

Living with interstitial lung disease

An information booklet for patients, carers and families



Written by the respiratory multidisciplinary team
at St Vincent's University Hospital

Name:

Date:

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If you feel unwell right now

Turn to page 38 for the signs of a flare-up, what to do, and when to get urgent help. There is a plan to fill in on page 41.

If you have sudden or severe breathlessness, chest pain, or blue lips or fingertips, call 999 or 112 free of charge from any mobile or landline, or go straight to your nearest Emergency Department.



Welcome

Being told you have interstitial lung disease (ILD) can bring uncertainty, a lot of questions, and often fear.

You may already be finding yourself short of breath, more tired than you used to be, or unable to do things you have always done without thinking. You may be worried about what happens next.

You are not on your own with this.

This booklet has been written for you by the whole respiratory team who look after you. It explains what ILD is, who each of us is and what we do, and, most of all, the practical things that help most. Some of what is here has come from what our patients have told us helps them.

You do not need to read it from cover to cover. Take the parts you need, when you need them. And if anything in it raises a question, please ask us. There is no such thing as a silly question, and we would far rather you asked.

What I most want to know

About this booklet and our programme

This booklet accompanies our new interstitial lung disease education and support programme: a six-week pilot for outpatients.

The programme is for patients who are newly diagnosed, or in the early to middle stages of their illness. Its aim is to give you information, education and practical support early.

It is a lasting resource you can keep and return to throughout your illness. As well as the illness itself, it covers:

- Hospital supports available to you
- Community and support services
- Welfare entitlements
- Information from partner organisations, including ILFA

My programme sessions

Session 1:

Session 2:

Session 3:

Session 4:

Session 5:

Session 6:

Time:

Where:

About interstitial lung disease

What is interstitial lung disease?

Interstitial lung disease, or ILD for short, is not one illness but a whole group of conditions, all of which affect the lungs in a similar way. They cause inflammation, and often scarring, of the lung tissue. Doctors call that scarring fibrosis, which is a word you will hear a lot.

Deep in your lungs are millions of tiny air sacs, and it is here that oxygen crosses from the air you breathe into your blood. The thin tissue around those sacs is called the interstitium. In ILD this tissue becomes inflamed and scarred, which makes your lungs stiffer and less stretchy, a bit like the difference between a new balloon and one that has gone hard.

This is why the main symptoms are breathlessness, particularly when you are active, and a persistent dry cough. Many people are also very tired, find their stamina is not what it was, and some notice discomfort in the chest.

Questions for my team

About interstitial lung disease

Good to know

- There are many different types of ILD. Common ones include idiopathic pulmonary fibrosis (IPF), hypersensitivity pneumonitis, sarcoidosis, and ILD linked to autoimmune conditions.
- Sometimes a cause is found, such as an autoimmune condition, a medication, or something breathed in over many years. Often no cause is ever identified, and that can be one of the hardest parts.
- How ILD progresses varies enormously from one person to the next. Please try not to measure yourself against anyone else, and be careful about statistics you find online. We will talk you through what your own type means for you.

Questions for my team

About interstitial lung disease

Tests you might have

To confirm the diagnosis and try to find the cause, we will do some tests. We will also ask you a lot of questions: about your medicines, your past health, anything you may have breathed in over the years, and any other symptoms you have noticed. Some of the questions may seem unconnected to your chest, but they all help us build the picture.

Tests most people have

- Blood tests: to look for causes such as autoimmune conditions.
- Chest X-ray: a simple picture of your lungs.
- CT scan of the chest: a detailed scan showing the pattern of changes in your lungs. This is the key test in diagnosing ILD.
- Breathing tests, also called pulmonary function tests: these measure how well your lungs are working.
- An ECG: a simple recording of your heart's electrical activity.

Tests some people need

- Echocardiogram: an ultrasound scan showing how well your heart is pumping.
- Bronchoscopy: we pass a thin tube into your airways to look inside your lungs and take a small sample. You are given something to keep you comfortable, and we explain exactly what happens beforehand.
- Lung biopsy: we take a small sample of lung tissue and look at it under a microscope. Most people never need this. We only do it if the other tests have not shown us the cause.

Once your results are back, we bring them to the ILD team meeting. All the specialists looking after you sit down together, talk through your case, and agree the best plan with you. You are never being looked after by just one person on their own.

About interstitial lung disease

Treatments you may hear about

What we do depends on the type of ILD you have and how it is affecting you. Not everybody needs every treatment. Some people are watched carefully rather than treated straight away, and that is a considered decision, not a case of doing nothing.

- Medicines to slow scarring, called antifibrotics, such as nintedanib or pirfenidone. These suit particular types of ILD, so they are not right for everyone, and we will decide whether they are suitable for you.
- Steroids, or other medicines that calm down the immune system (immunosuppressants), to reduce inflammation.
- Oxygen, if the level of oxygen in your blood is low (see Section 5).
- Pulmonary rehabilitation: a programme of supervised exercise and education, run by physiotherapists, that is proven to help. Ask us whether it can be arranged for you (see Section 4).
- Vaccinations, to protect you from infections that could cause a flare-up.
- In some cases, lung transplant. We will raise this with you if it may be an option for you.

A word about lung transplant

- Around a third of lung transplants worldwide are for people with ILD. It is a real option, not a remote one.
- It is not right for everyone, and the assessment is careful. Being referred does not mean you will have one.
- If it might suit you, your ANP or consultant will raise it. You can also ask them yourself at any time.



Staff you may meet

During your care you will meet a team of health and social care staff. You are at the centre, and each person has their own skills to help you and your family. We all work together and share what we know about your care.



Staff you may meet

These are the main people in the team looking after you.



Doctors

Your respiratory consultant is a specialist in lung disease and leads your medical care. They diagnose your ILD, plan your treatment, and review you at clinic. You will also meet other doctors on the team.



Respiratory ANP-ILD

The Respiratory Advanced Nurse Practitioner (ANP) in ILD is often your main contact. They check how you are, arrange tests, prescribe medicines and oxygen, and organise your care, including reviews by phone or video. They can also refer you to other specialists and services.



Physiotherapists

Physiotherapists help you manage breathlessness, stay active and keep your strength. They teach breathing and cough control techniques, and show you how to use oxygen with confidence during everyday tasks such as showering, shopping and gardening. They can also talk to you about pulmonary rehabilitation.



Dietitians

Dietitians give practical advice on eating well with ILD. They can help you hold on to your weight and muscle, manage a poor appetite or breathlessness at mealtimes, advise on supplements, and help with reflux or side effects that affect eating.



Occupational therapists

Occupational therapists help you manage fatigue, save your energy, and stay independent in daily activities such as washing, dressing and cooking. They can advise on pacing, planning your day, and equipment or adaptations for the home.



Speech and language therapists

Speech and language therapists help with cough, swallowing problems, and any difficulty with your voice or speech. They can show you ways to make eating and drinking safer and more comfortable.



Medical social workers

Medical social workers offer a private space to talk about how your diagnosis affects you, and practical help with benefits, medical cards, housing, leaving hospital and planning ahead. They can link you with community services and support groups.



Others who may be involved

Your GP, your community pharmacist, the Public Health Nurse and the palliative care team may also be part of your care. You will find more about them later in this booklet.

Names of my team



Tips for living well with ILD

Living well with ILD is about more than treatment. These are the things we would most like you to know, and Section 4 has more detail on each symptom.

Keep active

- When you are breathless it is tempting to do less. But the less you do, the less you are able to do.
- Building up gently makes you stronger and everyday tasks easier.
- Ask about pulmonary rehabilitation. It is proven to help.

Eat well

- Your body works harder to breathe, so it uses more energy.
- Eat little and often. Smaller meals are easier when you are breathless.
- Protect your muscle: include a protein food at every meal.

Pace yourself

- Plan your day and spread activities out.
- Break big tasks into smaller parts, and rest before you are exhausted.
- Prioritise what matters most to you.

Stay well

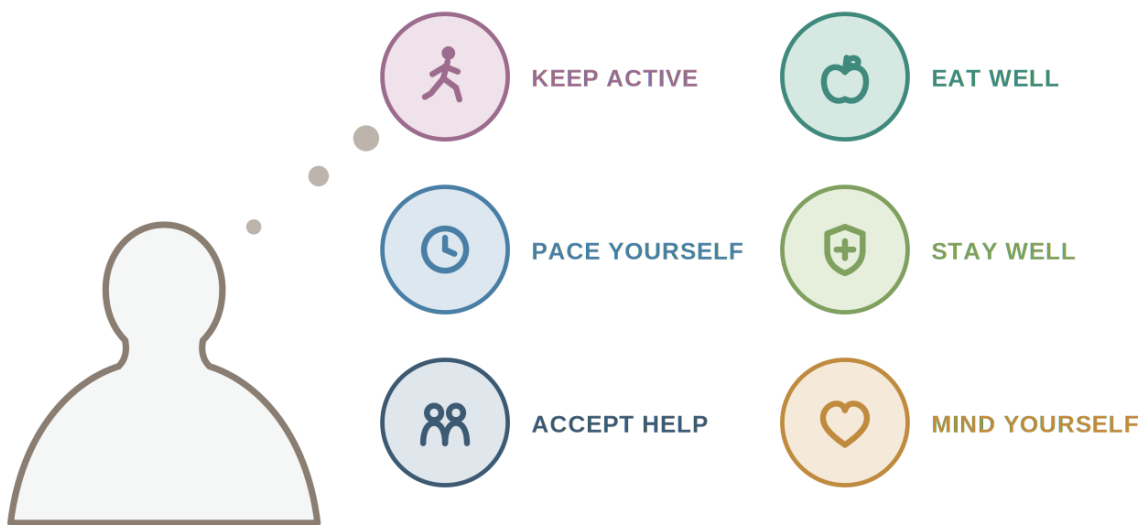
- Keep your flu, COVID-19 and pneumonia vaccines up to date.
- Take your medicines as prescribed. Never stop them without asking us first.
- Know your normal, so you spot changes early.
- If you smoke, we can help you stop (see page 31).

Accept help

- Family and friends usually want to help, but often do not know how. Tell them.
- Practical help with shopping, cooking or lifting saves your energy for what you enjoy.
- Ask us about supports available to you.

Mind yourself

- Shock, fear, anger and low mood are all normal reactions.
- You do not have to cope alone. Talk to someone you trust.
- If you feel low most of the time, tell us. Support is available.



My goals for the programme



Managing your symptoms

This section covers the symptoms you are most likely to meet with ILD, what helps, and which of us to ask. You may not get all of them. Tell us about anything that worries you, however small.

It is grouped by the part of your life it affects, because these things are connected. Poor sleep makes fatigue worse, and reflux can make a cough far worse. If you are not sure where to start, start with breathlessness. Many people find it the hardest to live with.

Quick find, A to Z

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Breathlessness

Breathlessness is the symptom most people with ILD notice first, and the one that affects daily life the most. It usually creeps up gradually. You might first spot it walking uphill, climbing stairs, or hurrying for a bus, and over time it can come on with less effort. It is frightening, and being frightened makes it worse, which is a horrible loop. The good part is that loop can be broken, and there is a lot we can do to help.

You will find the things that help below.

What can help

- Breathing control techniques and exercises (page 16). Your physiotherapist will teach you these.
- Positions that ease breathing, such as leaning forward with your arms supported on a table or on your knees (page 17).
- A small hand-held fan held close to your face. It sounds too simple to work, but it does help, and it costs almost nothing.
- Relaxation techniques. Tension and panic make breathlessness worse.
- Pacing yourself, so you do not run out of breath in the middle of a task (page 18).
- Pulmonary rehabilitation, a supervised exercise and education programme that is proven to reduce breathlessness. Ask us whether it can be arranged for you.
- Oxygen, if your blood oxygen level is low. We will assess whether you need it (see Section 5).

Who can help: physiotherapy, respiratory ANP-ILD, medical team



Managing breathlessness without medicines

You can do a lot about breathlessness yourself, with no medicine at all. These techniques cost little or nothing, and they work best if you practice them while you are calm, rather than reaching for them for the first time when you are struggling.

Your physiotherapist will go through them with you and work out which ones suit you. Do not worry about getting them exactly right. Even part of a technique helps.

Breathing techniques

- Breathing control. Sit comfortably, drop your shoulders, and breathe gently in through your nose and out through your mouth, using as little effort as you can. Let your tummy rise as you breathe in.
- Pursed-lip breathing. Breathe in through your nose, then breathe out slowly through pursed lips, as though you were blowing out a candle. Take about twice as long to breathe out as you do to breathe in.
- Recover properly. When you are short of breath, stop, get into a position that eases breathing, and use your breathing control until it settles. It will settle.
- Relaxation. Tension tightens your chest and makes breathing harder. Dropping your shoulders, unclenching your jaw and slowing your breathing out all help to break that cycle.

Positions and some everyday tactics are on the next page.

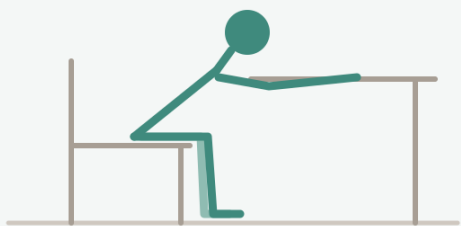


Positions that ease breathing

How you hold yourself makes a real difference when your breathing is hard work. These positions take the weight off your chest and give your breathing muscles a better angle to work from. Try them while you are well, so they are familiar when you need them.

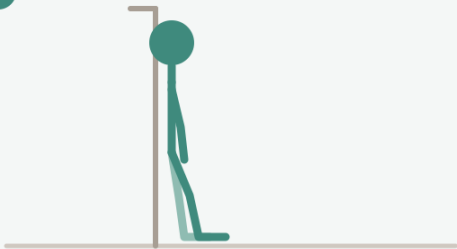
Questions for my team

1



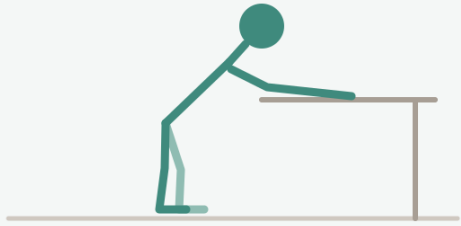
Sitting, leaning on a table

2



Standing, back against a wall

3



Standing, leaning on a surface

Whichever you use

Drop your shoulders, unclench your jaw, and let your breath out slowly. Do not rush it.



Everyday tactics

Small habits like these make a big difference, and most cost nothing.

What can help

- A hand-held fan. Hold it about 15cm away and aim the air across your nose and mouth, not at your chest. That is the part that does the work. An open window does the same job.
- Blow as you go. Breathe out on the effort: as you stand up, lift something, or climb a step. Never hold your breath while you are making an effort.
- Pace your breathing with your steps. On stairs, try breathing in on one step and out on the next two, and find the rhythm that suits you.
- A rollator, or wheeled walker. Leaning on the handles takes some of the work off your chest, and it helps some people walk further. Ask your physiotherapist whether one would suit you.

If your breathlessness is sudden or severe, turn to Section 6.

Who can help: physiotherapy, occupational therapy, respiratory ANP-ILD

Questions for my team



Cough

A dry, hacking cough is very common in ILD. Many people with ILD find it one of the hardest symptoms to live with: it is exhausting, it disturbs sleep, and it can be embarrassing in company. Please do not feel you have to put up with it.

Reflux can make a cough worse, and so can post-nasal drip (mucus running down the back of the throat). Treating often helps the cough.

What can help

- Respiratory physiotherapists are trained in cough control techniques.
- Breathing control and relaxation techniques can reduce the urge to cough.
- Sipping water or sucking a sweet can help break a cough cycle.
- Treating reflux, or a post-nasal drip, often improves the cough (see reflux and heartburn).
- Airway clearance techniques, if you are producing phlegm.
- Tell us. There are techniques, and sometimes medicines, that help. You do not have to put up with it.

Who can help: physiotherapy, respiratory ANP-ILD, medical team, speech and language therapy

Questions for my team



Fatigue

Fatigue is a tiredness or exhaustion that is not explained by activity and is not relieved by rest. It is very common in ILD, and different from ordinary tiredness.

It can affect everything: washing and dressing, concentration, mood, and the things you enjoy. It can vary a lot from day to day.

What can help

- Plan your day and your week in advance. Spread demanding activities out rather than doing them all at once.
- Pace yourself. Take your breaks before you are exhausted, not after. Pushing on until you are wiped out only means a longer recovery.
- Prioritise. Work out what matters most to you, and let the rest go, or hand it to somebody else.
- Think about position. Sitting down to do a job, rather than standing, saves a surprising amount of energy.
- Keep gently active. Resting completely makes fatigue worse, not better.
- Protect your sleep and eat enough to fuel your body. There is more on both elsewhere in this section.

Who can help: occupational therapy, physiotherapy

Questions for my team



Sleep

Breathlessness, coughing, reflux and worry can all disturb your sleep. Poor sleep then makes fatigue, mood and breathlessness worse, so please do not ignore it.

What can help

- Keep a regular routine. Go to bed and get up at around the same time each day.
- Use your bedroom for sleep, and keep it dark, quiet and comfortable.
- Wind down before bed. Avoid screens for the last half hour.
- Limit caffeine to earlier in the day and avoid heavy meals late in the evening.
- Raising the head of the bed or using additional pillows for support can help both reflux and breathlessness at night.
- A sleep hygiene factsheet is available with more guidance; ask the respiratory ANP-ILD or another team member for a copy. If cough or breathlessness is keeping you awake, tell us. Do not just put up with it.

Who can help: occupational therapy, medical team, physiotherapy

Questions for my team



Staying active and keeping your strength

Breathlessness can make you want to avoid activity, and it is easy to slip into doing less. Over time this weakens your muscles, so everyday tasks take more effort and leave you more breathless. This is sometimes called the cycle of inactivity, and it can be reversed.

Muscle strength matters more than most people realise. It affects your balance, how steady you feel on your feet, and how tired ordinary jobs leave you.

What can help

- Pulmonary rehabilitation is very useful for people with ILD. Led by physiotherapists, it combines exercise and education for people with lung disease. It can help you walk further, feel less breathless and improve your quality of life. Ask us about a referral.
- Stay active and eat well.
- Eating enough protein helps maintain your muscles, while regular activity helps keep them strong. A dietitian can advise you on eating well. See the section on appetite and weight loss for more information.
- Your physiotherapist can also help you exercise safely at home and can assess what training would suit you.
- You may need oxygen to exercise safely. If you do, your doctor, nurse and physiotherapist will sort it out between them.
- Registering with the Irish Lung Fibrosis Association (ILFA) also gives you access to their online exercise classes, pulmonary rehabilitation and yoga sessions.

Who can help: physiotherapy, dietetics, medical team?



Appetite and weight loss

When you have a lung condition, your body works harder just to breathe, so it uses more energy than usual. At the same time, breathlessness, tiredness, a dry mouth, reflux or medication side effects can all make it harder to eat enough.

The result is that some people lose weight and muscle without meaning to, and often without noticing until it has happened. Holding on to your weight and your muscle helps you stay active and feel stronger.

- Keep an eye on more than the scales. Rings, a watch, a belt or clothes feeling looser can be the first sign you are losing weight. Tell us early if you notice it.

Ask any of us to refer you to the dietitian if you are losing weight or struggling to eat. The booklet *Making the Most of Every Bite*, available from the ILD team, has more ideas.

Easy ways to add energy and protein



Milk powder

Stir into milk, porridge, soups or sauces



Cheese

Grate onto potatoes, pasta, soup or beans



Butter or oil

Add to vegetables, potatoes and bread



Cream

Add to porridge, soups and desserts



Eggs

Mix into mash, or have as an easy snack



Milky drinks

Hot chocolate, milky coffee or smoothies

Appetite and weight loss (continued)

What can help

Getting more from what you eat

- Eat little and often: five or six small meals or snacks, rather than three large ones.
- Fortify your food to add energy and protein without eating more (see the ideas on page 23).
- Have a protein food at every meal, such as meat, fish, eggs, beans, lentils or dairy.
- Choose nourishing drinks like full fat milk, smoothies or hot chocolate, rather than filling up on tea, water or fizzy drinks.
- Keep easy snacks to hand: cheese and crackers, full-fat yoghurt, or nuts if swallowing is not a problem.

When breathlessness gets in the way

- Rest before meals, sit upright, and eat when your breathing has settled.
- Put your cutlery down between mouthfuls, and take your time.
- Choose softer, moist foods, such as mince, mashed potato, casseroles and milk puddings, with plenty of sauce or gravy.

If food alone is not enough, your dietitian may suggest supplement drinks containing additional protein and calories for a period of time, alongside your usual food.

Who can help: dietetics



Reflux and heartburn

Acid reflux is common in ILD. As well as being uncomfortable, it can make your cough considerably worse. It can usually be treated, which is why it is well worth mentioning.

What can help

- Eat smaller meals more often, rather than large meals.
- Avoid eating within about 3 hours of going to bed.
- Stay sitting upright for a while after eating rather than lying down.
- Raising the head of your bed or using additional pillows under your head can help night-time symptoms.
- Limit triggers such as very fatty or spicy foods, if you notice they affect you.
- Tell us. Medicines that reduce acid are often very effective.

Who can help: medical team, dietetics

Questions for my team



Safe swallowing

Every time you swallow, you briefly hold your breath. That is what keeps food and drink out of your lungs. If swallowing becomes difficult, which doctors call dysphagia, food or drink can go the wrong way, into your lungs rather than your stomach. This is called aspiration, and if it keeps happening it can lead to chest infections or a type of pneumonia.

When breathing is already hard work, it can be tricky to coordinate breathing and swallowing at the same time. Tell us if eating and drinking have become harder. There is a lot we can do to make it safer and more comfortable.

Signs your swallow may need looking at

- Coughing or throat-clearing while you eat or drink.
- Watery eyes, or feeling more short of breath, after eating or drinking.
- A feeling of food sticking in your throat, or difficulty chewing.
- Meals taking a long time to finish.
- Repeated chest infections or losing weight without a clear reason.

Questions for my team

Safe swallowing (continued)

What can help

- Sit up straight to eat and drink and stay upright for about 30 minutes afterwards.
- Take your time. Eat slowly and take one sip at a time.
- Try not to talk while eating or drinking, as it adds to the work of breathing.
- Make sure you are fully awake and alert before you eat or drink.
- Rest before meals to settle your breathing and avoid eating at times when you need all your energy just to breathe.
- Look after your mouth: brush your teeth regularly, and make sure your mouth feels moist before eating, as oxygen can dry it out.
- If tablets are hard to swallow, try taking them with yoghurt, or ask your pharmacist about other ways to take them.
- If your speech and language therapist has given you advice on softer foods or thickened drinks, please follow it.

Who can help: speech and language therapy, dietetics, medical team

My safe swallow recommendations



Medicines and side effects

Medicines used to treat ILD can cause side effects, but there are often ways to manage them. Do not stop any of your medicines without talking to us first.

What can help

If you take nintedanib or pirfenidone

- Antifibrotic medicines (nintedanib, pirfenidone) may cause nausea, a poor appetite, diarrhoea and sensitivity to sunlight. Taking them with or after food often helps.
- If antifibrotics make you feel sick, eating small amounts often, sipping cold drinks and getting some fresh air can all help.
- For diarrhoea, take your medicine with food and drink plenty of fluids. If it keeps happening, tell us rather than stopping the medicine yourself. There are treatments that help.
- If you are on pirfenidone, protect your skin from sunlight by using high-factor sunscreen and covering exposed skin.

Dry mouth and taste changes

- Oxygen and inhalers can cause dry mouth or alter taste. Regular sips of water, sugar-free sweets, ice lollies and rinsing your mouth after using inhalers may help. Stronger flavours and sauces can also improve the taste of food.

Medicines and side effects (continued)

If you take steroids

- Steroids may increase appetite and weight, affect sleep and mood, and raise blood glucose levels. We will keep an eye on these.
- Long-term steroid use can also weaken bones, so ask us about calcium and vitamin D supplementation and whether a bone-density (DEXA) scan is appropriate.

Getting the most from your medicines

- Your pharmacist or team can explain how and when to take your medicines to get the most benefit and the fewest side effects.
- Your dietitian can help if side effects are affecting your appetite.
- Bring an up-to-date list of all your medicines to each appointment, so we can review your treatment safely.

Who can help: medical team, dietetics, your local pharmacist

Questions for my team



Avoiding infections

A chest infection can cause your symptoms to worsen quickly and is one of the most common triggers of a flare-up. Preventing infection is an important part of managing ILD.

What can help

- Keep your vaccinations up to date: annual flu vaccine, COVID-19 vaccine, and the pneumococcal (pneumonia) vaccine. Your GP can advise.
- Where you can, avoid close contact with anyone who has a cold, flu or chest infection.
- Wash your hands regularly, especially before eating and after you have been out.
- Wearing a face mask in crowded places can reduce your risk, especially if you are on an immunosuppressant medicine.
- Get to know what is normal for you: your usual breathlessness, your usual cough, and any phlegm you normally produce. That is how you will spot a change early.
- Act early if something changes. Section 6 sets out the signs of a flare-up and what to do.

Who can help: medical team, respiratory ANP-ILD, GP

Questions for my team



Stopping smoking

Most people with ILD have never smoked, and smoking does not cause most types of ILD. If you have never smoked, this page is not about you, although it may be useful to someone close to you.

If you do smoke, stopping is the best thing you can do for your lungs. It lowers your risk of chest infections, helps protect the lung function you have, and matters if you are ever considered for a transplant. It also removes a serious fire risk if you use oxygen.

We are not here to lecture you. Most people who smoke have tried to stop before, often more than once. Nobody here counts that against you, and every attempt makes the next one more likely to work.

What can help

- Ask any of us for a referral to the hospital's stop smoking service. You are far more likely to succeed with support than on your own.
- The HSE QUIT service gives free advice, a quit plan and follow-up, by phone, by text or online. Freephone 1800 201 203.
- Nicotine replacement, and some prescription medicines, make stopping much easier. Your pharmacist, GP or team will check they are safe alongside your other medicines.
- Pick a date, tell the people around you, and plan for the situations you most associate with smoking.
- If you use oxygen, never smoke while wearing it, and never smoke near it. Tell us if anyone in your household smokes.
- If you slip, tell us rather than abandoning the attempt. Most people who stop for good do it on a later try.

Who can help: stop smoking service, respiratory ANP-ILD, your local pharmacist, GP



Emotional wellbeing

Coming to terms with a long-term lung condition is hard, and everyone copes differently. It can feel especially difficult if the cause of your ILD is not known.

You may feel shock, as though it is not quite real. You may find yourself pushing it away, which is your mind protecting you in the early days. Anger is common, and it often lands on the people closest to you. So is fear about what happens next. Feeling low at times is natural.

What can help

- Talk to someone you trust. Bottling it up rarely helps anyone.
- Let your family know how you are feeling and what you need. They usually want to help but have no idea how.
- Talking to someone else living with the same condition can help in a way nothing else does. The Irish Lung Fibrosis Association (ILFA) can put you in touch (see Section 8).
- Ask us for a referral to medical social work or psychology. This is a normal part of care, not a sign you are not coping. ILFA also offers a grant towards seeing a clinical psychologist.
- If you feel low most of the time, or you have lost interest in things you used to enjoy, please tell us. There is help, and it works.

Who can help: medical social work, psychology, respiratory ANP-ILD



Using oxygen safely

This section is for people who use oxygen. If you do not, you can skip ahead to flare-ups on page 38, which everyone should read.

If we have prescribed oxygen for you, treat it as a medicine, because that is exactly what it is. We set the flow rate for you personally, after assessing you, and we prescribe it because the oxygen level in your blood is low, not simply because you feel breathless.

Our team and your oxygen supplier will show you how to use your equipment. Your physiotherapist can help you feel confident using it during everyday tasks such as showering, shopping and gardening.

Do

- Use your oxygen exactly as it has been prescribed. Only adjust the flow rate yourself if you have been advised to use the STALL technique and have had it explained to you. Otherwise, do not turn it up: more is not better, and too much oxygen can make you unwell.
- Switch your oxygen off when you are not using it, even for short periods.
- Keep cylinders upright and secure so they cannot be knocked over.
- Use your oxygen in a well-ventilated room.
- Keep your mask and tubing clean, and check the tubing regularly for damage. Keep it tidy, so nobody trips on it.
- Report any worsening breathlessness, drop in your activity level, or need for a higher oxygen flow rate to the ILD team promptly. Attend your oxygen review appointments.

Do not

- Do not smoke, and do not let anyone else smoke near your oxygen. This includes e-cigarettes and vapes.
- Do not use oxygen near naked flames, candles, oil burners, gas hobs or open fires, and do not cook while wearing it.
- Do not use oil- or paraffin-based creams on your face or hands while using oxygen. Use a water-based alternative instead. A saline nasal spray can help if your nose feels dry.
- Do not let anyone else use your oxygen. It is prescribed for you, and for you only.
- Do not store oxygen in a warm place, or run tubing close to a heat source. Do not wear your oxygen while using a hair dryer.

Oxygen makes fires burn far more fiercely. Naked flames and heat sources near oxygen risk severe burns or an explosion.

Help with electricity costs: if you use an oxygen concentrator, ILFA suggests asking your local health centre whether they can help with the extra electricity it uses. ILFA also advocates for wider financial relief for people who rely on home oxygen. This is separate from the national Household Benefits Package.

Be prepared: if you have prescribed backup oxygen, keep it where you and your carer can reach it, and make sure you both know how to use it. Ask your supplier how to reorder tubing and other supplies, and how far ahead to order.

When breathlessness takes hold, it is easy to panic, and panic makes it worse. STALL is a simple way to remember what to do. Work through the five steps in order until your breathing settles.

The STALL method for breathlessness



Stop

Stop what you are doing.



Try

Try to stay calm, and turn up your oxygen.



Assume

Assume a comfortable position.



Let

Let your mind go somewhere calm and relaxing.



Let

Let your breathing return to normal.

Using oxygen safely

Signs you may be getting too much oxygen

You cannot always tell whether your oxygen level is right, and it does not always match how breathless you feel. That is exactly why your flow rate is set for you after an assessment.

Contact your respiratory team straight away if, while using oxygen, you:

- Feel drowsy, sleepy or muddled.
- Develop headaches, particularly in the morning.
- Become confused.

Practical points

- Tell your home insurance provider that you have oxygen at home. It should not cost you any more.
- Let us know if anyone in your household smokes, so we can advise you properly.
- Keep your oxygen supplier's helpline number somewhere you will find it in a hurry.
- Ask your electricity supplier to register you as a vulnerable customer. You will then get priority in a power cut and notice of planned ones. ESB Networks power cut line: 1800 372 999.
- Plan for a power cut. Know how long your back-up cylinder lasts, keep it where you can reach it in the dark, and keep your supplier's number beside it.
- Let your local fire station know that oxygen is used in the house. They would far rather know in advance.
- Never try to repair the equipment yourself. If it alarms or stops working, ring your supplier. The helpline is there day and night.

Travelling and flying

A lot of people assume a lung condition means the end of holidays and travel. For most people it does not, but it does need a bit of planning, so talk to us early rather than the week before you go.

- Air in a plane cabin holds less oxygen than the air on the ground, so you may need oxygen in flight even if you do not use it at home.
- You may need a fitness-to-fly assessment. Ask us well in advance, as this takes time to organise.
- Airlines have their own rules about oxygen, and most need several weeks' notice. Contact them early.
- Take enough medication for the whole trip and some extra, carry it in your hand luggage, and bring a letter from us listing your condition and medicines.
- Get travel insurance that covers your lung condition. Declare it. Cheap cover that excludes it is worse than no cover at all.

Who can help: the respiratory ANP-ILD, who can arrange or carry out a fitness-to-fly assessment if you may need oxygen while travelling.

Questions for my team



Flare-ups: when to seek help

Sometimes your symptoms can worsen quite quickly. This is called a flare-up, or an exacerbation. It may be triggered by a chest infection, or it may be a flare of the inflammation in your lungs.

Symptoms rarely settle if they are ignored, so please act early. Read this page with your family or carer, so they know what to watch for as well.

Signs of a flare-up

- You are more breathless than usual, or breathless doing things you normally manage.
- You are coughing more often than usual.
- You are producing more phlegm, or it has become thicker or stickier.
- Your phlegm has changed colour, for example from clear to yellow or green.
- You have a fever, or feel generally unwell.
- You notice new swelling in your ankles or legs, or a sudden increase in your weight.

What to do

- Contact your GP or respiratory team for advice. Do not sit at home hoping it will settle on its own.
- Keep taking your medicines as prescribed.
- Drink plenty of fluids.
- If you can, give a phlegm sample to your GP. If you cannot get it in the same day, keep it in the fridge overnight.
- Not every chest infection needs antibiotics, but if you are unsure, get reviewed.

Seek urgent help if you have:

- Sudden or severe breathlessness.
- Chest pain.
- Blue lips or fingertips.
- Confusion, or you become very drowsy.

In an emergency, call 999 or 112, or go to your nearest Emergency Department.

Your flare-up traffic light

Your normal



- Your usual breathlessness, cough and phlegm.
- Keep taking your medicines as prescribed.
- Stay as active as you can.

Keep going with your usual routine.

Signs of a flare-up



- More breathless than usual.
- Coughing more often.
- More phlegm, thicker, or a new colour.
- A fever, or feeling generally unwell.
- New ankle swelling, or sudden weight gain.

Contact your GP or respiratory team. Do not wait for it to settle.

Emergency



- Sudden or severe breathlessness.
- Chest pain.
- Blue lips or fingertips.
- Confusion, or becoming very drowsy.

Call 999 or 112, or go to your nearest Emergency Department.



My flare-up plan

Fill this in with us while you are well. It is much harder to work out who to ring when you are struggling to breathe. Keep it where you and your family can find it.

What is normal for me

My usual breathlessness, on a good day:

My usual cough:

My usual phlegm, how much and what colour:

My usual oxygen level, if it is measured:

Who I contact first

In working hours:

Out of hours, and at weekends:

My GP, and the out-of-hours number:

Medicines I have been told to start or change:

Straight to the Emergency Department: severe breathlessness, chest pain, blue lips, or new confusion. Call 999 or 112.



Support and planning ahead

We understand that a diagnosis of interstitial lung disease affects every part of your life, not just your health. You do not have to face these changes on your own. We are here to listen, to support you, and to help you plan safely for the future.

Medical social workers work alongside the rest of the team to support you at every stage.

Emotional and adjustment support

- Help adjusting to life with ILD, and to the effect it has on you, your family and your day-to-day life.
- A space to talk through worries, uncertainty, and how you are feeling, at any stage.
- Help for you and your family to talk openly as things change.
- Family meetings, where they would help, to work through difficult conversations and changing roles at home.
- Support when your health changes, when your care is changing, or when you face difficult decisions.
- Help to find what gets you through: your own strengths, and the people and services around you.

Questions for my team

Financial and practical guidance

Medical social workers can give you information and advice, and speak up for you, on:

- Social welfare payments, including Illness Benefit, Invalidity Pension and Disability Allowance.
- Carer's Allowance, and support for family members who care for you.
- The Medical Card, GP Visit Card and Long-Term Illness Scheme.
- Work: your options around returning to work, reduced hours, sick leave, or retiring on health grounds.
- Housing worries, including accessibility and keeping your tenancy.
- Money worries that come with a long-term illness, and where to turn for help.
- Help finding your way around health, community and voluntary services, so you know what support is out there.
- Speaking up for you and your family with government departments, health services, housing bodies or community groups.
- Other supports you may be entitled to. These are explained on the next pages.

Questions for my team



Supports you may be entitled to

Not everyone will qualify for every scheme, and the rules can change. Your medical social worker can help you work out which apply to you, and help you apply.

Help with health costs

Medical Card

Helps with: GP visits, most prescribed medicines and public hospital services.

How to apply: Through the HSE. Your income and circumstances are assessed, and medical costs can be taken into account.

GP Visit Card

Helps with: Free visits to your GP. Medicines and other services are not included.

How to apply: Online through the HSE. It is means tested.

Emergency Medical Card

Helps with: A medical card issued quickly in certain urgent situations.

How to apply: A healthcare professional, such as your hospital social worker, consultant or GP, applies for you with a medical report.

Drugs Payment Scheme

Helps with: Puts a monthly limit on what your household pays for approved prescribed medicines.

How to apply: Through the HSE. You do not need a medical card.

Long-Term Illness Scheme

Helps with: Approved medicines and appliances, free of charge, for certain conditions.

How to apply: With a report from your GP or consultant. It is not means tested, but it only covers specific conditions, so do not assume ILD qualifies. Ask us.



Supports you may be entitled to (continued)

Income support

Illness Benefit

Helps with: Short-term income when illness stops you working, if you meet the medical and PRSI conditions.

How to apply: Your doctor certifies that you are unfit for work, then you apply through MyWelfare. Apply as soon as you can.

Invalidity Pension

Helps with: Long-term income support if you meet the medical and PRSI conditions.

How to apply: Through the Department of Social Protection.

Disability Allowance

Helps with: A means-tested weekly payment for people of working age with a disability that meets the scheme conditions.

How to apply: To the Department of Social Protection, with supporting medical information.

Work

Work and employment supports

Helps with: Changes at work, a phased return, occupational health input and employment advice.

Where to start: Talk to your employer or HR, your GP or an occupational health service. Your medical social worker can help you plan.

Questions for my team



Supports you may be entitled to (continued)

For carers

Carer's Allowance and Carer's Benefit

Helps with: Income support for people who provide full-time care.

How to apply: Which one applies depends on the caring situation, income and PRSI. Your medical social worker can help you work it out.

Carer's Support Grant

Helps with: A yearly payment for carers. It is paid automatically with certain carer payments.

How to apply: If you do not get one of those payments, you may still qualify if you meet the full-time caring conditions. Apply to the Department of Social Protection.

Help with household costs

Fuel Allowance

Helps with: Means-tested help with home heating costs.

How to apply: Through the Department of Social Protection or MyWelfare.

Household Benefits Package

Helps with: Help towards electricity or gas bills, and a free TV licence. One package is paid per household.

How to apply: Through MyWelfare, or on a paper form if you cannot apply online.

Additional Needs Payment

Helps with: Essential costs you cannot meet from your regular income, including some exceptional household or medical costs.

How to apply: Through MyWelfare or your local Community Welfare Service.



Supports you may be entitled to (continued)

Help at home

Public Health Nurse

Helps with: Nursing assessment, monitoring and support at home.

How to contact: Through your local HSE service.

Home Support and Home Care Packages

Helps with: Help with personal care and daily living tasks, and extra support for people with assessed care needs.

How to apply: Through your local HSE community service.

Community occupational therapy

Helps with: Saving energy, pacing, equipment, preventing falls and adapting your home.

How to get it: Referral routes vary, and may be through your GP, Public Health Nurse or hospital OT.

Housing Adaptation Grants

Helps with: Grants for eligible home adaptations. An OT assessment may be needed.

How to apply: Through your local authority.

Where to check official information

hse.ie: medical cards, GP visit cards, the Drugs Payment Scheme and the Long-Term Illness Scheme.

mywelfare.ie: applying for social welfare payments online.

gov.ie: Department of Social Protection schemes.

citizensinformation.ie: plain-English guides to schemes and entitlements.

Please note: eligibility, payment rates and contact details can change. Always check with the official service before you apply. Being listed here does not mean you will qualify.



Support and planning ahead (continued)

Planning ahead and support at home

- Discharge planning: organising practical supports at home so you can leave hospital safely.
- Referral to community services where they would help, including your Public Health Nurse, home support services and community rehabilitation.
- Linking you with support groups and, where appropriate, palliative care.
- Future care planning, which is explained below.
- An Advance Healthcare Directive lets you set down in writing the treatment you would, or would not, want in the future, in case there comes a time when you cannot tell us yourself.
- You can also name someone you trust to speak for you. Medical social work will explain how this works, and can point you to the Decision Support Service.
- Doing this while you are well is not giving up, and it does not change your treatment now. Most people feel lighter once it is settled.

How to contact medical social work

- Ask any member of the respiratory medical or nursing team to refer you.



Thinking about the future

Almost everybody wants to know what the future holds, and almost nobody finds it easy to ask. You may have looked online and found figures that frightened you.

What we can do is talk about your own type of ILD, your own results, and how things have gone so far. Some people want that conversation early, others later or not at all. Both are reasonable.

What can help

- Ask us. You will not be told more than you want to know, and you can stop the conversation at any point.
- Bring someone with you if you would rather not hear it alone.
- Write your questions down beforehand. There is space at the back of this booklet.
- Be careful with figures you find online. Bring anything you have read to us rather than sitting at home with it.
- Living with uncertainty is one of the hardest parts of ILD. Medical social work and psychology can help with that, not only with practical matters.
- Planning ahead, when you feel ready, leaves most people feeling more in control. Earlier in this section, we explain what this can involve.

Who can help: medical team, respiratory ANP-ILD, medical social work, psychology



Palliative care

What it really is

Palliative care is often misunderstood, so we want to be clear about it.

Many people believe palliative care is only for the very end of life, and that a referral means their team has given up. That is not what it is.

Palliative care is specialist help with symptoms: breathlessness, cough, pain, poor sleep, anxiety. It sits alongside all your other treatment, and it can be brought in at any stage of your illness.

People who get palliative care input early often feel better and cope better. It means another team is helping you, alongside ours.

- You can be referred at any point, and you can keep having all your other treatments.
- It can be provided in hospital, at home, or through community services.
- Your ANP, consultant or social worker can arrange it. You can also ask for it yourself.

Questions for my team



For your family and carers

This page is for the people around you. If you are the patient, this is the point to pass the booklet across.

Watching someone you love struggle for breath is frightening, in a way that is hard to explain to anyone who has not seen it. You may find yourself listening to their breathing at night, or hovering at the bottom of the stairs. Most carers do this, and it comes from caring.

Some things worth knowing

- Your usual breathlessness, the level you have come to know, is distressing to watch but is usually not dangerous in the moment. A sudden or unusually severe change in your breathing is different, and you should treat it as urgent (see the flare-up section). Staying calm helps, because panic is catching and makes breathing harder.
- You do not have to fix it. Sitting quietly with someone, opening a window or fetching the fan is often more use than talking.
- Ask before you help. Doing things for people can take away independence they are working hard to keep.
- Practical help is the most valuable kind: the shopping, the heavy lifting, the driving. It saves their energy for what they enjoy.
- Read Section 6 together and agree who rings whom if things change.
- Your own health matters too. Carers who put off appointments, sleep badly and lose touch with friends have less to give.



Contacts and resources

Your team

Respiratory Advanced Nurse Practitioner:

01 221 5070, 086 885 7425, lbrown@svhg.ie

Rare Lung Disease Co-ordinator:

01 221 4060, hhibaler@svhg.ie

Respiratory Ward / Department:

Hospital switchboard 01 221 4000 (ask for the respiratory clinic)

Physiotherapy Department:

01 221 4467

Dietetics Department:

01 221 4225

Medical Social Work:

01 221 4208

Oxygen supplier / helpline:

Vivisol 1800 350 300, or Air Liquide 1800 24 02 02

Other helpful numbers

ILFA Nurse-led Adviceline: 1800 99 88 11

ESB Networks power cuts: 1800 372 999

ALONE (support for older people): 0818 222 024

SAGE Advocacy: 01 536 7330

MABS (money advice): 0818 07 2000

Citizens Information: 0818 07 4000



Contacts and resources

Support organisations

Irish Lung Fibrosis Association (ILFA)

The national patient organisation supporting people living with lung fibrosis and their families. It offers:

- Patient and carer support groups.
- Online exercise classes and yoga.
- Pulmonary rehabilitation, exercise support and education.
- Psychological and counselling support, where available.
- Information on ILD, oxygen, breathlessness, entitlements and community supports.
- A STALL breathing technique card, and a medical alert card for people using oxygen.
- Patient information days, webinars and advocacy.

Nurse-led Adviceline: freephone 1800 99 88 11, Monday to Friday, 10am to 3pm, for specialist ILD nursing advice and support. It is not an emergency service.

Contact ILFA: phone 01 592 2501, email info@ilfa.ie, website www.ilfa.ie

Questions for my team

My medicines

Keeping a list of your medicines saves a lot of guesswork. Bring it with you to every appointment, and to hospital if you are admitted.

Medicine	Dose	When I take it	What it is for

My questions and notes

It is hard to remember everything you meant to ask once you are in the room.
Write it down here beforehand.

Three questions worth asking

- What are my options?
- What are the benefits and risks of each option for me?
- What support is there to help me decide what is right for me?

Additional notes

About this booklet

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If you need this information in a different format, please ask any of us.

If you have any comments about this booklet, or anything about your care, please tell any of us, or contact the hospital's patient liaison service.