PALLIATIVE CARE FOR SICK LUNGS

HEALTH INFORMATION FOR PATIENTS
This resource has been designed to help you and your family better understand your journey with lung disease.

This book will help you and your family:

• Talk to people who care for sick lungs (The Respiratory Team).
• Help you and your family understand how the health care team can support you on this journey.
• Help you and your family plan for when you will finish up.

A special acknowledgment is extended to the Aboriginal support services in the Northern Territory including the actors and others who have made a significant contribution to this resource.

Disclaimer

Aboriginal and Torres Strait Islander people are advised that this resource may contain images of deceased community members. Some of the people that appear in this resource are actors and the roles in which they play are roles acted out purely for the purposes of this resource, health promotion and education. The views expressed in this work are the views of the author(s) and not necessarily those of the Commonwealth of Australia.
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Aboriginal Interpreter Services

If there is anything you do not understand about your lung story and what will happen to you, ask the health clinic to get an interpreter and tell your story again.
What is Palliative Care?

Palliative Care is for people that have a sickness that cannot be cured or fixed and they will finish up soon.
What can Palliative Care do for me?

The respiratory, health clinic and palliative care teams will work together to help your family and community look after you when you get too sick to take care of yourself.

They will help with:

- Medicines and equipment to make you feel comfortable.
- They can help you to finish up where you want to.
Important decisions

When your lungs get really sick it is harder for them to keep working and you will pass away. You will need to make some important decisions about what treatment you want.

Some treatments can help to make you feel better and help you live longer.

If you don’t want certain lung treatments in town or to go to hospital then you can stay at home and finish up in your community close to your family.
Important decisions

People with lung disease often have other illnesses;

- High blood pressure and blood circulation problems.
- Chest infections.
- Heart problems.
- Weak bones.

Talk to your doctor and health care team about your sick lungs.
Important decisions

It is important to understand that no one really knows when you will finish up. Finishing up can happen quickly or you may feel well and stay strong for some time. No one can tell, it is different for every person.

Sometimes it might be a chest infection that may not get better when you have antibiotics and you could finish up real quick.
Important decisions

You can decide where you want to finish up;
• At home.
• At the hospice.
• At the hospital.
• On country.
Important decisions

If you get really bad lung sickness you might have to go to the Intensive Care Unit (ICU) at the hospital. You might go a few times through your sickness but then there might come a time when it will not do you any good and you will finish up even though you have gotten better before. If you are sick and you do not go to hospital, the health teams will help you at home.
If you decided not to go to the hospital again, you can change your mind at any time. If you stay in community the health clinic will help with some medicines, but sometimes your body is too weak and medicines won’t make you get better.

The respiratory team will be able to do some tests, so they know which medicines might be able to help with your sickness, such as:

- Blood test.
- Oxygen level.
- Breathing test.
- Blood pressure.
- Walk test.
Important decisions

You need to talk about all of these things with:
• Your family.
• Your health clinic.
• The respiratory team.
• The palliative care team.

Talking with these people will help you and your family make the right decisions to manage your sick lung journey.
Important decisions

When you and your family have made a plan about how to manage your lung disease the respiratory or the health clinic can write your story on a form.

This is called an “Advanced Care Directive” or a “Statement of Choices”. The Advanced Care Directive tells the doctors and your family what you want, when you are really sick and can not speak to tell your story.
Things to think about

Who are the important people in your family and community that need to know if you want to have more treatment like:

- Going to hospital.
- Going to Coronary Care Unit.
- Or if you want to stay at home and finish up?

Talk with your family:

- Do they understand your story?
- Do they know where you want to finish up?
- Does your family really understand the story on your Advance Care Directive or Statement of Choices?
- If you have decided to stay at home, is your family happy to look after you when it comes time to finish up?
Things to think about

You may want to think about somewhere outside your home, like your favourite place so that your family don’t have to move out after you pass away.

You and your family could find a place for you to pass away where family can be with you to keep you company, sing and tell stories.
Things to think about

Things you may need to do;

• Do you need to fix up your bank account?
• Do you need to make a will?
• Do you have anything that you want to buy?
• Do you have any superannuation?
• Do you have funeral and ceremony money?

You might want to get a letter from the health clinic to give to Centrelink. This explains to them what is happening to you.

You should decide who is your carer and let Centrelink know, the clinic can help you with this.
I don’t feel sick

Even though you find it hard to breathe and sometimes it’s hard to walk very far you still may feel OK.

You should still go to the health and respiratory clinics, they will help you stay strong for as long as possible.

You have lung disease but you feel ok and you don’t want to leave your community.
I don’t feel sick

You should;

• Still have blood tests if you need them.
• Still have antibiotics when you need them.
• Take your medicine daily and eat good food. This will help you be more active and stay stronger for longer.
• Keep being active when you can and do the things that make you feel happy and strong.
• Talk about getting a breathlessness plan and medications to help you when you get really breathless (This is your choice).
• Ask for a fan, it may make your short wind feel better.
I don’t feel so good anymore

It may get harder to breath and you might not be able to walk very far, even to the bathroom.

The clinic will help you and your family manage your sickness.

When your lungs get really sick they will stop working and you will finish up.
I don’t feel so good anymore

You will have feelings of sickness called “symptoms”, because your lungs are not working like they used to. You could have problems such as;

- Very short wind.
- Cough.
- Pain.
- Scared and worried.
- Hard to sleep and have to sleep sitting up.
- Confusion.
- Feeling too tired to eat.
I don’t feel so good anymore

As you get worse, you may feel;

• Very breathless.
• Tired and weak.
• Very sleepy.
• Sadness and worry.
• Cannot walk.
• Cannot leave the house.
• Need help getting up and getting dressed.
I don’t feel so good anymore

The health clinic, respiratory and palliative care teams will look at things that everyone can do to help you and your family. They do this by holding a meeting either in person, over the phone or via TeleHealth so everyone hears the right story.

The Doctor or nurse will give you a breathlessness plan to help you and your family when you get very short wind. This can help you feel better.
I don’t feel so good anymore

The health clinic and palliative care teams may be able to help you with some equipment such as wheelchairs, mattresses, shower chairs and fans. This can help you and your family to keep comfortable at home. Health clinic staff can visit you at home and bring medicines that you may need.
I don’t feel so good anymore

Things that may help you feel strong when you are unwell;

• Family visit.
• Visiting country.
• Pastor and church groups.
• Telling stories.
• Passing on important information.
• Bush medicine and bush tucker.
Medicines

You might want to use traditional medicine and healers as well as the clinic medicines.

Talk to your doctor or clinic about what you can use.
These are examples of some other medicines used in palliative care. Some medicines have different names but do the same thing. Your health care team will explain these to you;

- Morphine syrup can be used for pain and/or short wind.
- MS Contin tablets are a long acting morphine tablet that can help short wind. These only need to be taken once or twice a day.
- Alprazolam is a tablet that goes under the tongue and can help you feel relaxed when you have short wind.
- You may have to have other tablets if you feel sick or if you can’t go to the toilet.
Medicines

A needle is used for some medicines, like Morphine or Fentanyl. This is a strong medicine for very bad pain or breathlessness. You can have a needle if you are having trouble swallowing, you can use these instead of tablets.

One medicine is given through a sticky patch that goes on your skin, and helps take the pain away.

It takes about half a day for it to work and you will keep it on for 3 days. After 3 days the clinic staff will change it for another one.
Oxygen is a medicine, some people may need oxygen and some people won’t.

When they have short wind, the doctors will make this decision. If you have oxygen at home, you need to take special care;

• Do not let anyone smoke in your house and stay away from fire.
• The oxygen concentrator needs a power supply all the time, if you need power cords make sure that you have enough.
You may be unsure about these medicines, some people say that they will make me pass away quicker.

THIS IS NOT TRUE.

The lung sickness is what will make you finish up, not the medicines. The medicines are to help you if you are having trouble breathing and have pain. They will help make your breathing easier and take the pain away, so that you feel more comfortable.
When someone is passing away they might be very sleepy and make some loud breathing noises due to the illness and medicines. If this worries you or your family, the clinic staff can help. Remember to keep your medicines away from children.
Nearly ready to finish up

If you are finishing up at home the health clinic staff can visit you at home or at your special place and see how you are. They will talk with family to let them know what is happening. They can check if you have any worries or questions.

It’s a good idea to have a family meeting to make sure everyone hears the right story.
Nearly ready to finish up

As you get closer to passing away the symptoms may get worse and you might need more help from your family.

You may have short wind because of your sick lungs, which make it harder to breathe.

The health clinic can give you some medicine to help with this.
Nearly ready to finish up

If you don’t want to finish up at home you can go to the hospital or hospice. The health care team will help take care of you, and your family can be with you.
Nearly ready to finish up

If you are at the hospital and want to pass away at home the health team may be able to help you to go home and finish up with your family. Sometimes if you are in hospital and you are too sick you might not be able to make it home to finish up.

This is why it is very important that your family understand your sickness and what will happen when you get very sick.

You might be too sick for transport by plane or car back home to community, the doctors and palliative care team will tell you and your family if this happens.
Just before I finish up

It is OK to pass away at your home and community.
Just before I finish up

Some people become very sleepy and pass away in their sleep, some people die very quickly or suddenly. They don’t feel like eating or drinking anymore, this is normal. Most people have noisy breathing, but they are still comfortable. Some people may have noisy breathing and there is medicine that may help this. Some people may make noises and move around a bit, this is called restlessness. This is normal but if you are unsure talk to the clinic.
Carers need support too

Sometimes looking after someone who is passing away is the job of one person. They might feel;

• Tired.
• Responsible.
• Unappreciated.
• Afraid of payback.

It is important for the carer to look after themselves and also to be supported by other family members and the community,
Carers need support too

If you are a carer these are some things you might want to think about;

• Tell your work that someone in your family is going to pass away and you will be helping to look after them.
• Talk to Centrelink about carers allowance and pensioner entitlements.
• Talk to your family and ask them to help while you care for your relative.
• Ask your clinic if there are any respite services in your community that may be able to help you if you are too tired or need a break.
Words to understand

• Palliative care
• Respiratory disease
• Respiratory team
• Interpreter
• Health care team
• Comfortable
• Blood pressure
• Hospice
• Noisy breathing
• Advanced care directive
• Respite
• Pass away
• Lung disease
• Interpreter
• Palliative care team
• Hospital
• Urine sample
• Blood test
• Patch
• Symptoms
• Equipment
• Sick lungs

If you have anymore questions, ask your health care provider.
Aboriginal Palliative Care Model

This model was developed and designed by Beverley Derschow to illustrate a holistic approach to the palliative care system. The model was supported by artwork from Indigenous from the Northern Territory. Available as a poster from www.healthinfonet.ecu.edu.au