

# Tips for Self-Managing your Health when Living with a Long-term Health Condition















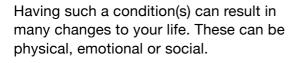


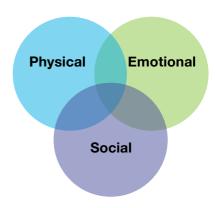
This booklet has been produced by the Self-management Support Coordinators, Health and Wellbeing Division, HSE.

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# What is a long-term health condition?

A long-term or chronic health condition is one, which can be treated and managed but usually not cured. Some examples are asthma, COPD, diabetes, and heart conditions. Others include multiple sclerosis, arthritis, Long Covid and Inflammatory Bowel Disease (IBD). Many people are living with more than one long-term health condition.





# What is self-management?

Self-management is what a person does everyday to manage their health condition(s).

### This may include:

- Recognising and dealing with symptoms.
- Monitoring your condition. For example, weigh yourself each day if you have heart failure. Check your peak flow (breathing test) if you have asthma. If you have diabetes, you may be asked to check your blood glucose (sugar) levels.
- Taking medicines and managing other treatments.
- Making lifestyle changes.
- Coping with the emotional effects of the health condition.

To do this well, a person needs to have the right information, support and services. Learning how to manage your condition may help you feel better, stay active and improve your health.

Self-management happens in partnership with your healthcare team. It is not about 'going it alone'.

# Here are some tips to support you to self-manage your health

# 1. Learn About Your Condition

Learn about your condition, what it is, how to manage it and how it may affect the way you live your life.

# You may be referred to healthcare professionals who:

 Can help you understand your condition.



- Can help you learn to manage and live well with it.
- May provide you with written information.
- May direct you to trusted websites or organisations.

Members of your healthcare team may develop self-management or action plans with you. These are step-by-step guides to help you manage your health condition. These plans also help you to know the signs or symptoms that may mean your condition is getting worse. This is often called a 'flare up' or an exacerbation. Learn the 'warning' signs or symptoms to watch out for. This can help you know the actions you need to take and when you need to look for help.

For some conditions, there are education and support courses available for you to attend. These include cardiac rehabilitation, pulmonary rehabilitation and diabetes support courses. Talk with your healthcare team about these courses.

There are many organisations that offer support for specific conditions. They have telephone advice or support lines to help you manage your condition. These are some of the organisations that may be able to help:

# Where can I get more information on self-management support?

Go to www.hse.ie/selfmanagementsupport

On that webpage you can click on the 'Resources for people living with a long-term health condition' link where you will get more information.

# 2. Get The Most From Your Appointments

Being able to talk to your healthcare team is an important part of selfmanagement. They may be an expert on your condition but you are the expert on you.

Nobody knows more than you do about how your health condition affects you.



- **1. Be prepared:** Before your appointment write down any questions or concerns you have. Write down the most important questions at the top of the list. If time is short, you can ask these questions first.
- 2. Bring a copy of your 'My Medicines List' to the appointment. If you do not have an up to date list, bring the medicines and inhalers you are taking, with you.
- **3. Bring someone with you.** It can be helpful to have someone for support when you go to your appointments.
- **4. Take notes.** Write down important information. This can help you remember the discussion after the appointment.

- **5. Language:** Healthcare professionals may use medical language that is normal for them. If you are having trouble understanding, do not be afraid to ask for a clearer explanation.
- 6. Patient safety: It's safe to ask. This leaflet gives you tips to follow when attending any health or social care service. For more information go to <a href="https://www.hse.ie/eng/about/who/complaints/ncglt/toolkit/complaintsofficerstoolkit/safetoask.pdf">https://www.hse.ie/eng/about/who/complaints/ncglt/toolkit/complaintsofficerstoolkit/safetoask.pdf</a>

# 3. Know Where To Look For Support

Support can come from many people. This includes your GP, practice nurse, members of your healthcare team, your family, friends and colleagues.

Support may also come from other people who also have a long-term health condition (peers).

Peer Support groups can provide a space for you to speak with others who are 'in the same boat' as you. This may support you with your own condition. These groups can be a great help for those who may not have family or friends to talk with.



- Many Peer Support groups also offer education sessions from healthcare professionals. Some groups offer exercise classes or other supportive activities.
- If you attend a support group, you may want to bring a family member, friend or carer along. This can help them learn about your condition and how to support you.

 Some organisations have online discussion groups. Showing family or friends some of the posts or topics may help them learn more.

Ask your healthcare team about peer support groups in your area. They may be run by voluntary or community organisations. For more information about peer support groups go to the HSE self-management support webpage.

**At work.** You may look and feel fine most of the time. Yet, at some point, you may feel ill or have less energy.

- You may not be able to work at your normal pace.
- You may need to take breaks for self-management tasks.

When this happens, you may want people you work with to know about your condition.

- Knowing your situation can help them understand what you are going through.
- They may also offer support and assistance if you need it.

# 4. Be As Healthy As You Can Be

Making healthier lifestyle choices can help you to manage your longterm health condition. They can also help reduce the risk of developing other health conditions.

# Healthier lifestyle choices may help you to:

- Improve your physical health.
- Boost your emotional health.
- Manage your weight.
- Manage stress.



### Lifestyle changes worth considering:

- Eat a healthy balanced diet.
- Try to achieve a healthier weight.
- Be as active as you can be.
- If you smoke, stop.
- Reduce or cut out alcohol.
- Try to get a good night's sleep.



These are all important steps you can take for your health.

## The following websites also provide information and advice:

Healthy Eating	www2.hse.ie/living-well/healthy-eating					
Physical Activity	www2.hse.ie/living-well/exercise/being-active-health-condition/					
	www.sportireland.ie/participation/lsp-contact- finder					
Stop Smoking	<u>www.quit.ie</u>					
Stop Smoking  Alcohol	www.quit.ie www.askaboutalcohol.ie					

# 5. Learn About The Medicines You Are Taking

When you have a long-term health condition, taking medicines is a part of the treatment. You may be taking many different medicines at different times of the day.

It is important to learn about the medicines prescribed for you.

### It is helpful to know:

- Why you are taking it,
- When to take it,
- How often to take it, and
- What common side effects to watch out for.



### When taking medicines, you should:

- **1.** Take it at the right time of day and at the dose recommended by your doctor.
- 2. Make sure you are taking it the right way. For example, some medicines should be taken on an empty stomach. Other medicines should be taken with food.
- 3. Check the use by date.
- **4.** If you use inhalers, make sure you are using them the right way. Ask your healthcare team or pharmacist for help if you are unsure.
- 5. Never take medicines prescribed for someone else.
- **6.** Tell your doctor or pharmacist if you have any side effects from your medicines. They will check if you are taking it the right way. They may want to change the dose or try a different medicine. Do not stop taking the medicine without talking to your doctor first.

- 7. Check with your doctor or pharmacist before taking non-prescription medicines or supplements. These may interfere with other medicines you are taking.
- **8.** Get your prescription filled on time, so you do not run out. This is very important in times of bad weather or holiday periods when some pharmacies may be closed.
- **9.** Talk to your pharmacist about helpful ways to manage your medicines. Medicines or tablet organisers (pill boxes/blister packs) can be useful. Smartphone apps may also be an option.

# 6. Keep An Up To Date Medicines List

A medicine list is a detailed list of all medicines and inhalers you are taking. It is helpful for your healthcare team to know what medicines you are taking. It helps them to make correct and safe decisions about your care.

It is important that those involved in your care know what medicines you are taking



also. This could be a family member or a carer.

### Why should you keep a Medicine List?

Having an up to date, written or printed list of your medicines can help:

- When you might not be able to remember your medicines, for example, at an appointment or in an emergency.
- When you are attending a new doctor.
- When you are going into hospital.
- When requesting a repeat prescription from your GP.
- When a new medicine is prescribed.

This list is very helpful to the people looking after you.

## What should your Medicine List include?

It should list all medicines you are taking. This includes all prescription and non-prescription medicine. Non-prescription medicine is often known as over the counter (OTC) medicine.

Your list should also include any vitamin or mineral supplements. You can buy these in supermarkets, health food shops or pharmacies. Some examples include vitamin D and calcium.

#### The list should also include:

- The strength (dose) of the medicine, e.g. 10mg or 20mg tablet.
- When and how often you take the medicine, e.g. 1 tablet at bed time or 2 puffs of your inhaler twice a day.
- Why you are taking the medicine e.g. for diabetes or for high blood pressure.
- Additional notes if required, for example take the medicine with food.

# Where can I get a Medicine List?

- You can get a "My Medicines List" on www.safermeds.ie.
- On that webpage you can click on the Get Started link where you can get more information and watch a video.
- You can order a printed copy from <u>www.healthpromotion.ie</u>.
- You can also ask your GP or Pharmacist to print out a list of the medicines that you are taking.

## 7. Be Vaccine Ready

There are vaccines available, which help protect against preventable infections. These include flu, pneumococcal disease and COVID-19 amongst others.

Having a long-term health condition can make it harder to fight these infections. You can also be at risk of complications if you get these infections.

Getting the recommended vaccines is an important part of selfmanagement. This is true even if you feel well and your medical condition is under control. These vaccines are an important part of staying healthy.

Ask your doctor, nurse or pharmacist about the vaccines recommended for you.

For more information go to www.immunisation.ie





# 8. Keep Well Whatever The Weather

The change in weather can affect people living with long-term health conditions.

#### Summer:

In the summer, hot weather means your body has to work harder to keep your temperature at normal levels. This can



put extra strain on your heart, lungs and kidneys.

When the weather is hot, you sweat to cool down. This means that you lose more fluid than usual from your body. This can drop your blood pressure and make your heart beat faster.

For people living with asthma or COPD, breathing in hot air can cause the airways to narrow. This can lead to coughing and shortness of breath. Higher levels of pollutants and pollen in the air during hot weather can also act as irritants. The heat can increase the risk of low blood glucose levels (hypoglycaemia) for people living with diabetes.

It is very important to stay cool and hydrated particularly during spells of hot weather.

For more information go to www.gov.ie/en/campaigns/9e76d-be-summer-ready/

#### Winter:

Winter weather can also make symptoms worse for some people. Cold air may cause airways to become narrower. This can make breathing even more difficult if you



have COPD or asthma. Cold weather makes the heart work harder to keep the body warm. This puts an extra strain on the heart particularly for people with heart failure.

The higher levels of pollutants in the air during the winter months may also affect some people.

It is important to make sure you know how to protect yourself whatever the weather.

For more information go to www2.hse.ie/living-well/winter/advice-patients-with-chronic-conditions/

## 9. Mind Your Mental Health

Your mental health is how you feel about yourself and things in your life. If your mental health is good, you feel happy and well. You are able to cope with things in your life.

# 5 Ways to Mental Wellbeing

There are simple things everyone can do to improve mental wellbeing:



- **1. Connect:** connect with the people around you your family, friends, colleagues and neighbours.
  - Spend time developing these relationships.
  - Social prescribing supports you to connect with your community.
     It can help you meet new people and become more social. This can help improve your health and wellbeing. It is a free service.
     Go to <a href="https://www.allirelandsocialprescribing.ie/">www.allirelandsocialprescribing.ie/</a> for more information.

- **2. Be Active:** take a walk, do some seated exercises, go cycling, dance. Find an activity that you enjoy and make it a part of your life.
- **3. Take Notice:** pay attention to the present moment. Take note of your thoughts, feelings and of the world around you.
- **4. Keep Learning:** learning can give you a sense of achievement and a new confidence.
- **5. Give:** giving to others is good for you. Even the smallest act can count, whether it is a smile, a thank you or a kind word. Volunteering or joining a community group can help you connect with others. This can improve your mental wellbeing.

### **Minding Your Wellbeing**

This is a free online HSE programme. It aims to help you develop a positive outlook by looking after your mental health and wellbeing. It includes a series of videos. Each video is about 20 minutes long.

For more information and to watch these videos go to <a href="www.hse.ie">www.hse.ie</a> and search for <a href="Minding Your Wellbeing">Minding Your Wellbeing</a>.

Being diagnosed with a long-term health condition can affect people in different ways. Some people may feel scared, anxious, depressed or angry. These feelings are completely normal.

The emotional effects of managing these conditions can be difficult. It is important to talk about your feelings.

### Speak to your GP or healthcare team if:

- You feel unable to enjoy the things you usually enjoy.
- You find it difficult to cope with everyday life.

For more information and help go to www.yourmentalhealth.ie

# 10. Look After Your Sexual Wellbeing

Romantic and physical relationships are an important part of your health and wellbeing.

Some long-term health conditions can bring many changes.

These may be physical, such as:

- Changes to your body.
- Side effects from the medicines.
- Fatigue (tiredness) and pain.

Other changes may be psychological, such as:

- Loss of self-esteem.
- Feelings of stress.

Anxiety and depression can also result in loss of interest in sex. These changes may affect your sexual relationship with your partner.

Keep in mind that a sexual relationship has both a physical and emotional aspect to it. Talk with your partner about your fears and concerns. This may help to make physical intimacy easier.

You can also discuss any worries or problems you have with your GP or healthcare team. It is important to discuss these concerns. There is no need to be shy or embarrassed.



# 11. Pace Yourself

People with long-term health conditions can often get into a habit of doing a lot on a 'good day'. This can leave them with very little energy and can lead to a 'bad day'. Finding a balance can be hard.

Everyone's ability and health condition is different. Pacing can be helpful for people with long-term health conditions.

### **Pacing**

- Means carrying out activities over time and not doing them all at once.
- Gives you a way to make everyday activities and exercise easier to manage.
- Involves taking breaks before your body tells you it needs a break.



Does not mean stopping activities you enjoy.

### Pacing is an important tool in self-management.

### It can help you to:

- Stay active.
- Do the day-to-day things you want and need to do.
- Reduce the chance of pain or fatigue.
- Feel more in control of your health condition.

### Tips to get started:

- **1.** Make a list of the things you need to do over the day. Allow for breaks between each activity or task.
- 2. Start by keeping the activities small and easy to manage. You can always increase the amount you do. It is better to do a smaller amount each day than tiring yourself by doing too much at one time.
- **3.** It is not underdoing or overdoing it but working to find a level right for you.
- **4.** Pay attention to your body and how you are feeling doing these tasks.
- **5.** You can break down some bigger tasks into smaller steps. For example, cooking a meal can be divided into stages, which you can do over time rather than all at once.

# 12. Join a HSE Living Well Programme

Living Well is a free group programme for adults with long-term health conditions. This 6-week HSE self-management programme supports you to develop confidence and skills. These can help you to better manage your health condition.



### What does the Living Well Programme involve?

- One 2.5 hour workshop each week for 6 weeks.
- You can do the programme in person or online. For the online programmes, you will receive support to get online, if required.
- Two trained leaders deliver the workshops.
   At least one of the leaders is living with a long-term health condition.
- Relaxed and friendly workshops so that all participants can learn from each other.
- Each person who takes part gets a free book about self-management.

### Who is the Living Well Programme for?

Living Well is for adults 18 years and over.

It is suitable for those:

- Living with one or more long-term health conditions.
- Caring for someone with a long-term health condition(s).

The Living Well Programme is not suitable for people with significant memory or learning difficulties.

For more information and upcoming dates go to www.hse.ie/LivingWell

## 13. Get SMART With Your Goals

A goal is something that you are aiming for.

#### It could be:

- Eat a healthier diet.
- Become more active.
- Stop smoking.
- Get better at managing medicines.
- Connect more with family or friends.

Goal setting can be a powerful way for people to improve their quality of life and sense of control.

Goal setting can give you a sense of direction and can motivate you. It is important that goals are personal and meaningful to you.

However, not reaching goals can lead to a sense of failure. By setting SMART goals, you can increase the chance of achieving your goals. You may have heard this term before.



**S = Specific.** What it is you want to do?

'Getting more active' sounds like a good idea, but what does that mean? Aim for a specific goal instead, such as 'I will walk 5 days a week at the local park at lunchtime'. The next step is to make sure it is measurable.

**M = Measurable.** Set goals that you can measure. How will you know when you have achieved your goal?

A goal of 'walking more' is not measurable. Changing it to 'I will walk for 15 minutes x 5 days per week' will help you to track your progress.

- A = Achievable. Set goals that you can achieve. Goals that are too difficult can be off putting and could lead to you giving up. If you have not been active for a while, walking for 10 to 15 minutes may be something you can achieve. However, setting a bigger goal of walking for an hour may be too difficult to achieve.
- R = Realistic. Set goals that are practical for you and your circumstances. Getting more active by going to the gym may not be possible for you. This may be for many reasons. For example, there is no gym close-by or you do not like the gym. Walking may be more realistic and enjoyable for you
- **T = Time-bound.** It is good to state the amount of time you intend to take, to reach your goal.

# 14. Keep An Action Plan



An Action Plan lists the steps you need to take to achieve your goal(s).

### When you write an action plan, be sure it includes the following:

- 1. What you are going to do (name the specific action)
- **2. How much** are you going to do? (e.g. walk 30 minutes every day, eat 5 portions of fruit and vegetables).
- **3. When** you are going to do it (time of the day, day of the week).
- **4. How often** or how many times a week or a day you are going to do it (3 times a week or every day).

# My Personal Action Plan

This	week	l will:								
									_ (What	<del>'</del> )
									_ (How	much)
									_ (Whei	n)
									_ (How	often)
Con	fidenc	e Lev	el							
How	confid	ent are	you th	at you	will sud	cceed v	with yo	ur plar	1?	
0	1	2	3	4	5	6	7	8	9	10
0 = n	ot at all	confide	ent 10 =	really c	onfiden	t				
Your	confid	lence l	evel sh	ould b	e 7 or l	nigher				
Cha	llenges	s that o	could r	nake i	t diffic	ult for	me to	achie	ve my r	olan:
Му р	olan to	overco	me the	se chal	lenges	:				
Wha	t suppo	orts do	I need	to achi	ieve my	y plan?				
Date	:			Sig	nature:					

# **Online Information**

# For more information and resources to help you self-manage your condition:

Self-management Support	www.hse.ie/selfmanagementsupport
HSE Living Well Programme	www.hse.ie/LivingWell
HSE Health A-Z	www2.hse.ie/conditions/
Asthma	https://www2.hse.ie/conditions/asthma/
	www.asthma.ie
COPD	www2.hse.ie/conditions/copd/
	www.copd.ie
Diabetes	www.hse.ie/diabetes
	www.diabetes.ie
	www.thriveabetes.ie
Heart Health	www2.hse.ie/conditions/coronary-heart-disease-chd/
	www.croi.ie
	www.heartbeattrust.ie
	www.heartfailurematters.org/
	www.irishheart.ie/
Health Promotion Publications	www.healthpromotion.ie

# **Telephone Support**

The following organisations offer telephone support for specific health conditions.

Organisation	Telephone Number
Asthma Society of Ireland Advice line	1800 44 54 64
COPD Support Ireland Advice line	1800 83 21 46
Diabetes Ireland helpline	01 842 8118
Croi Connects Heart Disease and Stroke Telephone helpline	091 544 310
Irish Heart Foundation Nurse Support line	01 668 5001



# My Notes

# You might like to use this section to:

Take notes at appointments.

Write down questions to ask at your appointment, or					
• Write down the names and contact details for your healthcare team.					

My Notes	

# Use this pouch to store information, which is important to you.

# **Examples may include:**

- My Medicines List
- Healthcare Appointment Letters
- Self-management Plans or Action Plans
- My Personal Action Plan
- Information leaflets

















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