# Kowhai Programme

### Support for families, whānau & carers

## Breathlessness or dyspnea

Shortness of breath is a common and distressing symptom for people with incurable cancer and some other illnesses at the end of life (such as chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF) and motor neurone disease (MND)). Breathlessness is a multifactorial and complex symptom and is an experience unique to the individual.

Breathlessness is not harmful, but it is very unpleasant and frightening. For many people the feeling of breathlessness is not constant (for example at rest you feel fine, but doing activity causes breathlessness).

Appropriate treatment of this distressing symptom requires both drug and non-drug methods. This information is to assist you to manage your breathlessness.

Your doctor will discuss the burden and benefits of any of the medical interventions that they offer to assist with management of breathlessness. These interventions may include:

- Treatment of the underlying malignancy with radiotherapy, chemotherapy and other targeted therapies.
- Chest drainage, pleurodesis and stenting of obstructed airways.
- Use of antibiotics, steroids and anticoagulants.
- Correcting anemia (low red blood cells)
- Ensuring that you have optimised treatment of any comorbidities you may have such as heart failure.
- Offer smoking cessation support.

#### Drug methods:

There are four main types of medications that are used to help manage breathlessness. These medications are:

- Bronchodilators (such as salbutamol or ventolin).
  These open airways and decrease dyspnea
- **Steroids** (such as prednisolone or dexamethasone). These help reduce swelling in the lungs that cause shortness of breath.
- Benzodiazepines (such as midazolam). These can help break the cycle of panic that can lead to more breathing difficulties.
- Opioids (such as morphine). These can make your breathing easier.

The use of oxygen can help some people, but not everyone – your doctor will suggest this for you if they think it will help your situation.

#### Non-drug methods:

It is important to understand how your muscles work to help you breathe:

The diaphragm: This is a large flat sheet of muscle that covers the base of your rib cage. As you breathe in, it moves down to help draw the air into your lungs. When you breathe out it relaxes moving upwards. It does not tire easily and therefore can move up and down all day, every day without getting tired.

The breathing accessory muscles: There are many muscles around your neck and shoulders with the role of moving your neck and arms. When you are breathless these muscles can pull on your upper ribs to help you draw air into your lungs. This is a normal response to breathlessness. These muscles however are not meant to be used for long periods of time, so if they are used a lot for breathing, they can become tight, stiff and sore.

## To relax your accessory muscles an affective strategy is doing slowed breathing:

#### Preparation:

- Place one hand on your tummy, just above your belly button.
- Relax your shoulders and upper chest.
- Rest your elbows in by your sides or on your thighs.

#### Spend as long as you need on the following points:

- Feel the breathing movement under your hand.
  - 1. Breathe in smoothly; allow your tummy to swell.
  - 2. Take in only the air you need.
  - 3. Breathe out, relax and let your tummy fall.
- Release each out breath until it comes to its natural end.
- As you breathe out narrow your mouth slightly, if this helps.
- Each time you breathe out; relax your upper chest a little more.

Breathing this way doesn't come naturally, so try to practice this for 10 minutes a time twice a day if possible. This will help you to slow your breathing down when you are having an exacerbation of breathlessness.

Sometimes an episode of difficult breathing can trigger coughing, or that coughing brings on breathlessness. Some people will have treatment or medication to assist them with managing this symptom.

Try sipping warm boiled water slowly as this can relieve the symptom sometimes and can make your mouth feel fresher.

Sometimes the coughing is related to your lungs trying to clear fluid. If you are finding it hard to cough, or exhausting from ineffective coughing, try these steps:

- Breathe in through your nose as much as you can comfortably.
- Take an extra sniff, holding that breath.
- Now cough

A chest infection can cause increased breathlessness and coughing. Be sure to check out the cause of the cough or phlegm especially it is not usual for you. If you usually have phlegm and it changes in colour or quantity, discuss this with your GP as soon as possible.

#### Relaxation techniques:

These are different from doing a relaxing activity or resting. They require us to use our minds to assist our bodies to achieve a comfortable state. The most effective techniques to manage breathlessness are progressive muscle relaxation and guided visualisation.

Not everyone finds these exercises comfortable to do and prefer to listen to music or explore other options that provided distraction from the anxiety of being breathless.

#### Positive self talk:

This is very helpful to reverse the unhelpful physical and emotional reactions to being short of breath. When you are aware that you are getting to a breathlessness reaction cycle, it can be useful to tell yourself reassuring words to reverse this response.

E.g. 'this will pass' 'slow down....' 'be calm' 'I can slow my breathing'.

## The Otago Community Hospice has two counsellors available to assist with anxiety management if needed.

Another helpful tool for you and your family/whānau is to complete your own personal action plan that has strategies that you and the people supporting you find helpful in overcoming your episodes of breathlessness

- Comfortable positions that help me breathe:
- Strategies that help me breath slowly and gently:
- How I relax my shoulders and upper chest:
- Positive self talk that works for me:
- Medications that help: (this needs to have input from you GP/specialist on when/how much to take/what to take).

If you would like assistance to develop an action plan, talk with your community care coordinator.

#### Positioning:

The following positions maybe helpful to manage your breathlessness.



Leaning forward and using your slowed breathing strategy is helpful – you can even do this leaning on the shopping trolley at the supermarket.

For sleep, having your head elevated with pillows and your legs apart can be helpful.



#### **Equipment:**

You may find benefit from having an occupational therapist and physiotherapist assessment to assist you with maintaining as much independence as possible. Occupational therapists will provide you with equipment to help with your everyday activities such as a shower stool, raised toilet seat and electric lazy boy chair and physiotherapists will provide you with mobility aids such as a walking frame.

#### Fans:

Using a flow of air from a fan (standing or hand held) or having an open window can help reduce the sensation of not having enough air to breathe. Having a breeze going over your cheeks (back and forth) helps people to feel that they are getting more air to breathe. It stimulates a nerve (trigeminal) which reduces the sensation of breathlessness. It is important not to have the flow of air directly into the front of your face, as this can make you gasp, causing increased breathlessness.

#### Eating:

Shortness of breath can make eating hard work. If you use all your energy preparing food, you may have no energy left to eat it. Here are some suggestions to help:

- Eat 5-6 small meals instead of 3 big meals a day.
- Plan to eat before you are too tired or hungry.
- Breathe evenly while you are chewing and eating.

- Stop eating if you need to catch your breath.
- · Relax at meal times.
- When cooking/baking try cooking three times the amount so you can freeze meals/foods down for times you don't feel like cooking/baking.
- Used prepared foods such as frozen meals/take away foods/meals on wheels to make things easier for you.
- Use a perching stool or sit at the kitchen table to prepare food (such as when peeling or chopping food).

#### Managing your everyday activity:

**Plan your day carefully:** What is essential? What can you do and what can be left for others to help with? Think about what you really want to do in a day so you can balance your day to manage the fatigue related to breathlessness.

Pace yourself: Most people find they have higher and lower energy points in a day. When is the best time to do what? Also allow yourself time to do things, try not to do too much in one day and try to work for short periods of time – alternate heavy and light work.

Carry out activities the easiest way possible: Avoid unnecessary bending, reaching, walking or climbing. Set up your home to make life easier e.g. shower stool, perching stool in your kitchen for when you are preparing meals.

Bending over at the waist can make breathing very difficult and can cause breathlessness so keep your back straight and bend at the knees. Having a long handled reacher can be helpful to limit the need to bend or getting assistance from carers for drying/dressing your lower body.

Ensure that your home environment is at a constant comfortable temperature. Warm your bedroom/bathroom before undressing. Extremes of hot or cold air can aggravate your feeling of breathlessness, so too can steam.

Avoid holding your breath during activities such as climbing stairs, or bending and instead "blow as you go". This means you need to breathe out on effort (i.e. exhale when bending, lifting, reaching or standing up from a chair).

Avoid rushing. People sometimes rush to do an activity as they wrongly think that if they move quicker they will be less breathless when they get there.

Pace your breathing (for example, take a breath in and out on each step when climbing the stairs). It is important for you to remain as active as your illness allows you to be.

If you need further support or further discussion regarding this information, please contact your Otago Community Hospice care coordinator team ph. 0800 473 6005

