effective dose can be given. Inhalers lessen the possibility of side effects as the medication is localised to the target area, i.e. the small airways of the lungs, rather than the whole body as happens when medications are taken orally.



You may find very occasionally, that you are given a nebuliser instead of an inhaler. This is becoming more unusual now, as it is recognised that in the majority of cases the same amount of drug deposition within the lungs can be achieved by using a metered dose inhaler with a spacer. However nebulisers are still used for administering some medications including normal saline (generally thought to moisten the upper airways to assist with sputum expectoration) and antibiotics (in cases of

Inhalers fall into two types: relievers and preventers.

### Relievers

particularly resistant infection).

Relievers are the inhalers that most people, with or without COPD, would recognise. The blue colour indicates an inhaler which rapidly opens up the airways (bronchodilator). These inhalers are short acting. Many people are given these inhalers the first time they present to the GP / hospital with increased breathlessness as a short term treatment by itself. It is important to recognise that if you have been given one of these, especially when unwell, you still need to see your GP again when recovered from the acute episode for further investigations (e.g. spirometry) and a formal diagnosis.

### Blue inhaler (salbutamol / terbutaline)

aka "short-acting beta agonists" (SABAs)

#### **Medication names:**

- Salbutamol (Ventolin, Respigen, Asthalin)
- Terbutaline (Bricanyl)

#### Notes:

Blue inhalers cause the smooth muscle in the small airways to relax and dilate.

They work by acting on the Beta 2 cells and are thus known as beta-agonists. They work within 2-5 minutes, but the effects do not last longer than four hours. Blue inhalers are used very commonly with COPD (and asthma) and with good effect. You should bear in mind that these are only a temporary treatment; if you find yourself needing to use your blue inhaler very frequently your GP may explore other options with you to try and prevent you becoming breathless in the first place.

If it is a Metered Dose Inhaler (MDI) it should be used with a spacer (see later in this section)

Terbutaline is administered by Turbuhaler only in New Zealand, although outside of the country it is available as a metered dose inhaler also. Salbutamol is available as metered dose inhaler or in a nebuliser.

### Side effects:

May include cramps, especially at night, a fine shaking (tremor) in the hands (which can, for example, make holding a cup of tea difficult) and feelings of heart racing (palpitations). It is important if you are already using medications from a group called beta-blockers that you discuss this with your doctor.

### Green and White Inhaler (ipratropium) <sup>8</sup>

#### **Medication names:**

• Ipratropium (Atrovent)

#### Notes:

Ipratropium helps to relax and dilate the smooth muscles that line the

airways, but works on the large airways (bronchi). This drug works by blocking a nerve transmitter called acetylcholine and is thus known as an anticholinergic drug. Similarly to blue inhalers, it works quickly, within 3-5 minutes, has a peak effect by 30 minutes and can last up to 5-6 hours and can be taken up to four times a day (every 6 hours).

It is a Metered Dose Inhaler (MDI) and should be used with a spacer (see later in this section).

### Side effects:

Common side effects may include prostatism (in men), and headache, nausea and dry mouth.

<sup>&</sup>lt;sup>8</sup> Image Credit: http://allergy.peds.arizona.edu/southwest/devices/inhalers-asthma/bronchodil.htm







### Preventers

Your GP may also give you a second inhaler once your diagnosis of COPD is confirmed. This inhaler may be a preventer, and is usually used regularly twice a day. The colour of the inhaler may be brown, orange, or red or purple. These are not usually used as a reliever, and it is easy to think that they are "not important" because you probably will not feel any immediate relief. Preventers are *very important* however and you should always use them. As the name implies they help prevent deterioration in your COPD.

Green Inhaler (salmeterol / eformoterol) 9

aka "long-acting beta agonists" (LABAs)

#### Medication names:

- Salmeterol (Serevent)
- Eformoterol (Oxis)

#### Notes:

Like the blue reliever inhalers these green preventer inhalers are also beta 2 agonists but work for a longer period of time (up to twelve hours). They are generally used twice a day as near as possible to twelve hours apart.

It is a Metered Dose Inhaler (MDI) and should be used with a spacer (see later in this section)

It is important to remember that these medications are **NOT** quick acting and should not be taken as a reliever.

### Side effects:

They have the same side effects as the blue inhaler, including the cramps and tremor.

#### Brown / Orange inhaler (fluticasone / beclomethasone / budesonide) <sup>10 11</sup>

aka "inhaled corticosteroid" (ICS)

#### **Medication names:**

- Fluticasone (Flixotide)
- Beclomethasone (Qvar, Becotide, Becloforte)
- Budesonide (Pulmicort)

#### Notes:

These contain man-made steroids of the glucocorticoid family, which mimic the naturally occurring cortisol made by the adrenal glands. Glucocorticoids have a powerful anti-inflammatory action, which help to prevent narrower airways by reducing the swelling and the spasm that would follow. Swelling and spasm are the two main issues which increase the breathlessness experienced by people





<sup>&</sup>lt;sup>9</sup> Image Credit: http://en.wikipedia.org/wiki/File:AsthmaInhaler.jpg

<sup>&</sup>lt;sup>10</sup> Image Credit: http://www.flickr.com/photos/mishl982/4552250403/

<sup>&</sup>lt;sup>11</sup> Image Credit: http://allergy.peds.arizona.edu/southwest/devices/inhalers-asthma/qvar.htm

with COPD. Obviously if this can be reduced then the breathlessness should theoretically be easier to control.

With the use of long term inhaled corticosteroids, a sunscreen should be recommended and moisturiser should be used to decrease / prevent the skin issues.

### Side effects:

In small doses it is thought there are no long term side effects, however they are often used in high doses which can lead to detrimental effects in other areas of the body. These effects can include voice changes, leading to a husky / croaky voice, a sore throat or oral thrush. Although this may seem insignificant to an outsider, oral thrush will change your sense of taste, and make it difficult or even impossible to eat or drink. It can also travel throughout the digestive tract resulting in severe debilitation and weight loss.

Adrenal suppression (the adrenal gland decreasing or stopping natural glucocortoid production) and osteoporosis (thinning of the bones leading to increased likelihood of bone fractures) are two other side effects which are frequently not recognised. Glaucoma, cataracts, and increasing fragility of the skin (increasing the risk of bruising or skin tears) are better recognised, but still disabling to the person experiencing it.

### Grey handihaler (Spiriva / tiotropium) 12

#### Medication names:

• Tiotropium (Spiriva)

### Notes:



A long-acting anticholinergic that helps to relax and dilate the smooth

muscles that line the airways in the lungs. This medicine begins to act within 30 minutes and lasts all day. It is important to take this medication daily and NOT as a reliever. This is the first inhaled medication specifically designed for people with COPD rather than using the medications which were designed for asthma.

### Side effects:

Most common side effects can include difficulty urinating (in men) as well as a dry mouth and constipation. This medication is available as a powder that is released from a capsule by a special type of inhaler. As with any new or unfamiliar medicine, it is important to have your prescriber, which maybe your GP or practice nurse or pharmacist demonstrate how to correctly take the medicine (We've heard of several patients swallowing the capsules whole)!!

<sup>&</sup>lt;sup>12</sup> Image Credit: http://commons.wikimedia.org/wiki/File:%22Spiriva\_HandiHaler%22-brand\_dry\_powder\_inhaler\_(open).png

### Combination inhalers (Seretide / Vannair / Symbicort) <sup>13 14 15</sup>

#### Medication names:

- Seretide
- Vannair
- Symbicort

### Notes:

As well as the individual inhaler medications there are also inhalers with combinations of medications. It is hoped that patients will reliably take their inhalers if they have to use fewer devices, and will also help with confusion about which inhaler to use when.

These combination inhalers break the rules as far as colour coding are concerned! They are now found as red or purple inhalers.

**Seretide**, is a purple inhaler which is available in a variety of strengths; the colour purple gets deeper as the prescribed dose of the inhaler is stronger. This is a mixture of salmeterol (Serevent) (LABA), and fluticasone (Flixotide) (ICS), and should only ever be used twice daily.

**Vannair** is a red inhaler, only available as a metered dose device. It contains a mixture of budesonide (Pulmicort) (ICS) and eformoterol (Oxis) (LABA). It should be used with a spacer and only ever should be used twice daily.

**Symbicort** is a red bottomed inhaler, and again is usually used twice daily. It contains a mixture of Pulmicort (ICS) and Oxis (LABA). Occasionally your doctor may suggest you use this as a reliever.



### It is important that you only use Symbicort as a reliever if your doctor recommends that you do this.

Only a few people with COPD will benefit from using this as a reliever. The majority of people with COPD still need a separate reliever such as salbutamol (Ventolin) or terbutaline (Bricanyl).

In December 2013, agreement was reached by Pharmac and Glaxosmithkline to drop the price of three of the medications in New Zealand; these being Serevent, Flixotide and Seretide. As part of this agreement, Seretide no longer has to be applied for under special authority. Symbicort, Oxis and Pulmicort, produced by Astra Zeneca have not had the same agreement applied to them, therefore Symbicort continues to need special authority application.





<sup>13</sup> Image Credit: http://www.seretide.co.nz/seretide-for-copd.html

<sup>&</sup>lt;sup>14</sup> Image Credit: http://www.vannair.co.nz/

<sup>&</sup>lt;sup>15</sup> Image Credit: http://www.symbicort.co.nz/

### Other Medication

#### Monteleukast (Singulair)

#### Notes:

For those of you who have an element of asthma within your COPD, if your doctor feels this is impacting and is difficult to control with the more "normal" treatments, you may have a trial of Monteleukast. This has recently become available in NZ under special authority.



Monteleukast is for treating wheezing, chest tightness, difficulty breathing and coughing. Another symptom it is used to treat is bronchospasm (causing breathing difficulties) during exercise, as well as seasonal (occurs at certain times of year) or perennial (all year round) rhinitis (itchy or runny nose).

It is not an emergency treatment and should be taken on a daily basis as a preventer.

It can be taken

- when suits at least 2 hours before exercise if this is the symptom needing treatment,
- in the evening for asthma and allergies, or
- in the morning or evening for allergies only.

It works by blocking natural substances that are produced called leukotrienes that can cause allergies or asthma to worsen by causing swelling in the airways.

#### Side effects:

stomach pain, headaches, thirst and increased bleeding tendency, as well as drowsiness.

A special authority application needs completing by your GP.

#### **Theophylline (Nuelin)**

#### Notes:

This medication may be prescribed for you either as short or long acting; in tablet form it is given in New Zealand as the medication Nuelin SR (meaning slow release) and is taken twice daily. It will not relieve acute breathlessness, and needs to be taken on a regular basis to be effective. It has a narrow therapeutic level (so you will have your blood monitored regularly) and is affected by many different



medications including antibiotics, oral contraceptives, flu vaccine, over the counter medications including St Johns Wort, and alcohol and smoking tobacco or marijuana.

It works by opening the airways by relaxing the smooth muscle around them, allowing air to flow into and out of the lungs more easily.

It can also be given by intravenous form when you are acutely unwell, however you will only have this when in hospital. It is important that you always inform any doctor you see that you are using theophylline as medications that may be given to you will be affected by it. This medication is best taken on an empty stomach either an hour before or 2 hours after a meal, however if you feel that the medication upsets your stomach it may be best to take it with food.

### Side effects:

Nausea, palpitations, shakiness and sleepiness, as well as a skin rash and fainting. It is important that you inform your doctor immediately if you experience any of these symptoms.

### How to Use Your Inhaler

Inhalers not only come in different colours but there are also different types. These are (in New Zealand)

- Metered Dose Inhalers,
- Accuhalers,
- Turbuhalers, and
- Handihalers.

### **Metered Dose Inhalers**

By using a 7 step method, the medication can be safely and effectively administered. Please note that this explanation includes the use of a spacer.

- 1. Remove the dust cap from the inhaler.
- 2. Shake the inhaler gently several times.
- 3. Place the inhaler into the spacer opening.
- 4. Place the spacer mouthpiece into your mouth and gently close your lips around it.
- 5. Press the aerosol canister once so that the inhaler "fires" into spacer.
- 6. Inhale the mist by breathing in deeply and holding the breath for 10 seconds OR by breathing gently in and out of the spacer for 5-6 breaths.
- 7. Repeat process if prescribed.





This video shows you how to use a Volumatic Spacer:

http://bit.ly/volumaticspacer

A spacer should be used by everyone who uses a metered dose inhaler. It is used to increase the amount of drug that ends up in the lungs (lung deposition) rather than hitting the tongue or the back of the throat as can happen when an inhaler is used "straight into the mouth". By reducing the amount of deposition onto the back of the mouth, the risk of oral thrush / voice changes is lessened. <sup>16 17</sup>



<sup>&</sup>lt;sup>16</sup> Image Credit: http://commons.wikimedia.org/wiki/File:Asthma\_spacer\_adult.JPG

<sup>&</sup>lt;sup>17</sup> Image Credit: http://allergy.peds.arizona.edu/southwest/devices/spacers/optichamber.htm



If your inhaler contains a steroid, after you have used your inhaler you should rinse your mouth and gargle with water then spit it out. This will help prevent the side effects of oral thrush and voice changes.

### Turbuhalers

- 1. Unscrew the cap and remove it from the Turbuhaler.
- 2. Hold the Turbuhaler upright (with the mouthpiece up) to ensure the medication loads correctly.
- 3. Hold the top steady and turn the bottom all the way to the right then back to the left. You will hear it click. This means the medication has been loaded.



- 4. With the Turbuhaler held away from your mouth, gently breathe out.
- 5. Seal your lips around the mouthpiece, then lift the bottom of the Turbuhaler so you are looking at where the wall and ceiling joins.
- 6. Inhale rapidly and deeply. Continue to take a full, deep breath.
- 7. Resume normal breathing.
- 8. Repeat steps 1-7 when more than one inhalation is prescribed.
- 9. Keep the Turbuhaler cap on when not in use. This will keep the Turbuhaler clean and dry.



If your turbuhaler contains a steroid, after you have used your inhaler you should rinse your mouth and gargle with water then spit it out. This will help prevent the side effects of oral thrush and voice changes.

### Accuhaler

- 1. Hold the Accuhaler at its base using one hand
- 2. Put your thumb of the other hand on the thumb grip
- 3. Open the Accuhaler by pushing the thumb grip around until you hear it click
- 4. Slide the lever until it clicks (Your medication is now loaded)
- 5. Breathe out, away from the Accuhaler
- 6. Put the mouthpiece in your mouth and form a good seal with your lips
- 7. Breathe in through your mouth for up to 5 seconds
- 8. Remove the Accuhaler from mouth whilst holding your breath for up to 10 seconds
- 9. Breathe out gently away from the Accuhaler
- 10. If further doses are required, push the lever back to the starting position and repeat the above steps
- 11. Close the Accuhaler <sup>18</sup>



<sup>&</sup>lt;sup>18</sup> Image Credit: http://commons.wikimedia.org/wiki/File:Seretide250.jpg


If your accuhaler contains a steroid, after you have used your inhaler you should rinse your mouth and gargle with water then spit it out. This will help prevent the side effects of oral thrush and voice changes.

### Handihaler

- 1. Open the dust cap by gently lifting upwards.
- 2. Open the mouth piece.
- 3. Take one capsule out of foil packaging.
- 4. Place in centre of handihaler.
- 5. Close mouthpiece.
- 6. Pierce capsule by squeezing the green button at the side. Only do this once.
- 7. Breathe out completely, away from the handihaler.
- 8. Seal your lips around the mouthpiece with the handihaler horizontal.
- 9. Breathe in.
- 10. Remove handihaler from your mouth.
- 11. Repeat steps 7 -10.
- 12. Breathe normally again and remove used capsule from handihaler. <sup>19</sup>





The handihaler should be cleaned monthly. See https://www.spiriva.com/using-spiriva/how-to-use-spiriva.html for a demonstration.

There are advantages and disadvantages to all of the different types of device listed above. The most important consideration should be that you are willing and able to use the device appropriately, as prescribed. If you have been provided with a device that you find difficult to use, ensure that you speak with one of your healthcare team. A different device can usually be found or further education on using the original device may be needed. Your doctor will know which types of medication you need but it is important that the decision is made in partnership with you as to the suitability of the device.

Although choice is useful, tiotropium (Spiriva) is only available in New Zealand in a handihaler.

<sup>&</sup>lt;sup>19</sup> Image Credit: https://www.spiriva.com/using-spiriva/how-to-use-spiriva.html

# SECTION 5 Living With COPD - Pulmonary Rehabilitation

## What is Pulmonary Rehabilitation?

Pulmonary rehabilitation, pulmonary rehab for short, has been described as a, "multidisciplinary program of care for patients with chronic respiratory impairment that is individually tailored and designed to optimise physical and social performance and autonomy"

Pulmonary rehab uses a variety of approaches and involves many members of the respiratory care team. It aims to improve the capabilities and quality of life of people with chronic lung disease. This is achieved by allowing people to learn more about their condition and improve their confidence in managing their disease and to participate more in social and physical activities.

Endurance exercise training is the cornerstone of rehabilitation programs, but along with exercise there will be sessions to increase understanding of the disease process, improve coping skills and a focus on empowering your self-management. Self-management education has been shown to reduce hospital admissions which is a great reason to take part in pulmonary rehab.

Pulmonary rehab is a well-researched treatment approach and is recognised as an important part of the management of COPD. It reduces breathlessness and fatigue, to increases exercise capacity, and enhances the sense of being in control.

There are no international guidelines as to exactly what should be included within a Pulmonary Rehabilitation Programme, and what you will find in your own area depends largely on the resources and healthcare staff available to run it. This section will give you ideas about what may be included, and different ways in which programmes can be organised and implemented.

## Who Benefits From Pulmonary Rehab?

Generally anyone who has a diagnosis of chronic lung disease and whose activities are limited by breathlessness may be considered.

It also helps to have the following:

- Motivation towards helping yourself become healthier.
- Be on optimum medical management (inhalers etc.).
- Currently be in a stable condition.
- Be able to commit to attending the whole programme.
- Be smoke free, or have some support to try to, or at least understand the importance of trying to become smoke free. See page <u>45</u>.

## How to Get a Referral to a Pulmonary Rehab Programme

Your GP or Respiratory Specialist may suggest you attend pulmonary rehab, but if they don't and you feel you would benefit then ask about attending a programme at your next appointment with them. In the unlikely event that they do not know about programmes running in your area try contacting your local DHB and ask to speak to someone in the physiotherapy or respiratory department to see if a programme does run there.

The person responsible for running the programme will need a referral from your GP, practice nurse or other healthcare professional with some basic health information about you. They will then arrange for an appointment to discuss the details of your local course. You may be required to do a 6 minute walk test or a shuttle walk test, (like the bleep test at school) and some quality of life questionnaires before starting the course. These are used as outcome measures / a measure of the improvements you make over the course.

## The BODE score and Other Questionnaires

This has been put together to help healthcare professionals predict mortality in people with COPD. The higher the resulting number the higher risk of death from COPD.

It is important to recognise that this does not necessarily correlate with quality of life; many people with very severe COPD actually self-assess as having a good quality of life <sup>20</sup>. Nor can it be used to predict how long you will live as some sites on the web try to claim.

Variable	Points on the BODE Index			
	0	1	2	3
FEV1 (% predicted)	≥65	50-64	36-49	≤35
6-Minute Walk Test (meters)	≥350	250-349	150-249	≤149
MMRC Dyspnea Scale	0-1	2	3	4
Body Mass Index	>21	≤21		

The BODE Index (Simplified)

The Chronic Respiratory Disease Questionnaire developed in 1987 by Guyatt et al <sup>21</sup>, is the most commonly used health related quality of life measurement in respiratory disease, as it focuses on 4 different domains; dyspnoea (breathlessness), emotional function, fatigue and mastery. You will almost certainly be asked to complete one of these if you are taking part in a pulmonary rehabilitation programme; this will be discussed at your assessment appointment and compared with another questionnaire after you have completed the programme.

<sup>&</sup>lt;sup>20</sup> Celli BR, Cote CG, Marin JM, et al. (2004) The body-mass index, airflow obstruction, dyspnoea, and exercise capacity index in chronic obstructive pulmonary disease. N Engl J Med 350: 1005–12

<sup>&</sup>lt;sup>21</sup> Guyatt GH, Berman LB, Townsend M, Pugsley SO, Chambers LW (1987) A Measure of Quality of Life for Clinical Trials in Chronic Lung Disease. Thorax 42: 773-778.

Very occasionally a different questionnaire will be used; the St George's Respiratory Questionnaire <sup>22</sup> This questionnaire *does* correlate well with lung function and health related quality of life, however it is more complex to fill in and must not be filled in prior to attending the clinic appointment.

## What's in a Pulmonary Rehab Programme?

A Pulmonary Rehabilitation Programme should involve:

- 1. Physical Exercise
- 2. Breathing Retraining, and
- 3. Education

## Pulmonary Rehab 1: Physical Exercise

Probably everyone knows that physical exercise improves fitness levels - being able to walk further, run, cycle etc. What you may not know is that this is also true for people who have COPD. Often the very thought of 'exercising' for people with COPD causes feelings of anxiety or "I can't do it" thoughts. Some COPDers have been known to laugh or try to escape the room when they are told they will be going to a gym and starting to exercise!



Don't freak out though. You will be supervised by people who have been trained in pulmonary rehab. Your exercise programme will be tailored to your individual abilities, and take into account any other medical problems you may have.

Exercise can be quite scary at first, and without a doubt it will make you breathless. It will also make you aware of muscles you never knew you had! However, you should never work so hard that you become uncomfortably breathless (see breathing scale (Borg) below) or experience pain.

### Modified Borg Scale

Scale	Severity
0	No Breathlessness
0.5	Very Very Slight (Just Noticeable)
1	Very Slight
2	Slight Breathlessness
3	Moderate
4	Somewhat Severe
5	Severe Breathlessness
6	
7	Very Severe Breathlessness
8	
9	Very Very Severe (Almost Maximum)
10	Maximum

The Borg Scale <sup>23</sup> is used to measure your how breathless you feel during activity. It provides important information to your healthcare team.

It is a very useful tool to use during your pulmonary rehab course and also when exercising alone, as it aims to help people increase their activities while maintaining control of their breathing.

During a pulmonary rehab programme we advise you to exercise to the point of being 'moderately breathless' indicated by a number 3 on the scale. This

<sup>&</sup>lt;sup>22</sup> Jones PW, Quirk FH, Baveystock CM. The St. George's Respiratory Questionnaire. Resp Med 1991;85 (suppl B):2531.

<sup>&</sup>lt;sup>23</sup> BORG, G. (1982) Psychophysical bases of perceived exertion. Medicine and Science in Sports and Exercise, 14 (5), p. 377-81

means you should be breathing harder and heavier, and will probably be breathing using your mouth. However, you should still be able to talk to someone without gasping for breath.

When exercising you should not go higher than 4 on the scale. If your breathlessness is "Somewhat Severe" or worse, you need to stop what you are doing and rest. This is when you should practice your recovery breathing technique (see page <u>38</u>).

If you are exercising and your breathlessness is only very, very slight (less than 1 on the scale), then you should work a little harder in order to gain benefit from the exercise.

It is useful to keep a record of this to demonstrate your improved fitness level and progress. For example, an activity such as cycling for 5 minutes that made you moderately breathless (3 on the scale) a month ago now may make you only very slightly breathless (1 on the scale). This would be your prompt to then increase your activity level again.

### Why Exercise? What are the benefits?

People with COPD tend to stop exercising because of muscle tiredness or shortness of breath, so a physical training component to pulmonary rehab is essential.

Exercise is often seen as a way to "get fit", but ideas about fitness can be very different. Pulmonary rehab aims to get people fit enough to carry out activities that they need to do in everyday life, or activities that they enjoy. This very much depends on the individual, but can be anything from walking to the mailbox, mowing the lawns, or competing in a half marathon.

By improving your fitness you will be able to use your energy more efficiently and effectively, and be able to live life to the full. By slowly building up your fitness level your heart and lungs will become more efficient, and will be able to provide the rest of your muscles with the oxygen they need to work.

Research has shown that exercise has many benefits for people's health and wellbeing:

- Improves air passage and lung fitness <sup>24</sup>
- Helps reduce and control high blood pressure <sup>25</sup>
- Helps control blood sugar levels <sup>26</sup>
- Reduces the risk of type 2 diabetes <sup>27</sup>
- Reduces the risk of heart disease <sup>28</sup>
- Improves circulation <sup>29</sup>
- Encourages good sleep patterns <sup>30</sup>
- Improves bowel function <sup>31</sup>
- Helps with relaxation
- Slows down the loss of bone minerals with age (improves bone density Osteoporosis) <sup>32</sup>
- Helps control weight <sup>33</sup>
- Reduces the tendency for blood clot formation <sup>34</sup>
- Releases endorphins that give you that 'good feeling' <sup>35</sup>
- Helps towards increasing social activities
- Muscles tendons and ligaments get stronger <sup>36</sup>

### Types of exercise

#### A) Cardiovascular Endurance (Aerobic exercise)

Cardiovascular endurance is the ability of the heart, lungs and blood vessels to deliver oxygen to working muscles and tissues, as well as the ability of those muscles and tissues to use that oxygen.

Cardiovascular endurance is more commonly called cardiovascular fitness or aerobic exercise. Throughout the rest of this book we will refer to it as aerobic exercise.

Aerobic exercise comes in many forms but in general, it should be performed at a moderate level of intensity over a relatively long period of time. The aim is to make you breathless (but not so breathless that you are uncomfortable or unable to talk).

When starting an exercise programme you should gradually ease yourself into it, and start gently. People always ask how long they should do aerobic exercise for (i.e. "How long should I stay on the

<sup>&</sup>lt;sup>24</sup> http://www.upgradeyourbody.com/articles/fitness/how-to-increase-lung-capacity.html

<sup>&</sup>lt;sup>25</sup> http://www.mayoclinic.com/health/high-blood-pressure/HI00024

<sup>&</sup>lt;sup>26</sup> http://diabetes.webmd.com/guide/exercise-guidelines

<sup>&</sup>lt;sup>27</sup> Sheri R. Colberg et al. (2010) Exercise and Type 2 Diabetes. Diabetes Care Vol 33 No 12 e147-e167

<sup>&</sup>lt;sup>28</sup> http://circ.ahajournals.org/content/107/1/e2.full.pdf+html

<sup>&</sup>lt;sup>29</sup> http://www.livestrong.com/article/371365-how-to-increase-blood-circulation-to-improve-health/

<sup>&</sup>lt;sup>30</sup> http://www.webmd.com/sleep-disorders/news/20110614/exercise-improves-sleep-nighttime-breathing-troubles

<sup>&</sup>lt;sup>31</sup> http://www.livestrong.com/article/372582-exercises-to-increase-bowel-movement/

 $<sup>^{32}\,</sup>http://sportsmedicine.about.com/od/tipsandtricks/a/ExerciseandBones.htm$ 

<sup>&</sup>lt;sup>33</sup> http://my.clevelandclinic.org/heart/prevention/exercise/ex\_wtcontrol.aspx

<sup>&</sup>lt;sup>34</sup> http://www.lifebridgehealth.org/Main/BloodClotsDeepVeinThrombosis.aspx

<sup>&</sup>lt;sup>35</sup> http://blog.bufferapp.com/why-exercising-makes-us-happier

 $<sup>^{36}</sup> http://fitness.mercola.com/sites/fitness/archive/2013/02/08/simple-activity-increases-muscle-strength.aspx$ 

bike for?"). This very much depends on your starting fitness level. The aim of aerobic exercise is to make you breathless. If after 2 minutes on the bike you would put yourself at a number 4 on the Borg scale, then that is enough. If it takes 15 minutes to get to a Borg 3 – 4, then that would be your starting point. From here, the aim is to gradually increase the length of time you spend on the exercise, then you can look at ways to make it harder – for example, walk on an incline on the treadmill, or give yourself a set time and try to cover more distance within this time.

Below are some examples of Aerobic exercise

#### Walking

This is a fantastic and free exercise that can be done by most people who attend a pulmonary rehabilitation programme.

If you are walking outdoors, set yourself a route to follow to begin with. Ensure it is not too long, nor too challenging. It would be ideal if there were places you could stop and rest if needed.

As mentioned previously, everyone's starting level is different, but just ensure you walk far enough to challenge yourself slightly and to get to a Borg level 3. Then rest and recover before continuing.

It is a good idea to record how far or how long you walked for so you can see your progress over the weeks. As your fitness levels improve you will notice that you can walk further within your set time, or that you can walk for much longer. You could then think about perhaps including a slight hill in your walking route as a challenge.

If you are walking on a treadmill at home or in a gym, then start on the flat at a comfortable walking pace. Over time you can increase your speed, or walk on an incline if the treadmill has this option.

#### Cycling

This is another potentially free exercise to do and gives a great cardiovascular workout. You can be out on the open road or local cycle paths, or if you do not want to do battle with the elements, then a static bike at home or in a local gym is a good option.

Ensure your bike is set up correctly for you. There should just be a slight bend in your knee when your leg is at the bottom of the

movement. It is helpful to set the seat to your hip height when you are standing next to the machine prior to getting on.

Start slowly with minimal resistance on the pedals. You do not want your legs to be whizzing round / freewheeling, but you do not want it so hard to push that it is a huge effort. Time yourself and stop when you reach a Borg 3 level. As you improve and are able to cycle for longer, you can challenge yourself by increasing the pedal resistance, or you could set yourself a time limit and see how far you can get within that time. This is a very good way to motivate yourself to improve – by trying to beat your personal best.





#### Rowing

This exercise is a great all over body workout. By combining the use of your legs with your arms you will work harder than on some other aerobic exercises. This may mean that you can only do a couple of minutes on this machine to begin with. As with walking and cycling, start gently, record your progress and gradually build it up in terms of time, distance or speed.



#### Swimming / aqua jogging or aqua aerobics



Swimming is another great all over body workout, but does not suit everybody. If you are unable to swim then participating in an aqua aerobics class is ideal. The water supports your body but also provides resistance. Brisk walking or jogging in waist / chest deep

water is also very effective.

Some examples of higher impact aerobic exercise include running, participating in aerobics classes or skipping.

#### B) Strength Training

This is a method of improving skeletal muscle strength by gradually increasing the ability to resist force through the use of free weights, machines, or your own body weight. Strength training is also known as resistance training.

When properly performed, strength training can provide significant functional benefits and improvement in overall health and wellbeing such as:

- Increased bone, muscle, tendon and ligament strength.
- Improved joint function.
- Increased bone density.
- Reduced potential for injury.

Strength training involves doing your weights in sets of repetitions or "reps" and sets. This can cause some confusion if you are new to it but with practice it will become easier.

As a general rule, we ask people to aim for 3 sets of 10 reps. This means selecting your weight and performing the exercise or movement 10 times, stopping to rest, and then repeating the whole thing two more times. This effectively means you will have done 30 repetitions of that exercise.

Three sets of 10 is a rough guide and something to aim for. If after doing 1 set of 10 your muscles are sore or tired, then you either have too much weight on, or that is your starting point.

If after three sets of 10 your muscles are not at all fatigued then you need to add more weight next time.

Do not expect to do the same number of 'sets and reps' on all your strength exercises, as some will use bigger muscle groups and you with therefore be able to lift more weight.

When starting a strength training programme it is important to begin gently and with light weights, then over time increase the weight to challenge yourself.

You can either decide to keep the weights light and do more sets or reps, or you could increase the weight you are lifting, and keep your sets and reps low.

It is very important that you know how to perform each strength training exercise correctly so that the appropriate muscle group(s) are used, as it is quite easy to 'cheat' and use other muscles to 'help' you lift a heavier weight.

If you attend a Gym, then there is likely to be a huge variety of resistance machines to use, and you should be shown how to use them correctly and safely by either a physiotherapist or a gym instructor before going it alone. You should also have a programme to follow, and someone to monitor your progress.

You do not have to attend a gym however to do resistance / strength training. This can be achieved at home with the use of hand held weights (dumbells) or by making your own weights - using a tin of beans, or used milk containers with water or sand in them. You can also use your bodyweight as resistance for certain exercises.

Below are some examples of weight resisted exercises that can be done at home, or in a programme with minimal resources and equipment. Balls or weights can be held to make each exercise more difficult if required. If your programme is held in a gym environment, then each gym will very likely have very different types of weight machines which you should receive proper instructions on before first use.

#### **Squats**

This exercise uses your own bodyweight as resistance. Stand with your feet hip distance apart. Slowly bend from your knees and hips (keeping your head and chest held high), and make sure your bottom sticks out behind you, so that you can see your toes.

You can add extra weight by holding dumbells in your hands if required.

#### Press ups

The easiest form of a press up is to do a **wall press.** To do this you stand arm's length from a solid wall. Place your hands on the wall at shoulder height and just a bit wider than your shoulders. Slowly bend your elbow (out to the sides) and lean in towards the wall. Then straighten your arms and return to the start position again.

To progress this, you can gradually move your feet further away from the wall, or you can go down into a kneeling position (if you can safely and comfortably get down to the floor and back up again). With your knees under your hips, and your hands under your shoulders, you then bend your elbows (out to the side), and lower your chest towards the floor as far as is comfortable. Straighten your arms / push up again and return to the starting position.

#### Calf raises

Stand near a chair, table, wall or kitchen bench so you have something to hold onto for balance should you need it. Keeping your knees straight, slowly rise up onto your toes, then return to the start position again.

#### **Dumbells**

Dumbells are hand held weights. You can either buy some, or make your own at home. You can start by using tins of beans and progress to a heavier weight when ready. Empty milk containers make great homemade dumbells. You can simply put water or sand in them to make them the appropriate weight.

#### • Bicep curls:

Hold your weights in your hands. Keep your elbows tucked into your sides. Slowly bend at the elbow bringing your weights towards your chest. Then straighten elbows and return to start position.

See the bicep curl in action in this video: http://bit.ly/COPD-BicepCurl

- Triceps press:
  - Hold the weights above your head with arms straight up.
    Bend 1 elbow so your hand and weight come down towards the back of your neck. Now slowly straighten your arm back up towards the ceiling.
  - The other option is to bend forwards slightly from your waist and place your hand / weight by your hip. Slowly straighten your arm from the elbow out behind you then return it back to your hip.

#### • Forward rows:

Hold weights in each hand. Knuckles facing to the ceiling with the weights held by your chest. Straighten your arms out in front of you - keeping them at chest height. Then pull arms back into your chest, making sure your elbows point to the back of the room. Imagine you were rowing a boat!

#### • Shoulder press:

Hold weights in each hand, next to your shoulders. Raise your hands (both together or one at a time) up towards the ceiling, then return to the start position.

• Upright rowing:

Hold weights in each hand with arms straight and weights just touching your thighs. Raise your hands up towards your chin (elbows come up high) and keep the weights in close to your body.

#### C) Other types of exercise

As well as aerobic and strength training a Pulmonary Rehab programme, or indeed a home programme, should also include a warm up, balance exercises, stretches and a cool down.

#### Warm up

This does not need to be anything specific or technical!

The aim of a warm up is to gently start to get your whole body moving and to feel slightly warmer with a sensation of a mild increase in your breathing rate.

A warm up need last only a few minutes, and some examples of what could be included are listed below:

- Marching on the spot either standing or seated in a chair.
- **'High Knees'** Lift your legs higher and touch your knee with the opposite hand, first one leg then the other, like marching.
- Squats make them nice and easy, and don't go too low.
- **Hamstring curls** Transfer your weight from side to side, and kick one foot up behind you to try to reach your butt.
- **'Waist twist and reach'** Keep your feet still and your body upright. Then slowly rotate your body to twist from side to side. You can reach further with your arms if you can.
- Arm circles make big circles with your arms.
- **'Punching out and up'** push both arms out in front of you then pull them back again, then take both hands up towards the ceiling.
- Roll your shoulders.

#### **Balance** exercises

Balance is extremely important to us all, and unfortunately it deteriorates as we age. Simply practicing a little bit each day will have a huge benefit. The simplest way to do this is to stand at the kitchen bench (or somewhere that you feel safe / have something to hold on to should you feel wobbly), then lift one foot off the floor. There is no need to lift it very high to begin with. It helps to look at a spot on the floor or the wall to 'focus' your balance. See how long you can manage to stay still like this for and aim to progress.



To make it slightly harder you could try moving your lifted leg out in

front of you and hold for a time, then take it out to the side, and then behind you. Try to stay as still as you can and hold your leg there for as long as you can. Remember to breathe though!

For those people who find this starter exercise quite easy, you can challenge your balance by moving your arms around as you stand on one leg. If you are attending a pulmonary rehab programme in a gym or a hospital then ask to try the balance / wobble boards also.

#### Cool down and stretches

Stretching after you exercise is very important to help minimise injury. Aim to hold each stretch still for at least 10 - 15 seconds.



See <u>Continued Exercise</u> on page <u>34</u> for some more information.

### Types of Pulmonary Rehab Programmes

As mentioned at the beginning of the chapter, pulmonary rehab courses can vary significantly depending on your location, resources and personnel available to run it.

Typically a larger hospital programme can run anywhere from once or twice per week for anything from 6 to 10 weeks, and would usually involve exercising with larger pieces of equipment such as treadmills and bikes. Smaller or more rural destinations may meet weekly and use more basic equipment such as chairs, steps, balls and hand held weights.

The exercise sessions may be in the following forms:

#### • Circuit of exercises:

You spend a set time at each station and then work your way round them all with a set break in between. Usually the time you spend exercising will increase as the weeks go on and the rest period would reduce if possible. This situation works best when the group of participants are all functioning at the same 'level of ability'. You could keep a record of how long you are exercising for and how breathless you feel at the end.

• Gym based:

This could involve using machines such as treadmills, bikes and weights equipment. You should be shown how to safely use all the equipment, and be given a programme to follow. We usually suggest doing one piece of aerobic exercise then move over to some weights to let your breathing recover, and then swap back to aerobic. Ideally you should be 'in charge' of how long you use each piece of equipment for, and record your efforts and your breathing score also. This type of programme can accommodate varying abilities and severities of COPD

• Other:

This may be in a church hall, or community building with minimal resources. All that is required essentially is a space to walk, some chairs, some hand held weights and exercise bands or different weights / sizes of balls. It is amazing how many exercises us physiotherapists can make up with even the most basic of equipment! In this situation you should have a programme to follow and be able to record it.

Essentially, to get the most out of any programme you need to try your best, challenge yourself and strive to improve. Remember you will be breathless - it's OK! Follow the guidance given and make the most of every opportunity or piece of advice the professionals (and other participants) offer you.

### **Continued Exercise**

After completing your pulmonary rehab programme it is essential that you continue with some form of regular exercise for the rest of your life. The pulmonary rehab programme is just the first stepping stone towards the new healthier you.

It helps people to have somebody who can motivate and encourage them with this, so ask your friends or relatives if they can be on board! Your healthcare team can also play a part in supporting you, but at the end of the day it is down to you as an individual to stick to it through thick and thin. There will be times when you are sick, injured or have other pressures on you, and it is ok to 'slow down' for a while. The important part is getting back on track, or at least knowing who to ask for help in doing this.

It is important to choose an exercise regime that will work for you and that you will stick to. Remember to choose exercises that you enjoy, and to vary the ones you do. Whatever option you chose, it is recommended to exercise 3 - 5 times per week. Ensure your programme contains a mixture of aerobic, strength and balance exercises over each week.

#### **Examples of ongoing exercise:**

• Join a local gym:

Ensure that you are shown how to work all the equipment by one of the staff, and in many places they can help you come up with a programme to follow. Ensure you remember to include some aerobic and some strength exercises in it.

Green prescription:

This scheme is available throughout New Zealand, but may be run differently and by different organisational 'bodies'



depending on your region. The best person to talk to about this would be your GP. The aim of Green prescription is to allow easy, low cost access to exercise to improve the health of people with various chronic conditions. The activities on offer vary from allowing low cost access to gyms, walking groups, aqua jogging, aqua aerobics, and group exercise classes held in local venues.

#### • Exercising at home:

If you chose this option you need to have a fair bit of self-motivation to stay on track. To help with this, have set times and a written programme of exercises to complete. You could also ask a friend or relative to do it with you. You could ask the staff running your rehab programme for some written information and ideas for exercises.

#### • Walking / cycling:

To help with motivation, it may help to do this with a friend or relative. Ensure you strive to increase the length of your route, or try to do it a bit faster, or attempt a hill somewhere along the way!

#### • Swimming / aqua jogging:

Ask your local pool what they offer. If lap swimming is not for you, then you could try an aqua aerobics session, or simply walk up and down the pool. If you choose this option

ensure that you also do some kind of weight bearing activity (on land) if at all possible. This is important for strong healthy bones.

• **Tai Chi**: This is a very beneficial form of exercise, and the focus is on breathing correctly too. If you decide this is for you, then it would be advisable to also add in an aerobic exercise session another time each week (walking, cycling, swimming, step ups). Ask at your local sports centre for information of local classes or simply search Google with the search term tai chi MyLocation

e.g. tai chi Auckland.

• Dancing, bowling, badminton, table tennis etc.

Look in your local paper for community based exercise programmes. Your GP may also be aware of what is available in your area as many groups such as Age Concern, or even local rest homes and community centres run classes.

### Pulmonary Rehab 2: Breathing Retraining

During a pulmonary rehab programme, there will probably be a fair amount of time spent on improving and controlling your breathing.

The starting point for this will focus on 'normal breathing'. This is also known as diaphragmatic breathing, breathing control or tummy breathing. This is simply how breathing is meant to be (See <u>Normal Breathing</u> on page <u>10</u>).

As we have seen, with COPD the diaphragm becomes less efficient and contributes less to the work of breathing. This means the intercostal and accessory muscles have to work harder. However, you can change this with practice patience and determination!!

### Abdominal breathing - how to do it

- Start by lying down in a reclined but supported position (e.g. on a recliner chair or propped up on the sofa or bed).
- Place one hand on your tummy and the other on your chest. Some people like to place both hands on their tummy, or behind their head.
- Focus on your breathing.
- Keep your breathing gentle and relaxed. This exercise is NOT about taking big breaths.
- Try to ensure you are **breathing in through your nose**. If you can't do this then see the section on <u>Nasal Rinsing</u> on page <u>55</u>.
- You can breathe out of your mouth if this feels more comfortable.
- Try to feel where most of the movement happens when you breathe in. Chest or tummy? Take your time about this. Remember not to take big breaths.
- Start to focus on breathing down into your tummy. As you breathe in, the tummy rises. This is not a big movement. Aim to produce more movement from your tummy than your chest.

This exercise can take many weeks for some people to really master. Start by dedicating time twice per day when you will not be interrupted. Practice the exercise for as long as you feel comfortable doing it.

When you are able to do it for 10 minutes without too much effort, then you are ready to progress to trying to do it in a more upright sitting position. Some people like to try it more often - perhaps every hour or so for a couple of minutes each time. The goal is to ensure that it is slow, gentle and relaxed. You are trying to "re-learn" how we were designed to breathe, and it does take time patience and practice so don't give up.

Some people feel they can manage it for a short time, then feel the need to take a large/ deep breath. Don't worry - this is quite usual. Just keep practicing. If you are not sure if you are doing it correctly, then seek the advice of a physiotherapist for a one to one session. Remember, the aim of this exercise it to use less energy by adopting a more efficient breathing pattern.

#### 36





See this video for a demonstration:

http://bit.ly/AbdominalBreathing

### Breathing during exercise

We don't often think about how we are breathing when we exercise - we are just aware that it gets faster, deeper and harder!

It is normal to get breathless when exercising, but remember to stop at the Borg 3 or 4 mark as discussed earlier in the book.

It is also normal to have to start breathing in through your mouth when exercising too (this is especially true when doing aerobic exercise).

When doing aerobic exercise, just remember to be aware of your breathing. Try to keep it regular and even as your breathing rate quickens. This will help keep your breathing more manageable and keep you in control.

Remember about your shoulder position and posture too (see the sub-section on <u>Recovery</u> <u>Breathing and Positioning on page 38</u>).

For breathing when doing strength / weight training, there are 2 rules:

- 1. Do **not** hold your breath.
- 2. Breathe **out** with effort.

Rule 1 may sound obvious, but it happens all too often. Keep focused on your breathing during your workout and this will help prevent you breath holding.

Rule 2 basically means that you breathe out during the hard part of the exercise.

For example, if you were to lift some weights above your head, you would breathe in before you started the movement, and as you lift your arms up to the ceiling, gently breathe out. As you bring your arms back down towards your shoulders, breathe in again.

This often feels very odd at first, but keep at it. Remember to keep your movements slow, and time them with your breath.

Before you start each exercise work out which part of the movement requires effort, and remember to breathe out with this movement, then breathe in again as you complete the movement.

This does take concentration, and some people find they then forget to count the number of reps of the exercise they are doing, but don't worry, you will get there. Keep focused on your breathing.

### **Recovery Breathing and Positioning**

There will be times, when you feel like your breathing has gone above the moderate number 3 on the Borg scale, and you start to feel uncomfortable and out of control.

This would be the time to try this technique.

To get the most from the breathing technique it helps to think about your posture and positioning also. Adopting the correct position can make a big difference to breathlessness. Remember people with COPD can be hyper-inflated, and often be using their accessory muscles to breathe. Positioning helps to support the work of breathing and 'offload' the exhausted muscles.

The majority of people with COPD prefer to lean forwards slightly when they are breathless. This is fine as long as you are aware of what your shoulders are doing!

By leaning forwards slightly it can help your diaphragm get into a better position to work more effectively. It is very important to make sure you do not prop yourself up with your arms with your shoulders up by your ears, or your breathing pattern will occur more in your upper chest than the diaphragm / tummy area.

If you are sitting in a chair put your elbows or forearms on your thighs. Your shoulders will relax down, but you will still be supported. It helps some people to sit with their hands in their lap and their palms facing upwards.

If there is nothing to sit on, then you can lean against a wall and again lean slightly forwards with your hands on your thighs, or on a walking stick or frame.

If you are severely breathless, sitting in a chair at a table with a pillow on the table is a nice position to try. Put your elbows and forearms on the pillow and lean forwards.

The use of a fan to circulate air is also helpful in these situations, or sit by an open door or window.

When people get uncomfortably breathless anxiety or panic sets in and they tend to focus all their attention trying to get more air in. However, people with COPD need to do the opposite and focus on breathing out a little bit more each time.

As you breathe out more, the easier the next breath in will be. This needs to be done slowly and gently (as if you were trying to make the flame of a candle flicker gently). Do not force air out or try to breathe out for a long time.



Leaning forwards



Leaning against a wall



Leaning against a wall



Leaning on a table



Leaning over a chair

See the book's website **DontForgetToBreathe.org.nz** for further information and videos.

With each breath you do, simply try to focus on the breath out, rather than the breath in. Blow out slowly and only for as long as is comfortable - it shouldn't feel forced or hard work.

Some people find that blowing out through pursed lips helps in this situation. Some find it helps to count how long each breath out lasts for. To do this, you need to know how long your **normal** breath out lasts for. Do this when you are resting, and count it for a few times to get a good idea.

The aim, then, when you are doing recovery breathing is to gradually extend the length of the out breath until it becomes more manageable and back to your normal resting count. Gradually you will start to feel your breathing slow down. This may take 2 minutes or 10 minutes. It doesn't matter, as long as you feel you are getting control back. You may feel a desire to take a huge breath in which is fine, just remember to try to focus on the breathing out. Let the breath in just happen how it wants to.

Recovery breathing is all about focusing on your breathing during times of anxiety and trying to bring it back down to a more manageable and comfortable level. Remember to think about your positioning when you are breathless - leaning forwards with your arms supported. Inform family / whanau or friends about this technique, and if they see you struggling with your breathing they can remind you about focusing on the out breath.

It can also help to talk to yourself when in this situation. Tell yourself that this has happened before, and you got through it. You know you can do it again. Some people find that by counting their breath out, it helps focus their mind and stop the anxiety escalating.

It always helps to practice the positioning and recovery breathing when you are 'comfortably breathless'. If you do this, you are more likely to then remember the techniques when you really need them.

### **Clearing Sputum**

Everybody has a thin layer of sputum lining their airways (breathing tubes). We need it to protect our lungs.

People with COPD often have more sputum and can have difficulty coughing it up (expectorating).

It is important to cough and clear as much sputum up as you can every day. Sputum which remains in your airways can cause increased difficulty with breathing and more frequent chest infections. It is ok to swallow the coughed up sputum, but ideally 'better out than in'!

To help clear sputum with more ease, it is very important to keep yourself well hydrated. This means drinking approximately 6 - 8 cups of fluid every day. Water, juice and teas and coffees all count. If you do not drink enough, it can cause the sputum to get thicker and then it is more difficult to cough up.

#### What else can you do to help?

• Exercise

Keep up with regular exercise that makes you moderately breathless. Exercise helps open up your lungs, and by breathing deeper it encourages sputum to move up and out.

• Steam inhalation

This helps to moisten the upper airway only, but for some people this can help make clearing sputum easier. Try adding some Vics to the water, and use a paper bag as a funnel over a mug of hot water. Put your mouth at the other end of the paper bag, and breathe in and out. This can be less claustrophobic than putting a towel over your head!

### Active Cycle of Breathing Technique (ACBT)

This is a simple exercise which is best done regularly (ideally twice per day). It only takes a few minutes to do, and is easily incorporated into daily routines.

This technique combines normal breathing, deep breathing and 'huffing', and is effective for the majority of people who have sputum.

- Sit in a comfortable position and do a few normal relaxed tummy breaths.
- Now take 4 long slow deep breaths in, as deep as is comfortable, and out. Breathe in through your nose. Take your time about this. If you can, you can hold your breath in for a couple of seconds. Breathe the air all the way out, keeping relaxed. It may help to breathe out through your mouth.
- Return to normal relaxed tummy breathing.
- Take another 4 long slow deep breaths as above.
- Return to normal relaxed tummy breathing.

You can repeat these few steps a couple of times if you are able to. This part is helping to open the airways, and get some air moving deeper into your lungs

When you feel there is some sputum to clear try 2 or 3 'Huffs'

A huff is a forced breath out.

- Start by taking a small to medium breath in.
- Open your mouth wide.
- Force all the air out of your open mouth. This should be fairly fast and you should feel your tummy muscles contract to help push the air out. Imagine you were steaming up a mirror with your breath.
- Remember a huff is quite short and sharp. People often get confused with the long slow blows out they do during spirometry (breathing tests).

Huffing helps to keep the airways splinted open and allow the sputum to move up and out. A huff uses less energy than coughing and is more effective.

After a couple of huffs, you may need to cough. This is quite normal.

Repeat the whole breathing cycle as often as you need to in order to clear as much sputum as you can.

#### Postural drainage

This simply means using gravity to help encourage sputum to move.

There are very specific positions to put a person in to clear different lobes of their lungs, and for this you should seek advice from a physiotherapist.

However, for a lot of people, lying on their side flat on a bed can be adequate. This needs to be done for at least 10 minutes in each position, so to do both sides it will take 20 minutes. For this reason alone, many people would rather not do this technique! While in your postural drainage position you simply go through the ACBT exercise discussed above.

Postural drainage tends to be used if the ACBT alone is not enough, and it can be combined with percussion. This is the technique of applying an external force (hands) over the person's chest and back. You **must** be taught to do this correctly and ensure its safe, so discuss this with your physiotherapist.

#### **PEP therapy**

PEP stands for Positive Expiratory Pressure.

This simply means applying a pressure or resistance to a persons out breath.

This pressure helps to splint open the airways allowing the sputum to move up with more ease.

There are many different devices on the market which apply the use of PEP:

- Acapella
  - Flutter
- PariPep

- Thera Pep
- The cornet
- Astra Pep

No one particular device has been shown to be more effective than another. A physiotherapist can help decide which device may suit an individual so seek their advice if you think this may suit you.

A simple and cheap form of Pep is known as **Bubble Pep** and is usually the starting point to assess if one of the devices above may be suitable.



Pep is not suitable for all patients so it is important that you discuss this with your physiotherapist before trying it.

## Pulmonary Rehab 3: Education

Education sessions presented by a variety of healthcare professionals are usually an integral part of a pulmonary rehab programme. Some rehab programmes may involve exercise only, but this is usually due to a lack of resources. Here we give an overview of the education sessions that are included in our local rehab programme in Hawke's Bay DHB.



### A) Breathing

This has been covered in SECTION 3 Understanding Your Breathing beginning on page 10, and in Pulmonary Rehab 2: Breathing Retraining on page 36, but it is so important to learn.

The sessions should involve a theory and practical element to breathing retraining, and these exercises should be practiced at home at least once or twice per day.

There are 4 main areas to cover when it comes to breathing (and these are covered in detail earlier):

• Abdominal / normal relaxed breathing

This is paramount to gaining better control of your breathlessness, and helps to utilise energy more efficiently.

• Recovery breathing

Used to help return your breathing to a more comfortable level after heavy exercise or just for those times when your breathing is unsettled, and you are struggling. This is great for helping to reduce and control panic when breathless.

• Breathing during exercise

Breathing correctly, and remembering not to hold your breath when exercising will make a huge difference to your ability to exercise

• Sputum clearance

This should be something that is incorporated into your everyday routine if sputum is an issue for you. The clearer your chest is the less likely you may be to developing recurrent infections, and your breathing will feel less of an effort. It also help to control coughing spasms if done regularly.

### **B)** Medications

This has been covered in depth in <u>SECTION 4</u> starting on page <u>13</u>, but this session always proves to be very valuable for patients. In this session patients get time with a pharmacist to really discuss what each medication does and how they can complement each other. It also provides a practical element to demonstrate how to use each inhaler device correctly, which is so important.

### C) What is COPD? Respiratory Anatomy

This is usually given by one of our respiratory consultants, but can be delivered by a doctor, nurse or other healthcare professional. It allows time to discuss what is actually happening in your lungs, and how you can help yourself and work with the healthcare professionals involved to improve your health.

### D) Occupational therapy

This usually will cover the "4 Ps" - Positioning, Pacing, Planning and Prioritising. It is also an opportunity for the group to begin to share experiences, hints and tips that they have developed over the months and years. Equipment is also discussed during this session.

### E) Social Welfare

This session can have 2 focuses:

- What is provided by social welfare in order to help the client financially, and
- Caring for the carers, who are often forgotten as everybody is frequently focussing in on the sick person.

Frequently people ask for a referral to the social worker following this discussion.

### F) Dietician

This session will include information regarding "healthy eating", for example covering the food groups, and portion sizes. Depending on the group make up however the dietician will tailor it to their needs, reinforcing the need for a healthy weight, usually regarded as a BMI between 20 and 25. Emphasis will be given to the importance of high protein meals, to assist with healing, and may sometimes go against the grain, advocating higher fat intake in order to easily increase energy intake. One to one referral will often be requested after this.

### G) Continence

Apart from the obvious breathlessness that is experienced with chronic respiratory disease, as mentioned earlier social isolation is frequently experienced. This can often be attributed to enforced isolation secondary to incontinence.

There are many different causes of incontinence: side effects of medications, constipation, and weak muscle structure aggravated by coughing are the most common. Sensitive discussion within a group without obviously singling anyone out can often lead to people seeking help with this extremely embarrassing and often treatable condition.

### H) Anxiety management

Anxiety induced by breathlessness can lead to more anxiety, leading to increased breathlessness, and on it goes in an increasing circle. Cognitive Behavioural Therapy (CBT) is now recognised as an effective treatment for this. CBT seeks to modify the response to the symptom, so making it more manageable by focusing on positive rather than negative thoughts. Medications may also be discussed during this session; it is important to recognise however that there are often many things a person can do to help with the breathlessness instead of always relying on medication.

### I) End-of-life care options

In the past medical teams have made decisions with regard to end of life care without discussing this with the patient. It is now recognised that the patient frequently wants and needs (psychologically) to be involved in decision making. For many years it has been accepted that people want to plan who they leave their worldly possessions to in a will, as well as planning their life for everyday living. The process of dying, however, has frequently been kept a mystery, especially in recent years of hospitalising it, and "keeping it behind closed doors so as not to upset people". In New Zealand, as in much of the Western world now, a movement is in place to help people start making decisions for themselves and supporting them with this; this is called advanced care planning.

Advanced care planning is slowly being introduced throughout NZ, with key healthcare professionals being trained to help people with these. Communicating in a sensitive manner with the client, and the family / whanau if appropriate (chosen by the client), is obviously paramount.

It is important to recognise that advanced care plans can be changed at any time - it may be that a person does not want artificial ventilation under any circumstances as they recognise that it would be extremely tortuous to wean from this. As long as this is recorded and witnessed then any healthcare professional should not override this wish. Artificial hydration and feeding are often covered in an advanced care plan, as well as hopes and wishes for the future if the patient were unable to communicate for some reason.



For more information: Discuss with your healthcare professional or look at

www.advancecareplanning.org.nz

See SECTION 8 on page 67 for more information on end-of-life / palliative care

# SECTION 6 Living With COPD – Smoking, Home, Travel and Other Stuff

## **Smoking Cessation**

The most important part that you can play in your treatment is to gain a smoke free lifestyle as soon as possible. In New Zealand all healthcare professionals are willing and able to support you to become smoke free.

The Ministry of Health in New Zealand is committed to helping all New Zealanders become smoke free by 2025. Obviously this is no small target,

and with nicotine being the second most addictive drug in the world (after methamphetamine) there is no quick fix solution.

There are two ways of tackling this target:

- 1. Stopping people starting smoking in the first place
- 2. Helping smokers to quit.

There is, at the time of writing this, a movement to ensure that all cigarettes are sold in plain paper packaging; research has shown that this may help prevent people from starting to smoke. The tobacco giants are not surprisingly fighting this very hard in Australia which is being used as a test case; many healthcare professionals are observing this with interest.

However if you have been diagnosed with COPD it is highly likely that you are a smoker or exsmoker.

**If you have stopped smoking**, "congratulations!" The next most important area for you to work on is ensuring that your family / whanau becomes smoke free also. Try making your house and section smoke free as well as your car. This will limit the amount of smoke exposure you experience. Encourage your family / whanau to discuss becoming smoke free with their healthcare professional (GP, Nurse, Pharmacist etc.).

**If you are still smoking** you need to QUIT to slow down future deterioration, and lessen the frequency of exacerbations (flare ups). Of course this is easier said than done, but now is the time to accept the help that will be there for you.

## Help to Stop Smoking

#### Nicotine Replacement Therapy (NRT)

This is available from appropriately trained health professionals - nurses, doctors, occupational therapists, social workers, physiotherapists etc. You will be asked questions about the amount of



cigarettes you smoke on a normal day, what time of the day you smoke your first cigarette, and sometimes your triggers to smoke. Please be honest! You will not be judged, this is so the dose of NRT can be tailored for you.

The healthcare professional will recognise how difficult it is to stop and will want to make things as easy as possible especially to start with. You will be offered support on an ongoing basis, either face to face on a one to one basis, or as a group, or over the telephone, via text or email. Make sure you tell the person what works best for you; be honest if you find yourself "cheating" or are finding it difficult, adjustments can be made. This medicine is subsidised.

#### Zyban (bupropion)

Zyban is an antidepressant medicine that has been found to aid in the stopping of smoking. It is used to help people stop smoking by reducing cravings and other withdrawal effects. There are many potential interactions and side effects, and for this reason Zyban has to be obtained on prescription only. You will be carefully monitored whilst using it.

The above sounds scary, however many people manage to give up smoking very successfully with the help of Zyban, so work with your doctor if it is suggested you start it.

#### Champix (varenicline)

The newest medication to enter the New Zealand market to help with smoking cessation is Champix. This works by reducing the cravings to smoke, and decreasing the pleasurable feelings obtained from smoking by changing the effects on the nicotine receptors in the brain. It is only available on prescription, a quit date should be set for a week after starting a course. Special authority is available for one course (3 months) in a 12 month period if 2 quit attempts have been made in the past. Further supplies are available to purchase after this time.

#### Group support

Of course all of the above cannot be effective without willpower and determination to quit. Many healthcare professionals in New Zealand are recognising that the medication alone is not enough to help with quitting, and many general practices are making smoking cessation groups available to offer extra support. Don't be proud; accept all the help that is offered.

## A Healthy Home

Your home and the temperature in it, as well as any dampness, moulds and condensation can cause health problems which can become long standing.

New Zealand houses have only been required to be built with insulation since 1978, and Statistics New Zealand showed in 2004 that only 5% of houses had central heating installed. "Warm-up New Zealand" introduced in 2009 aims to provide insulation into more than 188,500



homes over four years. This will provide increased comfort and improve household energy efficiency as well as the health benefits especially for people with respiratory conditions which can be derived from or worsened by living in cold damp conditions. Grants are available to anybody, regardless of income to ensure insulation is retrofitted. For people who have an established respiratory illness, have been admitted to hospital in the last 12 months secondary to this, live in a house built before 2000, and have a community service card, as well as living in areas of higher deprivation are able to get this done free of charge with funding from their local DHB.

Moulds can aggravate respiratory conditions, if pre-existing, or can cause allergic asthma which if untreated can lead to the long term fixed airway damage. Aspergillus is probably the most common of these mould groups and is found worldwide. Allergic bronchopulmonary aspergillosis (ABPA) is found in around 5% of adult asthmatics, and treatment with steroids and antifungal medications is required. It is caused by an allergy to mould spores.

Warm-up New Zealand aims to eradicate the potential for these moulds to be in houses in the first place.

Heating for New Zealand homes is obviously as important as insulating them. For many years heating has been woefully inadequate in many homes; open fires often burning inappropriate wood for example, damp / wet wood which will cause toxic fumes. The Resource Management (National Environmental Standards for Air Quality) Regulations 2004 prescribed air quality for all in New Zealand to be of good quality. As part of this, open fires within air sheds are now banned. Encouragement is being given to change methods of heating to cleaner types, such as newer wood burners, pellet fires and heat pumps. Portable gas fires which have no flue are strongly discouraged. Assistance is available under the healthy homes scheme to help with the costs of installation.

## **Dealing with Exacerbations**

Exacerbations are often seen as the "curse of people with COPD lives". This is the part that people find the most difficult to live with. An exacerbation is defined as:

"an event in the natural course of the disease characterized by a change in the patient's baseline dyspnoea, cough and/ or sputum that is beyond normal day-to-day variations, is acute in onset and may warrant a change in medication in a patient with underlying COPD" Global Initiative for Obstructive Lung Disease (GOLD)<sup>37</sup>

The top 2 causes of exacerbations are known to be infection and changes in air quality / air pollution. It is known that many exacerbations are secondary to not following a drug regime correctly, for example the misuse of an inhaler. However in ½ of cases the cause is unknown, although many hypothesise it may be due to stress or anxiety. Prompt treatment of the exacerbation is vital.

When treating an exacerbation the aim is to treat the symptoms:

- treat the infection with antibiotics,
- treat the breathlessness with steroids to improve the inflammation in the airways,
- treat the excessive sputum with physiotherapy and occasionally medication,
- treat the hypoxia (low oxygen levels) with supplemental oxygen,

<sup>37</sup> http://www.who.int/respiratory/copd/GOLD\_WR\_06.pdf

• there may be times when breathing support is necessary either using medication or mechanical ventilation.

Prompt treatment can be managed by pre-planning; it is almost unheard of for a person to have COPD and never have an exacerbation. Regular reviews by one of the healthcare team, respiratory nurse specialist, respiratory consultant, GP, practice nurse, or another healthcare provider will ensure lung function is regularly checked, oxygen levels monitored, and management plans reviewed, as well as weight, diet and exercise tolerance being checked.



A management plan is essential to assist with the understanding of medications; what to take and when. Download this one and fill it in ready for when you need it.

http://bit.ly/COPD-ManagementPlan

The management plan should list the medications taken on an everyday basis when feeling "well".

The plan then "steps up" to when you have a worsening of one or more symptoms. It should tell you what to do for each of these symptoms; for example start antibiotics when the sputum colour changes / darkens/ gets thicker / increases in volume.

The next step is to watch your symptoms to make sure they are improving. If there is no improvement or you feel worse it is essential that you get help, either from your nurse or doctor, or local hospital.

It is very well documented, in many research papers that you may be able to decrease the frequency of needing to go to hospital by starting your management plan sooner. Living with your disease, you will learn the signs and symptoms of your exacerbations and realise the importance of acting quickly. If you typically have infectious exacerbations you may want to keep paracetamol with your emergency kit as well to help with the fever that often accompanies this. If you usually become a lot more breathless and find it hard to eat or drink until the oral steroid tablets start working it is worth keeping some small easy to eat meals / soups at home and some supplies of food supplements such as Complan.

There are many nurse led schemes that concentrate on supporting you to remain at home during your exacerbation rather than automatically needing to go to hospital. These schemes will have access to other members of the team such as an occupational therapist or a physiotherapist, also often a team of carers who help you through the more difficult times with personal care needs. Drinking enough (hydration) is essential throughout the exacerbation, and often the care team will make up jugs of juice or flasks of hot drinks if you are confined to bed. Urinals and commodes can be provided on short term loan if mobility is more difficult because of the breathlessness, and chairs can be raised to help you get up and down.

Some of these schemes have oxygen provision to help you through the difficult times of exacerbation; it is important that you leave this on the level that has been set and NEVER turn the flow rate up. This will probably be removed afterwards as it will no longer be necessary for everyday use. However there will be follow-up by the nurse around six weeks after the exacerbation; during this visit your oxygen level will be checked and if it is lower than 90% then a formal assessment will be made to check whether oxygen needs to be placed long term in the home. If this is your first exacerbation then a follow-up visit should be made to your doctor / practice nurse to reassess your regular medications and refill your management plan prescription for next time. Referral should be made to pulmonary rehabilitation if this has not happened already.

If you do get admitted to hospital, either because there is not a scheme available to help you through at home, or because you are considered too unwell to remain at home, then you will see many different healthcare professionals, who will need to question you about your general health and medications you take on a day to day basis. Therefore if you do go to hospital, taking your self-management plan and your regular medicines with you can provide information for the team. You may be given oxygen during this admission; if you are taken to hospital by ambulance it is extremely important that you tell the ambulance officers that you have COPD, as sometimes you may not be able to have high flow oxygen.

Once you arrive at hospital you may have a chest x-ray, an ECG, arterial blood gas measurements, and other blood and sputum tests taken. The team will be looking for causes of the exacerbation so that it can be treated effectively. You will be examined by doctors, nurses and maybe a physiotherapist. Throughout your hospital stay the opportunity should be used not just to treat the current flare up but also to provide information and education regarding management of your illness and preventing another hospital admission. You may be surprised about the amount of encouragement you are given not to stay in bed all of the time when you are in hospital, but instead to get up and walk around the ward, to the bathroom etc. This is to prevent you from losing muscle tone which can happen very quickly secondary to immobility.

You may find that the nurse led team follows you up at home, ensuring that you are aware of how to treat future exacerbations, and that you fully understand the importance of maintaining health and remaining active.

You should leave hospital with a management plan for next time an exacerbation occurs or an updated previous one.

## Travel



Debra and Judy were on a long haul flight returning from seeing their children in Europe. All was fine until Debra got up half way through the 14 hour flight to stretch her legs and go to the toilet. They were only two rows from the toilets, but the starboard side toilets, which was nearest, were engaged so Debra went round to the port side.

Debra felt ill in the toilet. She stumbled back to her seat and Judy could immediately see something was wrong. Debra was panicking, "I can't get my breath" she said. Judy sat Debra down and quickly pressed the call button to raise a steward. For Debra things happened in a blur, but in reality the cabin crew went calmly into action. They ascertained from Judy that Debra had an existing lung condition and that she was short of breath but otherwise OK. The chief steward was called and he then brought over some oxygen which brought relief. He moved the other passenger in their row to give more room and then on seeing that things seemed to have settled left the pair to rest a while. Once recovered enough Debra used her inhalers then rested.

The cabin crew checked on Debra for the rest of the flight but thankfully everything was fine.

Nothing like this had happened to Debra before whilst flying and it was a frightening experience for both the women. "You are in mid-air and helpless" said Judy, "You just have to trust that the cabin crew know what to do and thankfully they did." Before they fly long haul again Debra will be asking her GP for advice.

So is there anything else that Debra and Judy could have done in order to pre-empt this situation?

Probably not, however it shows the importance of being well prepared for all eventualities.

A six minute walk test could have been performed to ascertain whether resting levels were below 95% or there was a drop in oxygen saturation during or after this below 84%.

A study performed in 2012 used high altitude simulation test (HAST), involving the person to breathe 15% oxygen rather than the normal 20%; simulating 8000 feet altitude, and monitoring the pulse oxygen level. However most normal hospital settings will not have access to this, therefore the six minute walk test remains the suitable way to investigate the need for most. Had Debra been found to have a low resting oxygen saturation level, then she would have needed to pre-arrange oxygen to take on the plane; depending which airline she was flying with would be whether she took her own or hired it from the airline. Costs can vary enormously with this, so it is definitely worth shopping around. Portable oxygen concentrators which are flight compliant are becoming more common in

New Zealand either being owned or hired, however it is advisable to check that the airline allows these, or insists on their own being hired.

Debra had planned in advance by being close by the toilet; however it would be worth in future her ensuring that Judy or one of the air stewards knew she was in the toilet and was close by to rescue her if necessary.

Debra had taken ample supplies of medication with her, including her inhalers; obviously these would not have been so useful had she not been prepared with a spacer device also. Some airplanes may allow use of an ultrasonic nebuliser to administer medication; again this needs checking beforehand.

And don't forget the letter from the GP/specialist to enable you to go through customs with minimal hassle!

There are no definitive agreed world-wide guidelines for air travel with COPD, but a working party from the British Thoracic Society recently has put together a "starter paper" <sup>38</sup>.

The working party agreed that pre-assessment is crucial for anybody who has severe COPD, those within 6 weeks of hospital discharge for acute respiratory illness, those who have recent pneumothorax, and those who have pre-existing requirement for oxygen or ventilator support.

Modern aircraft are pressurised to cabin altitudes of up to 2438M (8000 ft) although this maximum may be breached in emergencies. At 2438 m (8000 ft) the partial pressure of oxygen will have dropped to the equivalent of breathing 15.1% oxygen at sea level (much less than the normal amount of oxygen at sea level which is 20.95%). In a healthy passenger the blood oxygen saturation level will fall (Spo2 85–91%). For a passenger with lung disease there is thus concern that altitude exposure may exacerbate low blood oxygen (hypoxia), and particular caution seems justified in those who are usually hypoxic at sea level.



The physiological compensations for acute hypoxia at rest are mild to moderate hyperventilation and a moderate raised pulse rate (tachycardia). Obviously if there is more strain put on the body then the person is very easily going to become distressed.

Assessment is recommended as described above. If there is a hypoxic challenge test required then it should be carried out by the respiratory specialist.

<sup>&</sup>lt;sup>38</sup> Edvardsen A (et al) (2012) Air Travel and Chronic Obstructive Pulmonary Disease: A New Algorithm for Preflight Evaluation. Thorax 67:964-969

Sea level Spo2		
>95%	Oxygen not required	
92–95% and no risk factor	Oxygen not required	
92–95% and additional risk factor, e.g. hypercapnia; FEV1 <50%	Perform hypoxic challenge test	
predicted, ventilator support; within 6 weeks of discharge for an	with arterial or capillary	
exacerbation of chronic lung or cardiac disease.	measurements	
<92%	In-flight oxygen	
Receiving supplemental oxygen at sea level	Increase the flow while at	
	cruising altitude	

At all times:

- Passengers should travel on a non-smoking flight. Ask your travel agent to check this, though most international flights and NZ flights are now non-smoking.
- Preventative and relieving inhalers should be carried in the hand luggage.
- Portable nebulisers may be used at the discretion of cabin crew. They may be connected to the aircraft electrical supply on some but not all airlines. Some airlines can provide nebulisers for in-flight use and patients should check with the carrier when booking. Spacers are as effective as nebulisers.
- Patients who are prescribed in-flight oxygen should also receive oxygen while visiting high altitude destinations.
- Many airports can provide wheelchairs for transport to and from the aircraft.

## Diet

Dietary management is very important with COPD to maintain a healthy weight. A healthy weight means a BMI (Body Mass Index) of between 20 and 25.

To calculate your BMI use the following formula:

Weight in Kilograms ÷ (Height in Meters)<sup>2</sup>

So for a weight of 68 KG and a height of 1.65 M (165 CM) the formula becomes

 $68 \div (1.65)^2 = 68 \div 2.7225 = 24.98$ 



#### Find your BMI score on this site:

http://www.heartfoundation.org.nz/healthyliving/losing-weight/bmi-calculator

Being overweight puts extra strain the lungs and heart, adds to shortness of breath, increases difficulty with exercise, and decreases quality of life. Large amounts of fat in the body also impairs the breathing process and increases the sensation of breathlessness.

Being underweight is also undesirable. The added effort of breathing for COPDers can increase resting energy expenditure (REE) by up to 10% to 15%. If the extra calorie requirement is not allowed for weight loss will occur. An estimated 30% to 70% of COPDers experience unwanted weight loss.

COPDers can lose weight as a result of an inability to eat rather than a lack of appetite:

- difficulty swallowing or chewing due to breathlessness,
- chronic mouth breathing, which can alter the taste of food,
- chronic mucous production,
- coughing,
- fatigue,
- morning headache or confusion due to high carbon dioxide levels (hypercapnia),
- anorexia,
- depression, and
- side effects of medications, for example dry mouth secondary to inhalers.

The aim is to prevent or minimize unwanted weight loss whilst maintaining pulmonary status. Research shows that COPD not only affects the lungs but can also have systemic effects, as well as resulting in severe weight loss. Combined, loss of weight and muscle wasting can adversely affect breathing by reducing the strength and function of the respiratory and skeletal muscles. In addition, a low body mass index (BMI) is associated with a poor prognosis. Therefore it is essential that the energy taken in is matched by the extra calorific needs.

COPDers can be at risk of malnutrition (which the American Dietetic Association (ADA) defines as a BMI of less than 20). Malnutrition can impair pulmonary function, increase susceptibility to infection, and lower exercise capacity. Most of the respiratory societies worldwide quote criteria for initiating caloric supplementation as a BMI of less than 21, involuntary weight loss of more than 10% during the previous six months or more than 5% in the previous month, or reduction in lean body mass.



Talk to your GP or respiratory nurse if you have a BMI of less than 21 or have concerns about being over or under weight.

COPDers are also at risk of decreased bone density due to use of oral steroids, inhaled steroids, and smoking (past or present). Malnutrition and decreased mobility are also risk factors. To prevent osteoporosis and bone fractures a calcium and vitamin D rich diet is extremely important. Vitamin D is absorbed by exposure to sunlight. If you are not getting out side enough or are taking antibiotics which make exposure to the sun difficult due to burning even with just a few minutes exposure, then you are at risk of not getting enough vitamin D. As vitamin D is needed for calcium absorption, calcium levels will be also affected.

Most people when trying to increase their weight and energy intake will do this by increasing their carbohydrate intake, however for people with COPD this is not ideal. As the body burns (metabolises) carbohydrates carbon dioxide is given off. This is normally expelled via the lungs. For COPDers however requiring the lungs to deal with the extra carbon dioxide can be difficult. Metabolism of fat and protein result in less carbon dioxide than carbohydrates and eating a lower carbohydrate and high fat diet will reduce carbon dioxide production and may help to improve the severe breathlessness (dyspnoea) and improve higher than normal carbon dioxide levels (hypercapnia).

### Tips for maintaining a healthy weight with COPD

- Eat meals when energy levels are at their highest, which is usually in the morning.
- When feeling well, make meals and freeze them in small containers to help you through the not so good days.
- Eat slowly and chew foods thoroughly to avoid swallowing air while eating.
- Choose foods that are easy to chew. Modify food consistency if mastication seems to increase fatigue while eating. Think about having soups with extra calories added in, in the form of cream, or skimmed milk powder.
- Choose foods that are easy to prepare to conserve energy for eating. Think about using meals on wheels services / microwave meals.
- Limit salt. Consuming too much can cause the body to retain water and can make breathing more difficult.
- Eat calcium-rich and vitamin D-rich foods to support bone health.
- Prepare meals that appear palatable and well presented.
- Eat several small, nutrient-rich meals to avoid becoming breathless while eating.
- Avoid foods that cause gas or bloating. A full abdomen can make breathing uncomfortable.
- Ensure your breathing is as comfortable as possible prior to eating; if you are breathless before you start eating, you will not manage to eat the meal.
- Eat while sitting up to ease lung pressure. Give up the TV dinners and sit at the table.
- Drink liquids at the end of the meal to avoid feeling full while eating.
- If continuous oxygen is prescribed, try using nasal cannula whilst eating. Eating and digestion require oxygen, so the body will need the extra oxygen.
- Make the meal more enjoyable by engaging in social interaction while dining.
- Avoid aspiration by breathing carefully, swallowing, and sitting properly and with good posture while eating.
- Consider having an aperitif to stimulate the appetite before eating such as one small sherry (remember that alcohol is empty calories though, it will not give you energy.)
- Rest before and after meals.

Remember that a doctor or nurse can refer you to a dietician for advice in helping you to keep your weight stable and in the advised guidelines BMI between 20 and 25. The dietician will advise on healthy eating for YOU, which may go against that which is being given to your whanau / family

member, in advising the high fat low carbohydrate method of nutrition. You may be commenced on supplemental feeding, usually given to you on prescription, although you may need to pay for it also. These prescribed foods should only be used in addition to normal foods rather than instead of it, although when you are unwell you may find you need more of this and less normal foods, as you may be much more breathless than normal, making eating extremely difficult.

### **Nasal Rinsing**

One of the therapies that is frequently advised for use by people with COPD is sinus rinsing or nasal rinsing. This replaces an age old method (the earliest findings in Sanskrit from ancient India) of sniffing salt water from cupped hands. The reason it is often advised is to assist with the removal of mucous, hypothesizing that it may decrease inflammation.

#### Salt Water Solution

240 mls cooled (baby bottle heat),previously boiled water,Combined with1/4 tsp rock or sea salt (iodine free), and1/8 tsp bicarbonate of soda.

The respiratory tract does not just include the lungs, windpipe and mouth but also the nose and sinuses which we have to help provide protection against viruses, bacteria and other harmful organisms. You will be advised during any pulmonary rehabilitation programme regarding breathing retraining, and requested to practice using your nose to breathe as much of the time as possible. Obviously if your nose is blocked this is going to be more difficult, hence the advising of commencing nasal rinsing. There are commercial substances that can be purchased, or a salt water solution can be made up (see insert). The addition of salt is to ensure the osmotic pressure is adequate, and frequently sodium bicarbonate is also added as a buffering agent which adjusts the solution pH to that of the body.

Nasal rinsing is often suggested for people who have post nasal drip; this is characterised by symptoms such as coughing, wheezing, continuous clearing of the throat, halitosis, runny nose, chronic sinusitis.

It is important that directions are followed as provided by your healthcare provider; especially in using previously boiled water to prevent the risk of amoebic meningitis (a rare but fatal inflammation and destruction of the brain and brain linings).

## **Practical Tips**

### Practical planning

Plan ahead. On good days pack a bag for regular events. Then when the day of the event comes around, if you're feeling rough, you don't have to worry about packing a bag, moving from room to room or trying to remember what you need. It's there at the door ready to go. Use checklists to help





Another useful method is to have bags packed with things for certain events. Different coloured bags help to identify what was for what. The red pulmonary rehab bag complete with fresh bottle of water was packed and ready to go at the door. The blue backpack for going to town with simple dried fruit/muesli bars or other snacks was hanging on the coat rack. The yellow duffel for overnight hospital visit or tests was packed with a piece of paper on top listing things to add such as toothbrush. The bum bag complete with some money, plasters, snacks and other needy items is hanging always in the same place for when the mood takes you to go out for a walk or a friend suddenly turns up to take you out for coffee. You can go out without losing the incentive whilst scrabbling around looking for stuff.

### Prioritising energy expenditure

In a house with stairs have a bag hanging at the top and bottom of the stairs. A string or see through bag is best so you can see what's in the bag in case you forget what you've put in there! Instead of travelling up and down the stairs you just go up once with a bag of items and come down once with a bag of items - simply swapping bags over.

A chair at the front door facilitates a space to sit for donning and doffing shoes plus time to read your checklists before venturing out.

An office chair in the kitchen set to your height or perhaps a little higher, just for you to use is useful to scoot about the lino areas freely, performing tasks without too much work.

In the kitchen have a perching stool which allows you to perch whilst making your meals or cuppaless energy is expended and you will get more done in the day because of it. On bad days, many people just do without rather than go through to effort of making a simple drink. On those days a stool can be invaluable. If it's already in the kitchen it won't seem like a big deal when you have to use it.

### The breathlessness moment

Have a couple of mini fans (they sell them in the \$2 shops) - one in the glove box, and one in your handbag or backpack. Sometimes a breeze across the face when there is no breeze to be had can be very soothing.

When it's hot and humid, place a dampened cotton sheet over the open window and set a fan in front of the sheet directing air inward; air is drawn across the sheet into the house and cooled as it comes through the sheet (a mini "air conditioner"). If you are prone to overheating, keep a pair of cotton socks in the freezer in a knotted bag. (Putting cold socks on when the humidity is high and you're becoming overwhelmingly hot is a quick fix to instant relief for some. For those with reduced peripheral sensation though, care is required when applying something which may have icicles!

Bathing and showering benefits are often forgotten due to the trauma of towel drying. Purchase a microfiber robe or dressing gown- shorten it to fit you- too much spare material adds work to your breathing. Wear the garment after your shower –a simple way to dry quickly whilst you relax with a cuppa.

For those with long hair a microfiber hair tube works on the same principle- easy to apply and dries your hair quickly without fuss.

### **Breathing control**

Help breathing control with a favourite poem, phrase, mantra, or image. Go to your happy space (not breathless space) when the breathlessness is perceived. A photo or phrase printed and covered in waterproof plastic and kept accessible (stuck on a photo frame, in

Breathlessness is a symptom and it's ok to be feeling like this- it will pass and I can do it.

your wallet, carried in a pocket or stuck on the dashboard) all serve as an immediate prompt for management and control. If nothing comes to mind, start with the statement in the box above to start the recovery process.

A mantra to try for those who like to try to rush and arrive so breathless that they cannot enjoy being there for some time is "stop, prop before you drop".

Take control and plan your propping spots. Whether you are walking 5km or moving from room to room, sitting or propping spots are worthwhile having. Using them to ensure that you get to your destination in control of your breathing and mental state is your part in the taking control part of COPD.

Distraction and focus can help when experiencing embarrassment through breathlessness or when trying to regain control. Carry a cut out crossword or game in your pocket. When you arrive at a table or a café and feel breathless, prop into position at the table and read the item/start the crossword or game. You won't feel quite so conspicuous and will be impressed how quickly your control is gained.

### **Bedtime choices**

Some pyjamas are easier than others move around in bed. Flannel particularly makes movement in bed harder work.

Smaller pillows are easier to adjust than the big ones. Putting a bigger pillow at the foot end of your bed inside the covers will help you to turn more easily avoiding the toes tangling with sheets and facilitating an easier night's sleep. If you are too tall- find an old tray or firm plastic or wooden board and slide in between the mattress and bed end. Ideally it should stand about an inch or so higher than your toes which will help to keep them warm. The sheets go over the board.

### Life control

Living with limitations presents many challenges which can on many occasion depress and overwhelm. When the weather is poor and your plans for the day have changed as your breathing is more laboured than usual have a stock of easily achievable tasks in a task box/basket which have stared at you all week- now's the time to fix them and your day will have had meaning. Over the week fill your task box with easy low physical challenge tasks (not a hobby- that's something you've had for pleasure) these are tasks that have to be done- fixing or mending, sorting photographs, repairing a tool, changing a small electrical item battery, a letter that needs writing etc. Something
that you can do propped at a table or in a position which uses low energy and is comfortable- even consider looking things up for people in your household on the net! You'll get more done than you imagined and completing these jobs helps you to be part of the fabric of your life. It tends to earn brownie points with your spouse and family too!

Family members are often looking for some suggestions at Christmas and birthday time as to what to buy- make a list when things come to mind either suggestions seen elsewhere or on the TV, get the product details and hand them the list if it makes your life easier many children are very keen to get just what you're after.

Don't let your mood rule your social life. Going out or seeing other people is important to ensure there is change, something to think about and moments to share. When you're tired you don't feel like making a date- plan ahead make and arrange regular catch ups as it's often more of an effort to cancel!

# House Work

If it's time to buy a new vacuum cleaner investigate the ones that have a drive assist as, a bit like power steering they help to drive themselves and you can be part of the household chore routine. Also who says you can't vacuum sitting down? Sit on an office chair or wheelie stool- if your carpet isn't too deep you can vacuum in 360 degree circles without much effort, you can prop and use breathing control strategies during the task.

# Cooking

Learn how to get really good at crock pot or one pot wonder meals. With a bit of organisation you can be set to work at a table or counter top perched on a stool, preparing and making the evening meal in a propped sit which is energy-conserving. Make enough for 6, freeze what's not used, contributing to the household chores is great for self-esteem.

Many people who suffer with breathlessness enjoy the treat of a roast meal but struggle to cook them. Use smaller pans instead of a big one it remains a good method for a full nutritious meal with food to spare.

# SECTION 7 Your Healthcare Team and Their Role in Managing Your COPD

As a patient with COPD, or carer of a loved one with COPD, you will interact with a lot of different members of the healthcare team. This section covers the main team members and provides information on their role in your care.

# Counsellor / Mental Health Team



When Debra first diagnosed with COPD Judy was shocked to find out how reduced Debra's lung function really was. They were both quite "shell shocked". Their GP referred them for counselling which helped them begin to come to terms with diagnosis and what it meant for the future.

Multiple studies have identified that a quarter of people with COPD and other lung diseases will at some stage experience mood changes. Whilst these feelings of grief for lost lifestyle / life quality / life quantity can be regarded as normal, this does not mean that it should go ignored and untreated. It is important that these feelings are recognised, and referral to relevant healthcare professionals sooner rather than later are made before the behavioural changes become ingrained the "the norm".

A counsellor can, if involved earlier rather than later, assist the person to develop coping strategies to manage the changes that they are experiencing in their life. This aims to reduce the incidence of clinical depression that may follow if the early signs are left untreated.

If depression does develop your GP may refer you to the mental health team. You will probably be visited first at home by a community mental health nurse, who will chat with you about your concerns, draw up a plan with you, and make an appointment for you to see the mental health specialist doctor in the team.

The mental health specialist has the ability to prescribe drugs not available to your GP and will also work with you on any other aspects of your mental healthcare which may need to be put into place.

Decreased quality of life is often the hardest part of needing to live with any chronic disease and COPD is no exception to this. Adapting to this is not easy; and resistance to changes can often decrease the quality of life even more, as strategies may not be employed that would help.

Resistance to using correct medications / becoming smoke free / exercising properly etc. can lead to more frequent exacerbations which are linked to decreased quality of life <sup>39</sup>. Thus the spiral can continue, leading to increased anxiety and depression as time goes on.<sup>40</sup>. With the help of a healthcare professional screening for depression and then referral to a psychologist strategies can be taught to manage these issues. Screening tools that maybe used include the Centre for Epidemiologic Studies Depression Scale and the Hospital Anxiety and Depression Scale.

Increased social support may be all that's needed, but often this sounds easier than it actually is. By the time a client reaches a psychologist they may have lost all of their friends, and be extremely socially isolated. Pulmonary rehabilitation can be the beginning of regaining links with the outside world once more; leading on from this, COPD support groups and / or Age Concern can help with this.



Depression has been an ongoing issue for Debra. After taking early retirement there was great sense of loss. There were feelings of loss about work achievements that would now never be, of not being ready to retire, and of not being in control of life. There was also grieving for the personal things which also would never be. Climbing Everest was never on the agenda but it might have been good to be able to walk the Great Wall of China or do the Tongariro Crossing.

Even with trying to concentrate on what's possible, rather than what's not, Debra's depression became worse. Her GP referred her to the mental health team and a community mental health nurse visited Debra and Judy at home. An appointment with the consultant was arranged who decided to change Debra's medication. She was warned that the changeover of meds could have side effects, which it did, but after two weeks these were completely gone. After a few weeks the new meds were working well and Debra was once again enjoying life, walking the dogs, weeding the garden, and growing seedlings in the greenhouse. We'll leave the last word on this to Judy, "It's just great to have my old Debra back."

# Dietician

The role of a dietician in managing COPD is to ensure that an acceptable weight is maintained, whilst ensuring that adequate nutrition is maintained at the same time. Frequently people with COPD are underweight because of inability to take in adequate calories, or overweight because of inability to exercise secondary to breathlessness. The dietician is able to guide the COPDer with balancing nutrition and weight. A variety of tools are used, such as food diaries, groups, cooking classes, but at the end of the day the COPDer is the only person who can influence their weight. The dietician is

<sup>&</sup>lt;sup>39</sup> Seemungal, TAR. Et al. (1998), Effect of exacerbation on quality of life in patients with chronic obstructive pulmonary disease. AM J Respir Crit Care Med. 157:1418–1422

 <sup>&</sup>lt;sup>40</sup> Di Marco, F. et al. (2006) Anxiety and depression in COPD patients: The roles of gender and disease severity. Respir Med. 100(10):1767-74. Epub 2006 Mar 13.

able to prescribe supplemental foods, frequently under special authority, to assist with weight gain. The dietician is also able to have influence with prescription of appetite suppressants.

The dietician will mainly work in an outpatient role, however if a person requires intensive input and is unable to leave the home, they can visit if required. The dietician will also assess and treat people in the acute hospital setting and has input when a person is needing parenteral feeding such as via a tube or via an intravenous line (which may happen during pre or postoperative phases.)

# **General Practitioner**

Similar to other chronic illnesses, COPD is a condition that relies on a team approach for best patient outcomes. Often your GP will be the first to suspect you have COPD and will help organize further tests in diagnosis (spirometry, chest x-ray, blood tests, etc.) and will introduce you to the rest of the healthcare team who will help you to navigate through your journey.

Once the diagnosis of COPD has been confirmed (see SECTION 2 Getting Your Diagnosis on page <u>3</u>), your GP will work with you to keep you as healthy as possible and to maximize your quality of life by helping with the following:

- Education about your disease and how to recognize an exacerbation.
- Control of daily symptoms, such as breathlessness or cough.
- Preventing and treating acute exacerbations, including chest infections.
- **Preserving** lung function by helping you to become and remain smoke-free and avoid other lung irritants.
- **Providing vaccinations** for pneumonia and influenza.
- Managing other aspects of your illness including any depression or anxiety.
- **Referring** you to other health professionals as necessary.
- Discussing end of life issues (see <u>SECTION 8 Palliative Care / End of Life Care</u> on page 79).

It is important that you understand your COPD and to feel comfortable asking questions, including asking for clarification if something isn't clear. Bringing a family / whanau member or friend with you to your appointments can help, especially when discussing new or stressful things. Write things down, including questions you have (before your visit) and things that are discussed during your visit. Remember, *you* are the most important member of y*our* healthcare team.

# New Zealand Asthma Foundation

The NZ Asthma Foundation is an organisation which exists to provide support, guidance and advocacy for anyone affected by a lung disease. Based in Wellington NZ the organisation liaises with government, advising on and raising awareness of respiratory illnesses. They also fund research and educate healthcare professionals and the public with regard to best practice.

There are 17 affiliated societies throughout NZ who provide education, support and advice to healthcare professionals and the public. Most provide COPD support groups also on a weekly / monthly basis.

# New Zealand Heart and Lung Transplant Service

In some cases a patient reaches a point where lung transplant may be considered to be a possible suitable option. If this is the case the hospital Respiratory Consultant will write a referral to one of the Consultants at the New Zealand Heart and Lung Transplant Service at Greenlane Clinical Centre in Auckland.

During a number of visits where you, and your carer, stay in the newly refurbished accommodation (aka Hearty Towers) you will be is assessed by the team for suitability for a lung transplant.

The Centre has a large team of specialists including Respiratory Physicians, Surgeons, Transplant Coordinators, Physiotherapists, Psychiatrists, Psychologists, Anaesthetists, Social Workers, Dieticians, Pathology staff, and ICU and Ward staff.

If you are found to be suitable the transplant team guide you and your family / whanau through the process.

# **Occupational Therapist**

"Occupational therapy is a profession concerned with promoting health and well-being through engagement in occupation" (WFOT 2012)  $^{41}$ 

An occupational therapist (OT) works with patients to achieve a balance between work, leisure and self-care that results in a satisfying level of independence.

Occupational therapists work with people who suffer from a mentally, physically, developmentally or emotionally disabling condition by using treatments that recover or maintain people's activities of daily living.

OTs who work with people with COPD can help with prioritising, planning and pacing activities in order to maintain a balance between work, rest and leisure. OTs also have a role in helping people with relaxation techniques, and also in supplying aids and adaptations to help make activities easier. Examples of this are:

- Long handled shoe horn; to help with easing shoes on as bending is often extremely uncomfortable
- Sock aid; a simple gadget found invaluable to help put socks / stockings on independently
- Perching stool; a lightweight heightened stool which a person is able to rest their bottom on to reduce energy use e.g. when drying after showering, peeling potatoes, washing up.
- Seat raisers; device fixed to a favourite stable chair to raise the seat safely, in order to reduce energy use when getting up and down
- Bed Lever; to assist with sitting up in bed.

You may come across an OT as an inpatient, outpatient, or as part of a pulmonary rehab programme. They can also visit people in their own homes if required.

<sup>&</sup>lt;sup>41</sup> http://www.wfot.org/aboutus/aboutoccupationaltherapy/definitionofoccupationaltherapy.aspx

# Pharmacist

The role of the pharmacist is often forgotten as an important part of the healthcare team, however you will probably see more of this person than you will of any of the others! Pharmacists have a wealth of knowledge at their fingertips and are only too happy to be asked for help by their customers. It is important that you find a pharmacist that you trust and when practicable use the same one each time you have a prescription dispensed.

When forming a relationship with this healthcare professional you have extra reassurance that another expert is ensuring no medications are adversely interacting with each other and giving you unwanted side effects. There is a move in New Zealand (following many other countries worldwide) to allow pharmacists to take on prescribing roles also, so reducing the need to see the GP at times. It should be noted that the pharmacist cannot take the place of your GP however, but is able to work in partnership with this person instead.

Many pharmacists will offer a medication use review on a yearly basis. This is time for you to sit down with your pharmacist and look at all your medications, ensuring you are taking them correctly. Your pharmacist will ensure that your symptom relief is at its optimum and that you are using your inhaled medication correctly, as well as feeding back this information to your GP with any suggestions for change.

There are also many medications that can be bought "over the counter" or without a prescription. This is another reason that it is important you use the same pharmacist. Many of these medicines can be safely and effectively used, however some can be detrimental to your health, especially when being used in conjunction with medicines that are prescribed. It is therefore extremely important that you consult your pharmacist prior to starting new ones.

# Physiotherapist

A Physiotherapist is a healthcare professional who works with people to identify and maximise their ability to move and function. Physiotherapy plays a key role in enabling people to improve their health, wellbeing and quality of life.

Physiotherapists recognise that physical, psychological, social and environmental factors can limit movement and function. They use their knowledge and skills to identify what is limiting an individual's movement and performance, and to help individuals decide how to address their needs.

Physiotherapy is an autonomous profession. This means that physiotherapists can accept referrals for assessment from a range of sources: from an individual themselves (self-referral) or from other people involved with that individual. Physiotherapy can offer a range of interventions, services and advice to improve individuals' health and wellbeing. Physiotherapy works to maximise an individual's movement capability at three different levels. It can help maintain and improve the body's movement and function by offering treatment when someone is acutely ill in hospital. It can also improve someone's function and independence (at home, at work) by offering rehabilitation and advice. It can also enhance their performance and participation (in their community and wider

society) by offering advice and by challenging the environmental or social barriers that limit participation.

A respiratory physiotherapist specialises in looking after people with a wide range of conditions that can affect their breathing, movement, confidence and exercise capacity.

Respiratory Physiotherapy has been defined as "the physical management of problems or potential problems in patients with respiratory conditions, in order to obtain and maintain maximal function and to minimize disease progression." <sup>42</sup>

You may come across a respiratory physiotherapist if you have been admitted to hospital because of your COPD. In this setting, they can help with sputum clearance, management of acute breathlessness, and assist with mobilisation and breathing control.

Respiratory physiotherapists can also see you as an outpatient in a clinic setting, or in your own home if required. Once you have been assessed, and your problems or difficulties are identified, a treatment programme will be agreed with you. They may give you a home exercise programme to increase your level of function before sending you to pulmonary rehab, some breathing control techniques and they can also help people who have difficulty clearing their sputum on a daily basis. There are many ways of doing this which have been covered in <u>SECTION 3</u> on page <u>10</u>.

Respiratory physiotherapists often work alongside a pulmonary rehab nurse to deliver the pulmonary rehab programme. They will be able to offer all the advice as mentioned above, and also assist people who may have other conditions which limit their ability to exercise (i.e. arthritis, back pain, previous surgery etc.).



If you feel you would like a referral to a physiotherapist, then discuss this with your GP, and they should be able to organise this.

Some physiotherapists who work in private practice have a special interest in respiratory conditions, so should you chose to go privately, ensure your chosen physiotherapist has this. These physiotherapists should have a good relationship with the respiratory team at your local DHB, and will also be able to refer into a pulmonary rehab programme. It would be worthwhile discussing this with them.

# **Practice Nurse**

Your practice nurse works alongside your GP, and maybe more accessible and is probably cheaper than seeing your GP! Practice nurses work in a variety of roles; some work as generalist nurses

See the book's website **DontForgetToBreathe.org.nz** for further information and videos.

<sup>&</sup>lt;sup>42</sup> http://www.cfww.org/docs/pub/edition11/06\_ipgcfglossary.pdf

providing many different services from dressings to immunisations, from skin checks to IV antibiotics. They also frequently "work on the floor" meaning they provide an accident and emergency facility; this may be your first encounter with a practice nurse from a respiratory point of view, to be given a nebuliser or taught to use an inhaler.

The close working relationship of GP and practice nurse means the nurse can see all of your past medical history, and make clinical decisions based on the wealth of knowledge they have. They may be able to administer medications without seeming to discuss with the doctor first; if this is the case do not be concerned; they will be acting under "standing orders" or some maybe prescribers in their own right.

The practice nurse will use a variety of skills in assisting the doctor with diagnosis and maintenance of the optimum quality of life. The practice nurse will usually have more time available than the GP to ensure that your inhaler technique is excellent, as well as making sure that you have had up-todate lung function tests, a flu vaccine, been referred to pulmonary rehabilitation and are managing personal care adequately. This nurse will also be heavily involved with your care plus scheme, and will act as a "sign poster" for you. Occasionally (and becoming more common) the nurse may have Flinders accreditation which is a qualification to work alongside you to strive to improve quality of life to the optimum by setting goals in partnership with you.

# **Pulmonary Rehabilitation Nurse**

This is another member of the respiratory team who you will hopefully encounter early on after your diagnosis. This person will be focusing on pulmonary rehabilitation (see page 23), which is one of the main treatments for COPD. The assessment, education programme and the tailoring of exercise programme for many who are unable to attend group programmes are essential for the safe running of the programme. In partnership with the physiotherapist the pulmonary rehabilitation nurse will support you through, providing continuity from initial assessment and examination of lifestyle, disease process knowledge, advocacy with other members of the team as required and coordination of the education programme.

This person will also provide assessment after the programme so you are able to see the evidence that you have improved. You will be asked to perform one of 2 exercise tests prior to starting the course; either a shuttle walk test (similar to the bleep test you may have done at school) or a six minute walk test. This is to ensure that you will be safe in increasing your exercise ability. You will repeat the test after the programme; this is useful in demonstrating the improvement you have made.

You will also be asked to complete a quality of life scoring prior to starting the course and when you have finished. This is another way of demonstrating the improvements; frequently deterioration in the quality of life for someone has occurred over many months or years quite insidiously, and improvements can in some people happen in the same way, and are not always be recognised.

# **Respiratory Nurse Specialist**

The role of respiratory nurses is to promote good respiratory health within individuals, families and communities. By building close relationships with doctors and patients in their community, respiratory nurses educate the public on the importance of healthy breathing and proper exercise in people of all ages.

Respiratory nurses are typically involved in the prevention, care and treatment of conditions such as:

- asthma,
- chronic obstructive pulmonary disease (COPD),
- cystic fibrosis,
- emphysema,
- respiratory failure, and
- tuberculosis (sometime dealt with by public health nurses).

Respiratory nurses meet with patients who are suffering from the conditions listed above, and help develop personal treatment plans to suit patient needs. This can include counselling the patient on prescribed medications, and helping them to bring about lifestyle changes that affect pulmonary health.

Prevention of the above conditions is also a part of the role of respiratory nurses. Since many of these conditions have been linked to smoking and the use of tobacco products, respiratory nurses may be involved in educating patients and community members on the effects of tobacco use, and enabling people to gain access to help to quit. Likewise, the spread of some lung conditions can often be prevented through proactive public health measures; respiratory nurses will often be the liaison between many different healthcare professionals. Respiratory nurses may take an active role in making sure that important health information is delivered to the public in a timely and effective manner.

Frequently respiratory nurses may choose to specialise even more such as in the field of cystic fibrosis or COPD. This aims to enhance the quality of care even more by providing continuity throughout a patients encounter with this nurse specialist.

# **Respiratory Consultant**

The Respiratory Consultant is a doctor who has opted to undertake postgraduate training (often needing between 5 and 7 years) to become a Specialist in Chest Medicine. The Respiratory Consultant does not work in isolation; she or he is a member of the respiratory team as detailed in this book.

However, the Respiratory Consultant carries special skills; they are experienced in interpreting the results of the tests generated by the Respiratory Scientists in the specialist pulmonary (lung testing) laboratories. They have skills at bronchoscopy (a technique in which a small flexible fibre-optic tube can be introduced into the airway to assess what is happening in the lung itself). They also work with other experts - radiologists for interpreting X-rays and CT scans, and pathologists for interpreting

blood tests or biopsy results. This knowledge is then used to manage the situation in which the COPD sufferer finds themself at that time.

Another major role of the Respiratory Consultant is to supervise drug therapy (the utilisation of different inhaled medications or oral medications), and to help manage crises (e.g. exacerbations) which may arise in the life of a COPD sufferer.

Respiratory Consultants tend to deal with the most complex or severe cases of lung disease. They have a role in assessing any possibility of surgical intervention in COPD, or if lung transplantation becomes an option for sufferers of COPD, then the Respiratory Consultant would liaise with the local transplant team (in Auckland see page <u>62</u>) to expedite and manage the assessment and work up for possible transplantation.

Respiratory Consultants also have a role in ongoing education and networking with other colleagues. Research can also be part of the Respiratory Consultant's job; assessing the efficacy and safety of new drug therapies.

As smoking is a major cause of COPD, Respiratory Consultants strongly support the drive to engineer a smoke free society, and advise all current smokers to seek help to quit via the Quitline (Me mutu) for nicotine replacement therapy, or with the aid of Zyban or Champix – discuss with your doctor.

Respiratory Consultants work with the other members of the team to ensure that the patient's journey with COPD progresses as smoothly and trouble-free as possible.

# Respiratory Physiologist / Technologist / Scientist

This member of the team will help you with respiratory function tests. They do this by ensuring that you are fully informed and encouraging you to perform to the best of your ability. They will take you through the test procedure and ensure the test is performed to the required guidelines (noting any discrepancies). To ensure the results are as accurate as possible they also ensure the equipment is up to standard and maintained and calibrated accurately.

# Social Worker

The role of the social worker can vary as regards the need and the other resources that may be available. The role exists primarily to "sign post"; to point people in the right direction to gain help / resources. In a large multidisciplinary team this may be where the social worker's role finishes and others will enter in their own specific roles such as counsellor / occupational therapist in helping with anxiety management or energy conservation. In smaller rural communities the social worker will take on extended roles working as a counsellor, or an advocate.

The social worker will work with individuals or organisations, supporting the client and the whanau to make positive changes in their lifestyles. Education is another part of the social worker role as is protection of vulnerable clients, and ensuring that their best interests are served.

# SECTION 8 Complementary Therapies

# Aromatherapy

Aromatherapy <sup>43</sup> is the controlled use of natural aromatic oils obtained from plants to achieve balance and harmony to the human mind, body and spirit. It is reputed to be as old as the pyramids of Egypt, at least 5,000 years old, and is derived from two words: aroma meaning fragrance or smell, and therapy meaning treatment. It is an art and a science, and works on all levels, and is an holistic treatment.

Essential oils are extremely concentrated, very aromatic and evaporate readily. They are quite



different from fatty oils having a consistency more like water than oil. An essential oil is a natural volatile extract of an aromatic plant obtained by distillation <sup>44</sup>.

It is vitally important to use only authentic and genuine essential oils from a reputable source and preferably organic if possible - Aromaflex for example, is New Zealand owned and operated and certified organic. Choose a qualified Aromatherapist from a reputable Academy or School of Aromatherapy. Aromaflex Academy, Nelson; and Wellpark College, Auckland; are both well-known internationally as well as locally. When you check out your local area for a Registered Aromatherapist. When appointing a therapist it is vital to request evidence of their qualifications.



Find a Registered Aromatherapist here - http://nzroha.netpotential.co.nz/

# Aromatherapy Treatments for COPD

Listed below are some essential oil blends to trial for some of the physical, emotional, psychosocial and spiritual symptoms associated with COPD.

<sup>43</sup> Image: https://www.flickr.com/photos/naomi\_king/7796400432/

<sup>&</sup>lt;sup>44</sup> Monrad, S. (2013). Course materials, Aromaflex Academy: Nelson, New Zealand.

If you use essential oils for massage treatments they need to be diluted in a carrier oil, such as Sweet almond; Apricot; Grapeseed; Hazelnut; Jojoba; Rosehipseed, Sesame and Wheatgerm oils. You may use more than one mixed together for everyday use.

Select 3 to 4 essential oils and dilute in your choice of therapeutic grade carrier oil(s) as follows:

- For women: take the dress size of the woman, i.e. for a size 12, pour 12mls of a carrier oil(s) into a small beaker. Half the number of millilitres to get the number of drops of essential oils you need. Thus ½ of 12 = 6. You then use 6 drops in total of your chosen essential oils.
- For men: take the chest size in inches and halve it, i.e. for a 40 inch chest, half would be 20. Pour 20mls of chosen carrier oil(s) into a beaker.

Divide the chest size by 4 to get the number of drops of essential oils.  $40 \div 4 = 10$  so you use 10 drops of essential oils in total.

For women X = Dress size Carrier oil(s) = X mls. Essential oils = ½ X drops.

For men X = Chest size in inches Carrier oil(s) = ½ X mls. Essential oils = ¼ X drops.

This is called a blend whereas a synergy is when selected essential oils are combined without the addition of, or dilution in a carrier oil or other medium. <sup>45</sup>

# Pain

Massage with analgesic oils may be beneficial but if massage is not advisable, a compress and/or a spray may well be effective (see below). Anti-inflammatory, antispasmodic and calming essential oils are very useful for pain, and include:

- Matricaria recutica (German Chamomile);
- Anthemis nobilis (Roman chamomile);
- *Helichrysum Italicum* (Everlasting);
- Lavendula angustifolia (Lavender);
- Citrus aurantium var. amara (Neroli). <sup>46</sup>

Arnica, Jojoba wax and Grapeseed carrier oils would be appropriate.

# Shortness of breath

Inula graveolens, 1-2 drops in 10mls of base oil e.g. Jojoba wax, rubbed on chest and back. <sup>47</sup>

**Feeling out of breath all the time / having difficulty breathing / anxiety and panic attacks** Calming and sedative essential oils such as:

- Anthemis nobilis (Roman chamomile);
- Cananga odorata (Ylang ylang);

<sup>&</sup>lt;sup>45</sup> Monrad, S. (2013). *Course materials, Aromaflex Academy*: Nelson, New Zealand.

<sup>&</sup>lt;sup>46</sup> Price, S., & Price, L. (2012). Aromatherapy for Health Professionals. 4th Ed. Churchill Livingstone, Elsevier Ltd. P277

<sup>&</sup>lt;sup>47</sup> Price, S., & Price, L. (2012). Aromatherapy for Health Professionals. 4<sup>th</sup> Ed. Churchill Livingstone, Elsevier Ltd.

- Canarium luzonicum (Elemi)
- Citrus sinensis (Orange)
- Citrus reticulata (Mandarin or Mandarin petitgrain) and/or
- Nardostachys jatamansi (Spikenard).

May be used as an inhalation – Fill a bowl of very hot water (near boiling) add 1-3 drops of Essential oils. **Take great care if children and/or the elderly are present**. Or massage a blend gently on to neck, shoulders, back, chest and soles of feet, using the therapeutic grade carrier oil(s) of choice. **Or** apply 1 drop of the following synergy of neroli, mandarin, orange, petitgrain, and spikenard to temples<sup>48</sup>.

**Spirituality** – Aromatherapy may help in spiritual care by bringing comfort and peace in the form of deep relaxation: uplifting and soothing oils that are an analgesic and/or tonic to the heart, relieving any fears: *Boswellia carteri* (Frankincense); *Anthemis nobilis* (Roman chamomile); *Citrus bergamia* (Bergamot); *Lavendula angustifolia* (Lavender); *Ocimum bascilicum* (Basil); and *Origanum majorana* (Marjoram, sweet). Use 3-4 essential oils in your choice of therapeutic grade carrier oil(s). Massage gently into neck, shoulders, back, chest and soles of feet. May be used in an electric burner also, just 6-10 drops in the water bowl of burner, **out of the reach of children**<sup>49</sup>.

Low mood – Uplifting essential oils see Spirituality, above.

**Fatigue, lacking in energy** – Stimulating oils such as *Cupressus sempervirens* (Cypress); *Juniperus communis* (Juniper berry); *Zinziber officinalis* (Ginger); *Citrus limonum* (Lemon); *Origanum marjorama* (Marjoram, sweet); *Mentha piperita* (Peppermint); *Rosmarinus officinalis* (Rosemary) and *Salvia officinalis* (Sage). Use 3-4 essential oils in your choice of therapeutic carrier oil(s) and apply to neck, shoulders, back, chest and soles of feet<sup>50</sup>

Blend for Insomnia/shock/grief – To 30mls of JoJoba Carrier oil add 1-2 drops of each of the following essential oils: *Rosa damascene* (Rose); *Citrus Aurantium var amara* (Petitgrain); *Eucalyptus citriodora* (Eucalyptus lemon scented); *Lavendula angustifolia* (Lavender); *Styrax benzoin* (Benzoin); *Cananga odorata* (Ylang ylang); *Jasminum officinale* (Jasmine); *Citrus aurantium var. amara* (Neroli); *Aniba roseaodora* (Rosewood); *Vetivera zizanioides* (Vetiver). (Dr.Wood, P., as cited in Schnaubelt,K., (2011), p.150).

**Dry mouth, taste affected** – *Melaleuca alternifolia* (Tea Tree); and *Crithmum maritimum* (Samphire) can be combined and diluted with a therapeutic grade carrier oil for gargling, or just use Tea tree diluted in water<sup>51</sup>.

<sup>&</sup>lt;sup>48</sup> Price, S., & Price, L. (2012). *Aromatherapy for Health Professionals*. 4<sup>th</sup> Ed. Churchill Livingstone, Elsevier Ltd. P275

<sup>&</sup>lt;sup>49</sup> Price, S., & Price, L. (2012). *Aromatherapy for Health Professionals*. 4<sup>th</sup> Ed. Churchill Livingstone, Elsevier Ltd. P276

<sup>&</sup>lt;sup>50</sup> Price, S., & Price, L. (2012). *Aromatherapy for Health Professionals*. 4<sup>th</sup> Ed. Churchill Livingstone, Elsevier Ltd.

<sup>&</sup>lt;sup>51</sup> Price, S., & Price, L. (2012). *Aromatherapy for Health Professionals*. 4<sup>th</sup> Ed. Churchill Livingstone, Elsevier Ltd.

**Dr Pam Taylor's Fall-Winter Respiratory Blend** – To a blend of 1 part castor oil and 5 parts Jojoba add the following essential oils at 2 drops each per 30mls of carrier oils: *Lauris nobilis* (Bay Laurel); *Cymbopogon martinii* (Palmarosa); *Styrax benzoin* (Benzoin); *Cupressus sempervirens* (Cypress); *Zingerber officinalis* (Ginger); *Eucalyptus radiata* (Eucalyptus Austaliana); *Hyssop decumbens* (Hyssop, mild form); *Pelargonium graveolens* (Geranium); *Syzygium aromaticum* (Clove bud); *Santalum album* (Sandalwood); *Thymus vulgaris* (Thyme); *Myristica fragrans* (Nutmeg); *Melaleuca alternifolia* (Tea tree). The blend can be applied to the throat, upper back, and chest hourly while awake. For infants apply to the bottoms of their feet and on the back to reduce the likelihood of the oil getting on their hands, and into their eyes<sup>52</sup>.

**Skin problems** - which may be due to high doses of steroids = dry, fragile skin, tears easily, bruising, rashes, inflammation – Anti-inflammatory ess. Oils such as: *Matricaria recutica* (German Chamomile); *Helichrysum Italicum* (Everlasting); *Lavendula angustifolia* (Lavender); *Citrus aurantium var. amara* (Neroli) in Rosehipseed carrier oil <sup>53</sup>. Rosehipseed carrier oil is a very effective skin regenerator.

# Ways of Applying Essential Oils to benefit people with COPD

# 1. Inhalations

are very effective and can be repeated during the day and night if required. You may also apply a few drops of essential oils to a tissue and inhale as required, or sniff directly from the bottle.

# 2. Blends

Gentle massage to throat, chest, back, neck and shoulders, and soles of the feet as the person can tolerate.

# 3. Compress

May use a facecloth soaked in a bowl with approx., ½ cup of water with 4-8 drops of essential oils added. Wring the cloth out and apply to affected area, cover with Gladwrap, then a bandage and finally a towel. Leave in situ. for up to 1 hour.

# 4. Spray

Prepare a spray bottle with purified water. Add 20 to 30drops of your chosen essential oils per 120mls of the water.

# 5. **Bath**

4-8 drops in a bath at a comfortable temperature. Soak the body for at least 5-10 minutes before applying soap or shampoo.

# 6. Vaporisation/burner/Diffuser

monitor if children are present. Fill dish of burner with water and add 6-10 drops of essential oils. Top up when water has evaporated, or after 4-8 hours of diffusing.

<sup>&</sup>lt;sup>52</sup> Schnaubelt, K. (2011). The healing intelligence of essential oils: The science of advanced aromatherapy. Healing Arts Press: Vermont. P143

<sup>&</sup>lt;sup>53</sup> Price, S., & Price, L. (2012). *Aromatherapy for Health Professionals.* 4<sup>th</sup> Ed. Churchill Livingstone, Elsevier Ltd.

# 7. As a gargle or mouthwash

1-2 drops in  $\ensuremath{^{\prime\prime}\!_{2}}$  cup of warm water, stir well, gargle, swish and spit out.

# 8. In the shower

Do this by beginning to shower, then interrupt your shower for a moment, and apply a small amount of oil while the skin is still wet (4-5drops). Because of their lipophilic quality, essential oils will be absorbed instantaneously; the shower can be resumed within 15 to 20 seconds<sup>54</sup>.

If a patient has sensitive skin or allergies it would be wise to carry out a **Patch Test** prior to commencing a treatment as follows: Dilute two drops of intended essential oil in 5mls of carrier oil and massage a small amount on to the inner aspect of their arm and leave for 20mins. If the area becomes inflamed or itches then do not use that particular oil – try another one. If the person does have an allergic reaction to essential oils, wash the area with cool soapy water and discontinue the use of that particular oil immediately and document on Client Chart or in their electronic notes. If essential oils splash into the eye, use cold running water to flush out and get medical help immediately if required.

# Acupuncture

Acupuncture<sup>55</sup> is increasing in New Zealand similar to other Western Countries but is still considered a Complementary and Alternative Medicine (CAM) (Rafferty et al, 2002). Acupuncture can be referred to as Traditional Chinese Acupuncture, Western or Medical Acupuncture or Dry Needling. Majority of Acupuncturists practice a mixture of techniques.



Acupuncture is a form of therapy which thin needles

are inserted into specific points on the body to help with pain relief, healing and general well-being. Needles are stimulated to gain the appropriate response, which can be done by twisting, flicking, heat or electrical pulse applied. Stimulation of the needles can cause a warm, aching, tingly and heavy feeling. Inform your Acupuncturist what you are feeling during your sessions as the sensations above are common.

However, there are common side effects with acupuncture:

- Minor bleeding or/and bruising can occur in 3% of treatments
- Pain during treatment can occur in 1% of sessions
- Worsening of symptoms initially
- Drowsiness/ fainting

Acupuncture is generally safe with few serious side effects (less than one per 10,000 treatments). If any concerns or questions ask your acupuncturist.

<sup>&</sup>lt;sup>54</sup> Schnaubelt, K. (1999). Medical aromatherapy: Healing with Essential Oils. Frog Ltd.

<sup>&</sup>lt;sup>55</sup> Image: https://www.flickr.com/photos/ggvic/2864311951

The treatment your therapist chooses will vary as will the patient's response to treatment. Your therapist will apply your treatment according to your condition and needs. Feel free to talk with a therapist in your area to find out more what acupuncture can do for you.



You can find a registered acupuncturist in your local area from the New Zealand Register of Acupuncturists acupuncture.org.nz/find-a-practitioner/ and The Physiotherapy Acupuncture Association of New Zealand paanz.org.nz/mainmenu83/component/practice.html

# **Medical Herbalist**

The medicinal use of herbs<sup>56</sup> to assist healing has occurred in different cultures and countries the world over for thousands of years. Modern day herbal medicine, blends traditional herbal principles and practices with modern science. There is an emphasis on safety, efficacy and the traditional use of herbs for health improvement. <sup>57</sup>



# Why Use Herbal Medicine?

Herbal medicine can be used to manage or treat a wide range of health disorders including COPD. A medical herbalist is a healthcare practitioner trained in the safe and effective use of medicinal plants.

When you visit a medical herbalist your treatment will be tailored specifically to your particular health concerns, taking your individuality into account. Herbalists understand that the body has an inherent capacity to heal itself, given the right conditions, and so the objective is to help your body regain this balance as far as possible.

According to the World Health Organisation, 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' In this way, medical herbalism has much to offer as it can help not only the main health complaint, such as COPD, but also provides additional healing support to other areas, such as balancing the mind and emotions, and supporting the digestive system.

In a nutshell, the herbalist's goal is to assist you in

- restoring health reserves,
- increasing resilience,
- improving wellbeing and
- being the best that you can be.

<sup>&</sup>lt;sup>56</sup> In the context of this section, the word 'herb' can be defined as any plant, plant derivative or plant extract that may be prescribed for health or healing.

<sup>&</sup>lt;sup>57</sup> Image: https://www.flickr.com/photos/okaramollaoglu/6980084465

In some situations, herbs may not 'cure' your condition, but with regular, supervised use they can make you feel better and improve your overall quality of life.

# Visiting a Medical Herbalist

At your first visit, a medical herbalist will take a thorough case history (in an outpatient setting) to understand the specific circumstances relevant to your experience of COPD and then formulate a prescription that addresses the underlying issues. Herbs have been found to be useful in addressing a huge range of respiratory complaints linked to COPD e.g. chronic inflammation, excessive mucous production, scarring of the respiratory tissue, and/or destruction of respiratory and connective tissue. Many patients are delighted to discover that herbal medicine is extremely helpful in managing their symptoms because particular herbs will work to expel mucous, soothe the respiratory passages, fight and/or resist infection, reduce excessive mucous production, reduce inflammation and increase the dilation of the airways to make breathing easier.

A herbalist will also support other aspects of your health such as the cardiovascular system by improving the circulation of your blood, your digestive function and your ability to absorb nutrients from your food, as well as your immunity to prevent or lessen the incidence of respiratory infection. Herbal medicine also assists with promoting relaxation and maintaining resistance against stress which can adversely affect COPD.

One of the most distinctive factors about seeing a medical herbalist is that the herbal medicine treatments can be prescribed in a variety of high quality formulations to best suit your specific condition and your own unique needs. One of the main advantages of seeing a medical herbalist rather than buying premade formulas straight off the shelf is that after a thorough case history is taken, individual herbs are chosen especially for the unique properties they contain, with their most active components gathered from leaf, fruit, seed, root or flower, and *blended to form an individualised prescription designed especially for you.* 

This formula is taken regularly, and subsequent visits to your medical herbalist are encouraged to check on your progress, and update your prescription as needed. Herbal formulas come as concentrated liquid extracts, which use alcohol to get the active ingredients. Non-alcoholic versions of liquid herbs are also available and other forms include tablets, teas, drops under the tongue, or as essential oil steam inhalations.

### Finding a medical herbalist

The use of herbs is not without risk which is why it is vital to seek the care of a registered professional trained in the use of herbal medicine. Medical herbalists understand how to safely prescribe and consider possible interactions with medications.



Find a medical herbalist registered with the New Zealand Association of Medical Herbalists (NZAMH) – www.nzamh.org.nz.

# Reflexology

Reflexology deals with the principle understanding that there are reflex points on the feet, hands and ears that relate to all organs, glands and parts of the body.

By the application of pressure to these reflexes, using thumb / finger movements, body function may be influenced to be effective in assisting:

- reduction in stress and tension symptoms
- improved efficiency of nerve and blood supply
- relieving pain
- revitalising energy
- restoration of the body to an improved state of harmony and balance commonly referred to as homeostasis.

Creams or powders may be applied during the treatment depending on the practitioners' reflexology style.

# Is Reflexology safe to receive if I have COPD?

Yes it is .... Your chosen Reflexologist will consult with you regarding how COPD is affecting your wellness level. Considerations of this, with medications and other treatment plans being undertaken will determine pressure and duration of each treatment.

# What happens during a Reflexology session?

After footwear is removed you will be made comfortable in a reclining position either in a chair or on a massage table. During the treatment you may experience:

A feeling of deep relaxation or the desire to sleep, the bodys' response to "rest and restore". Twitching, warmth and / or tingling in the body as the reflexes return to rebalance.

# What happens after a Reflexology treatment?

Usually you will feel relaxed and possibly tired. Rest or quiet time is recommended following your Reflexology treatment. Your body is your best gauge for this quiet time.

It is also advisable to increase water intake to assist the body to flush cleared toxins and impurities.

As the body adjusts to an improved 'balance mode' over 2-3 days

- sleep patterns and dreams may alter
- you may experience emotional changes with a greater awareness of your feelings
- urination may increase/ or vary in colour and there may be an increase in bowel movement
- coughing and secretions from the lung/ nasal areas as the body releases congestion

# Please note: symptoms vary for each individual and generally only one or two may occur.

It is important If you have concerns please contact the Reflexology practitioner to discuss.



# So how could Reflexology actually help my COPD symptoms?

When the body, mind and spirit are feeling relaxed, breathing and circulation work more efficiently.

There are also specific reflexology application techniques to enhance lymphatic flow which can assist to help clear congestion and also to balance the endocrine system governing the messenger pathways activating responses in the brain for the release of hormones that assist with inflammation as well as soothing the nervous system.

# How often can I have Reflexology?

Short sessions can be carried out for an acute condition and once a week for a chronic or long term condition or as wellness levels improve over 1-6 weeks.



You can find a professional reflexologist from Reflexology New Zealand - www.reflexology.org.nz

# **SECTION 8**

# **Caring for the Carers**

Carers need care too. Yes, that's right; those who care need to be looked after as well.

If you care for someone with COPD, we'd like to say a big thank you. Without you their lives would be a lot harder. But we know that this doesn't come without some strain on you. So in this section we look at ways to help you our unsung heroes, the carers.

# **Getting Out and Keeping Healthy**

It's ok to still have a life. In fact it's very important that you do. You need to take time out for yourself and your own interests. So don't feel guilty about going for a coffee with friends or learning a new skill, or just relaxing. These things all help to keep you well and therefore better able to care for your loved one.



# **Getting Information**

Coping with the unknown is difficult so get as much information about COPD as you can. This book is an excellent start, but you can ask questions from professionals, and other carers, read books (the library should help you get hold of them, but there may be a charge for interlibrary loan) or source reliable information from the web.

# Take Help When Offered or Ask for Help

When people genuinely offer help take it. Caring for someone can be exhausting and even small amounts of help can revive you. Being open with family and friends may be all it takes for them to offer help. They may not have wanted to offer help for fear of offending you.

# **Coping With Stress**

Whether you are supporting someone who has just been diagnosed with COPD, someone who has had the disease long term or someone who is having end of life care, it is not unusual to find yourself suffering from stress. This may be due to:

- feelings of helplessness or frustration not being able to help someone get better, or prevent their death,
- fear about the future, or not knowing what to do,
- anger that this is happening, that people don't understand the demands, that people don't help
- grieving for the future you would have had if COPD hadn't come along

• guilt – about feeling helpless, angry, fearful or grief.

These feelings are normal. So don't beat yourself up if you identify with any of these feelings. It's OK to have these feelings.

Whilst talking with family/whanau or friends may help, you may want to seek out extra support. Your GP will be able to help and can refer you onto other professionals such as a counsellor (sometime cost free). There are also telephone support lines that you can ring.

- Lifeline 0800 543 354
- Youthline 0800 376 633
- Healthline 0800 611 116
- Depression Helpline 0800 111 757

# Services to Help You

Talking to a professional can help you identify things that you need help with. These may include aids such as perching stools or bath stools, home help or gardening help. Getting help organised can take time so be prepared for a wait and try not to get stress about how long it all takes. Don't take on too much at a time. Having too many balls to juggle will only make it seem harder. One step at a time is definitely the way here.



Carers NZ http://www.carers.net.nz/ Caring for Carers http://www.caringforcarers.org.nz/

# SECTION 9 Palliative Care / End of Life Care



When the time came Jean was referred to the palliative care support team that provided outreach from the hospital. She was allocated a primary nurse and a team who would provide support to her and her family.

She was offered the opportunity to visit the local hospice, and was able to attend the day centre there one day each week <sup>58</sup>. The palliative care team worked with Jean to create travel plan, and Jean and Bob made short trips in their motor home for three months, while still supported by the hospice.

Jean died in her bed in her motor home very peacefully one night; she had spent the evening before putting the finishing touches to her memory quilt; a blanket which consisted of materials from her own, her husband's and her children's clothing.

When palliative care is mentioned there are usually a lot of questions. Some of them might be:

- 1. What is palliative care?
- 2. What are hospices?
- 3. What are the principles of palliative care?
- 4. How can they help me and my family / whanau?
- 5. Does this mean I am dying?

There are a lot of misconceptions about what palliative care is and what hospices do. Probably the main one is that palliative care is only about care of those who are dying and that hospices are somewhere to go when you are dying. This is too restrictive a view and palliative care should be regarded as "care for people of all ages with a life limiting condition" <sup>59</sup>.

This section looks at what palliative care is and the principles or ideas behind palliative care. It will also look at what hospices are and what they do. As well as why someone who has COPD may be referred to palliative care services and/or hospice.

As we age and respiratory disease progresses our lungs worsen and symptoms may increase. It is the management of these symptoms and quality of life issues that may precipitate a referral to palliative care services. Within New Zealand these are often provided or coordinated by the hospice in the area.

<sup>&</sup>lt;sup>58</sup> Only some hospice offer day programmes and some areas of NZ only have outreach teams not a physical hospice as such

<sup>&</sup>lt;sup>59</sup> http://www.healthpages.co.nz/health-topics/where-to-go/palliative-services-dying

# What is palliative care?

The World Health Organisation defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Palliative care is a specialist branch of healthcare that instead of focusing on active interventions and treatments intended to prolong life it focuses on symptom relief and support to manage the stress and impact of serious illness for someone with a life limiting illness. A life limiting or threatening illness means a patient is in the last 6 – 12 months of life.

However more and more patients are being referred to palliative care services earlier. It is not uncommon that patients who are being actively treated with chemotherapy and other treatments will be referred to hospice or palliative care services, mainly for support and symptom management. It is also important to remember that palliative care and hospices are not just for those who have cancer.

Palliative care comes the Latin word "palliare" meaning to cloak. The aim of palliative care is to cloak i.e. wrap care around those with advanced disease and their carers/whanau. Palliative care looks to address physical, emotional, spiritual and social concerns of patients who have advanced illnesses and those around them.

# **Key Principles of Palliative Care**

There are some key principles of palliative care that are useful to understand.

# **Provides symptom management**

looks at providing relief from physical aspects of life limiting illness. These may be pain, shortness of breath, nausea, fatigue and a whole range of other distressing symptoms. Other symptoms may be emotional, spiritual or psychosocial.

To manage symptoms in palliative patients a lot of medications are used differently. Often routes will also be different for example a lot of medication may be given subcutaneous that is injected under the skin as opposed to the patient swallowing this. This may be because the patient has difficulty or may no longer be able to swallow because of the disease process and absorption via the oral route may not be as effective.

# Palliative care looks at affirming life

Quality of life and the promotion of living every moment of that life are key ideas in both palliative care and hospice new Zealand practice. Palliative care promotes and supports patients to live as actively and fully as possible. Hospice New Zealand logo includes 'living every moment'.

# That dying is a normal process

Dying is a natural process, coming to terms with death and aspects that are important to the individual are looked at. This could be do you wish to be at home, when do you want active treatment to stop or continue.

Palliative care does not do anything to either hasten or postpone death. Palliative care is not euthanasia or assisted death, nor does it look at prolonging life through artificial intervention.

# Palliative care encompasses both psychological and spiritual aspects of an individual

It also helps in the provision of support systems for family / whanau of patients to help them cope and to give respite whilst caring for the patient.

# Palliative care is multi-disciplinary

That is, there is a whole team that makes up the palliative care approach in caring for a patient and their family / whanau. This includes not just doctors and nurses, but social workers, counsellors, chaplaincy, pharmacists and a variety of other allied health professionals which may include occupational therapist, dieticians, physiotherapists, complimentary therapists - music therapy, art therapy etc., volunteers, care givers.

The treatment of 'total suffering' or 'total pain' is important in palliative care. That is not just dealing with a patient's physical suffering but also their emotional, psychological and spiritual suffering or pain. In practice this may be prescribing pain killers such as morphine for pain but at the same time a social worker, counsellor or chaplain working with the patient and possibly their family / whanau as well. This may be to address other factors that cause distress such as loss of independence, financial insecurity, worries about the future and/or impact of feeling like a burden. This ongoing support is crucial to quality of life for the patient. Also included are the needs of the family / whanau / loved ones that surround the individual.

# What Are Hospices?

Originally hospices were a place of rest for travellers of long journeys. In the early 11th century they were places that dedicated themselves to the care of terminally ill Crusaders and pilgrims. By the 19th century hospices had started developing further. They had started looking at the discrepancies between access to healthcare for the poor and impoverished, especially in



terms of adequate care in sanitary conditions. Throughout the 19th century hospices opened around the world to care for those dying from predominately tuberculosis and cancer.

In the 1950s the modern hospice movement developed in UK by a registered nurse called Dame Cicely Saunders. She developed key principles that have been regarded as the foundations of the modern hospice movement. One of these leading principles was focusing on the patient not the disease. This is everyday practice now but at the time was ground breaking.

Although viewed by many as a place that cares for cancer patients, hospices also look at anyone with chronic terminal disease such as respiratory, renal, cardiac or neurological. Hospices also provide grief counselling and bereavement support to families of patients.

Within New Zealand a lot of palliative care services are run from a central hospice for that area. But hospice services are not just provided within the hospice building. Hospice care is increasingly provided within the patient's own home in response to wishes of the individual their family /

whanau. It is also provided with hospice support in aged residential care facilities and hospitals have palliative care teams that work alongside their colleagues to provide hospice philosophy care within the hospital environment.



# What symptoms can palliative care help to manage?

For respiratory patients this is most likely to be breathlessness. Management of breathlessness in a palliative context is quite different than in an active treatment phase. In some cases breathlessness may be managed both actively and palliatively to improve a person's quality of life and the impact breathlessness may have upon them.

Oxygen is not always the best way to manage breathlessness. If you have low oxygen levels then oxygen will be effective in relieving breathlessness. However it is possible to experience breathlessness without having low oxygen levels and even patients that are on oxygen can sometimes experience breathlessness.

With palliative care a different approach is taken and the 'gold standard' medication used to manage breathlessness is Morphine. This often surprises people.

Morphine is a strong and potent analgesia or pain killer that is often used to treat severe pain. A lot of people have ideas and/or experiences with morphine and are often reluctant to use morphine. There are concerns about addiction, overdose and side effects.

Morphine elixir, which is quick acting, has been proven to be effective in the relief of breathlessness. As an opiate medication it acts on the central nervous system and sends messages to the brain to slow breathing and calm the feeling and distress of struggling to breathe.

The amounts of morphine that are used are much smaller than would usually be used for severe pain.

Another medication that may be used is Midazolam. This medication is an anti-anxiety medication. Often it is in a nasal spray bottle that patients are able to administer themselves. It is quick acting and short acting and like morphine relieves the sensation of struggling to breathe.

# Who should be referred for palliative care?

The decision about a referral for palliative care is a matter for discussion between you, your family / whanau (if you wish) and your healthcare team. However these factors are likely to be taken into consideration:

- Having severe (less than 30% FEV1) airflow obstruction.
- Having respiratory failure.
- A low BMI.
- Being housebound (with a MRC dyspnoea score of 5) <sup>60</sup>
- A history of two or more admissions for exacerbations in the last year.
- Need for non-invasive ventilation (NIV) during an exacerbation.
- Eligible for long term oxygen therapy.

There is no 'right time' in a patient's journey when they should be or need to be referred to palliative care services. But increasingly the value of palliative care in conjunction with active medical treatment is being recognised.

# Advanced care planning

Most people are aware of the wisdom of making a will for after they have died; so ensuring that their property and precious possessions go to the members of the family / whanau / friends / clubs or societies that they would want. So we all think about and plan for after we die, but what about before we die? Shouldn't we be planning for this as well?

- 1. Think about what values and beliefs around end-of-life issues are important to you. What makes life meaningful to you and what situations might make it seem pointless?
- 2. Talk to health professionals to learn about medical treatments for the very ill or injured. Ask about the benefits and risks of these treatments.
- 3. Decide at what point you would want your future healthcare to focus on comfort care rather than life-saving measures which may be uncomfortable or unpleasant.
- 4. Choose what medical care you do or don't want, to honour your values, beliefs and faith.
- 5. Discuss your choices and wishes with those closest to you, so they know what you would want if the worst should happen.
- 6. Choose who you would want to speak for you if you could no longer make your own medical decisions, and sign over 'enduring power of attorney' to them.
- 7. Put your advance care plan in writing and keep a copy in your medical record. It will not be used while you are capable of making your own decisions and speaking for yourself.

<sup>&</sup>lt;sup>60</sup> www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationserviceforpatientswithcopd/mrc\_dyspnoea\_scale.jsp
<sup>61</sup> Our Voice, To Tatou Reo: Advance Care Planning http://www.hqsc.govt.nz/assets/Other-Topics/QS-challenge-reports/Conversations-about-death-and-dying-Toolkit.pdf



There is a full document that explains this in detail, along with the legalities of advanced care planning at

www.advancecareplanning.org.nz

It is important that your advance care plan is discussed with all members of your family / whanau in order that if and when you are unable to speak for yourself, your wishes continue to be carried out.

# SECTION 9 Glossary

Understanding the jargon! During your conversations with various healthcare professionals you are bound to come across terminology you don't understand. Here is a list of terms associated with COPD and their meanings.

## Abdomen:

The part of the body containing the digestive organs. It lies below the diaphragm and above the pelvis. Sometimes called the belly.

#### **Abdominal breathing:**

Breathing that results from contracting the diaphragm. This type of breathing is marked by expansion of the abdomen rather than the chest.

# ABPA:

See Allergic bronchpolmonary aspergillus:

# ACBT:

See Active cycle of breathing technique

#### Active cycle of breathing technique:

An airway clearance technique used to clear mucous and phlegm.

### Aerosol spray:

A drug given as a fine mist for inhalation.

# Acute:

Severe symptoms which are sudden in onset and/or of short duration.

#### Adrenal suppression:

The adrenal gland decreasing or stopping natural glucocortoid production

# Airways:

The tubes which carry air to and from the lungs.

#### Airway obstruction:

A blockage of the airways causing difficulty in breathing.

## Allergic bronchpolmonary aspergillus:

An allergy to the spores of Aspergillus moulds.

### Alpha 1-antitrypsin deficiency (α1-antitrypsin deficiency, A1AD or Alpha-1):

A genetic disorder that causes defective production of alpha 1-antitrypsin

# Alpha 1-protease inhibitor:

A protein that protects tissues from the enzymes of inflammatory cells

# Alveoli:

The air sacs at the end of tiny airways in the lung.

#### Amoebic meningitis:

A rare but fatal inflammation and destruction of the brain and brain linings.

### Aerobic exercise:

Exercise of long duration but low intensity e.g. walking, cycling and swimming. Also called cardiovascular endurance.

# Antibiotic:

A drug which is taken to fight bacterial infections.

#### Antibodies:

Cells produced by the body's immune system to protect the body from harmful substances called antigens.

## Anticholinergic:

A class of drugs that work by blocking a nerve transmitter called acetylcholine in the brain. It helps to relax and dilate the smooth muscles that line the large airways (bronchi).

## Antigen:

A "threat" to the body such as bacteria, fungi, parasites, viruses and chemicals, which result in the body producing antibodies.

## Anti-inflammatory

Reduces inflammation.

# Artery:

A blood vessel that carries blood from the heart to the lungs and the rest of the body

# Aspergillus:

A type of Mould.

Asthma:

Inflammation of the airways, resulting in wheezing, coughing, chest tightness, and shortness of breath.



# Beta agonists:

A group of drugs which work by telling the muscles around the airways to relax, thus widening the airways.

# Borg scale:

A tool used to measure your how breathless you feel during activity.

### Bronchi:

The large tubes that carry air to and from the lungs. Bronchi divide into smaller and smaller bronchioles.

### **Bronchiole:**

The finer branches off the bronchi that carry air into and out of the lungs.

### **Bronchiolitis:**

Inflammation or infection of the bronchioles.

# Bronchitis:

Inflammation or infection of the linings of the bronchi (large airways)

### Broncho-constriction:

Narrowing of the airways.

# Bronchodilator:

A drug (usually taken by inhalation) that widens (dilates) the bronchi and bronchioles.

# Broncho-pulmonary:

Relating to the airways (broncho) and the lungs (pulmonary).

# Bronchoscopy:

A procedure for looking inside the airways with an instrument called a bronchoscope.

# Capillaries:

Very thin blood vessels.

# Carbon dioxide:

A waste gas given off by body when energy is used. It is excreted by the lungs.

# Cardiovascular endurance:

Exercise of long duration but low intensity e.g. walking, cycling and swimming. Also called anaerobic exercise.

Cell:

The structural units that make up every living organism.

## **Chest X-Ray:**

A test which produces images of the inside of the chest.

#### **Chronic:**

A disease that is long lasting.

## Continuous positive airway pressure:

A treatment to keep the airways open during sleep, using mild air pressure.

## Cor pulmonale:

Enlargement of the right side of the heart.

## Corticosteroids:

Drugs that closely resemble one of the body's own hormones cortisol. These are used in COPD to reduce inflammation (anti-inflammatory) and help widen (dilate) the airways (bronchi).

CPAP:

See Continuous positive airway pressure

### **CPAP** machine:

The machine used to provide CPAP to the airways preventing them from closing (obstructing) during sleep.

# Crackles:

Clicking, crackling or rattling noises made by the lung (usually heard with a stethoscope)

# CT scan:

A Computed Tomography scan (also known as a CAT (Computer Axial Tomography) scan) is a technique that produces images of "slices" of the body.

## CXR:

See Chest X-ray.

#### **Cyanosis:**

A bluish colour of the skin caused by reduced levels of oxygen in the blood

# **Cystic fibrosis:**

An inherited disease causing the production of abnormally thick mucus, which leads to the blockage of the bronchi and other organs.



### Depression:

Intense and persistent feelings of unhappiness that don't go away.

# Diffusing capacity of the lung for carbon monoxide:

The extent to which oxygen passes from the air sacs of the lungs into the blood.

The test used to determine this parameter.

#### Diffusion:

The movement of oxygen from the air sacs of the lungs into the blood, and of carbon dioxide from the blood into the lungs.

#### DLCO:

See Diffusing capacity of the lung for carbon monoxide

#### Diaphragm:

A dome shaped layer of muscle that separates the chest cavity from the abdominal cavity. It is responsible for approximately 60 - 80 % of the air that enters the lungs during quiet (resting) breathing.

### **Diuretics:**

Drugs which help reduce the retention of too much fluid and therefore cause an increase in the amount of urine.

#### Duct:

A tube which allows the passage of fluids or air.

## Dysplasia:

Abnormal development or growth of an organ.

#### Dyspnoea:

Difficulty in breathing.

#### ECG:

See Electrocardiogram

# Elastase:

An enzyme that digests elastin.

### Elastin:

Tissue in the lungs (and other parts of the body) that are able to stretch and contract.

#### **Elastase inhibitors or Antielastases:**

A substance which slows down the digestive properties of elastase.

## Electrocardiogram:

A test that measures the electrical activity of the heart.

#### Emphysema:

A disease where the air sacs of the lungs have become enlarged, resulting in breathlessness.

# Endorphins:

Natural chemicals produced by the body that a feeling of well-being.

## **Exacerbation:**

Increase in severity.

Excema:

Chronic inflammation of the skin.

## Exhalation:

Breathing out.

#### Expectoration:

The action of ejecting phlegm or mucous from the throat or lungs by coughing

# FEV1:

See Forced expiratory volume in one

#### Forced expiratory volume in one second

The volume of air that you are able to exhale in the first second of forced expiration.

#### Forced vital capacity:

The total volume of air that you can forcibly exhale in one breath.

FVC:

See Forced vital capacity

#### Gas exchange:

The transfer of oxygen from the air sacs (alveoli) to the blood and of carbon dioxide from the blood to the air sacs (alveoli).

#### Genetic:

Inherited through the genes of one or both parents.

# Glaucoma:

A disease of the main nerve of vision (the optic nerve), which leads to a loss of peripheral vision. If left untreated glaucoma can progress to loss of central vision and blindness.

## Hypercapnia:

High levels of carbon dioxide in the blood.

#### Hyperinflation:

Over inflation or more precisely, breathing in before you have fully breathed out.

#### Hypertension:

High blood pressure.

#### Hypoventilation:

Slow breathing resulting in increased levels of carbon dioxide in the blood.

## Hypoxaemia:

Low levels of oxygen in the blood.

#### Hypoxia:

Insufficient amounts of oxygen reaching the tissues of the body.

#### Immunization:

Being made immune (usually by injection) to an infection e.g. 'flu.

## Inflammation:

A localised reaction to injury or infection where part of the body becomes red, swollen, painful, and hot.

#### Influenza:

A serious infection caused by influenza viruses. Not to be confused with the less serious common cold. For COPDers it is important to get immunised against the 'flu each year.

# Inhalation:

Breathing in.

### Inhaler:

A device used to deliver medication to the lungs.

## Intermittent positive pressure breathing (IPPB) machine:

A machine which assists breathing by providing compressed oxygen under positive pressure into the patient's airway.

#### Lavage:

Washing out a hollow organ (e.g. bronchial lavage) to obtain a sample for diagnosis or evaluation of treatment.

#### LABAs:

# See Long Acting Beta Agonists

# Long-acting beta agonists:

Green inhalers that cause the smooth muscle in the small airways to relax and dilate. Like SABAs they work by acting on the Beta 2 cells and are this known as beta agonists. LABAs work for a longer period of time (up to twelve hours) and are generally used twice a day as near as possible to twelve hours apart.

#### Lung diffusion testing:

Measures how well the lungs exchange gasses (e.g. oxygen and carbon dioxide).

#### Lung function tests:

A group of tests which measure how well the lungs are working.



See Metered Dose Inhaler

# Membrane:

A thin layer of tissue, such as the outer layer of an organ.

## Meningitis:

Inflammation of the covering (meninges) of the brain and spinal cord.

# Metered dose inhaler:

An inhaler that delivers a specific (metered) amount of medication to the lungs, as a short burst of aerosolized medicine that is inhaled.

#### **Mucous:**

A protective secretion of the mucous membranes which, in the nose, throat and lungs serves the function of trapping bacteria.

# Nebuliser:

A device used to deliver medication as a mist inhaled into the lungs.



# Oedema:

Swelling of the tissues (e.g. in the legs), caused by the retention of too much fluid. **Oral thrush:** 

A fungal infection of the mouth.

#### Osteoporosis:

Thinning of the bones leading to increased likelihood of bone fractures

#### Oxygen:

Part of the air we breathe which is necessary for the body to function.

# **Oxygen saturation:**

The amount of oxygen carried in the blood.

### Paroxysmal nocturnal dyspnoea:

Shortness of breath that awakens a person at night, often after 1 or 2 hours of sleep.

Pathogenesis:

The development of a disease.

#### Pathophysiology:

The abnormal functioning of the body associated with disease.

### Peak flow:

The maximum speed of expiration.

PEP:

See Positive expiratory pressure.

#### PND:

See Paroxysmal nocturnal dyspnoea.

## Positive expiratory pressure:

Pressure or resistance to a persons out breath. This helps to splint open the airways.

#### Pneumonia:

Inflammation of the lungs(s) caused by infection, resulting in air sacs (alveoli) becoming filled with pus.

## **Pneumothorax:**

Where air gets between the lungs and the chest wall.

### Postural bronchial drainage:

The drainage of fluids from the lungs by means of posture i.e. lying the patient on a bed with their hips on pillows to elevate the chest above the head.

## **Postural drainage:**

Using gravity to help encourage sputum to move. This technique MUST be taught by a physiotherapist.

#### **Preventer inhaler:**

An inhaler used to prevent symptoms. Usually used twice a day.

#### **Progressive:**

Increasing in severity or extent.

## **Pulmonary:**

Relating to the lungs.

#### **Pulmonary hypertension:**

Abnormally high blood pressure in the blood vessels of the lung.

## **Pulse oximetry:**

A tool used to monitor oxygen saturation.



## **Recovery breathing:**

A technique used to help breathing return to a more comfortable level after heavy exercise or just for those times when breathing is unsettled, and a person is struggling.

## **Reliever Inhaler:**

Short acting blue inhaler which rapidly opens up the airways.

**Respiration:** 

Breathing

## **Respiratory failure:**

Inadequate exchange of gases between the lungs and the blood resulting in abnormal levels of oxygen and carbon dioxide in the blood.

# **Resistance training:**

A method of improving skeletal muscle strength by gradually increasing the ability to resist force through the use of free weights, machines, or your own body weight. Also known as strength training.

#### **Risk factors:**

A characteristic of a person (e.g. their ethnicity, sex, age, weight) or a variable (e.g., smoking) that increases the likelihood of a disease.

#### SABAs:

See Short-acting beta agonists.

## Short-acting beta agonists:

Blue inhalers that cause the smooth muscle in the small airways to relax and dilate. They work by acting on the Beta 2 cells and are thus known as beta-agonists. They work within 2-5 minutes, but the effects do not last longer than four hours.

#### Spacer:

A specially designed plastic tube for use with a Metered Dose Inhaler. An MDI used with a spacer delivers more medication into the lungs than using an MDI on its own.

#### Spirometry:

A type of lung function test which measures the amount of air you can inhale and exhale, and how fast you can exhale.

#### Sputum:

A mixture of saliva and mucous coughed up from the respiratory tract.

#### Steroid:

An anti-inflammatory medication.

## Strength training:

A method of improving skeletal muscle strength by gradually increasing the ability to resist force through the use of free weights, machines, or your own body weight. Also known as resistance training.

#### Surfactant:

A wetting agent. In the lungs surfactants help keep the air sacs (alveoli) open.

#### Symptom:

Signs of a disease as felt or experienced by a patient.

#### Symptomatic treatment:

Treatment aimed at easing symptoms rather than curing a disease.

#### Trachea:

The tube that caries air from the voice box (larynx) to the large airways (bronchi)

# Tuberculosis (TB):

A disease caused by infection with the tubercle bacillus, most frequently affecting the lungs.

# Vaccination:

Having an injection as a precaution against catching an infection such as the 'flu.

# Vaccine:

A medicine (usually injected) that improves immunity to a particular disease.

## Ventilation:

Getting air into and out of the lungs.

Ventilator:

A machine that breathes for a patient when they are not able to do this for themselves.

### Vein:

A blood vessel which carries blood from the body and lungs back to the heart.

## V/Q scan:

A nuclear isotope scan that compares ventilation of the lung versus perfusion (blood flow through the lung).



# Wheezing:



A whistling or rattling breathing sound.

A test which produces images of the inside of the body.

# SECTION 10 Resources

# Books

- Froggatt, Wayne (2004) Choose to Be Happy. Harper Collins World; Revised edition. 978-1869504953 http://amzn.to/ChooseToBeHappy
- Remen, Rachel Naomi (2006) Kitchen Table Wisdom. Riverhead Trade; 10 Anv edition. 978-1594482090 http://amzn.to/KitchenTableWisdom

# Organisations

All these organisations also cover COPD despite their names!

- Asthma Foundation http://asthmafoundation.org.nz/
- Asthma New Zealand http://www.asthma-nz.org.nz/
- Asthma Societies http://www.spacetobreathe.co.nz/get-support/asthma-societies
- Green Prescription http://www.health.govt.nz/our-work/preventative-health-wellness/physicalactivity/green-prescriptions
- Hospice New Zealand http://www.hospice.org.nz/

# Social Media

- Facebook NZ COPD Group https://www.facebook.com/groups/nzcopd/?fref=ts
- Facebook COPD UK Group https://www.facebook.com/groups/19449002400/?fref=ts
- Facebook COPD Scotland https://www.facebook.com/groups/100716733304663/?fref=ts
- Facebook COPD Alternative Therapy https://www.facebook.com/groups/COPDalternatives/?fref=ts
- COPD Foundation (@COPDFoundation) on Twitter https://twitter.com/COPDFoundation/

# Web Sites

- COPD International http://www.copd-international.com/
- Depression http://www.depression.org.nz/
- Home Insulation Funding http://www.energywise.govt.nz/funding-and-programmes/insulation-and-clean-heating
- Mayo Clinic http://www.mayoclinic.com/health/copd/DS00916
- Ministry of Health http://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/chronic-obstructive-pulmonary-disease
- Wikipedia http://en.wikipedia.org/wiki/Chronic\_obstructive\_pulmonary\_disease