



Living well with long-term health conditions



Thank you

We would like to thank those who shared their experiences as this guide was being developed, and those who reviewed it for us.

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Contents

About this guide	2
1. How your condition might affect you	3
2. How you might be feeling	7
3. Coping with challenges	12
4. Getting the most out of medical appointments	22
5. Where to get support	35
6. Ways to help yourself	44
Dorothy's story	52

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We spoke to older people about their experiences. Their quotes appear throughout. We have changed the names of some of the interviewees who wished to be anonymous. Some of the images seen throughout this guide are posed by friends of Independent Age.

The PIF TICK is the UK-wide Quality Mark for Health Information.

About this guide

This guide is intended for people living with one or more long-term health conditions. These are conditions that can't be cured but can be managed with medication or other treatment. Some examples are diabetes, arthritis, high blood pressure and some forms of depression.

Anyone can have a long-term health condition, but as we get older they become more common and we're more likely to have more than one condition.

This guide looks at how to live well with long-term conditions, including how to help yourself, where to look for support and information, and how to get the most out of medical appointments.

If you need medical advice or information on a specific condition, speak to your GP or consultant.

In this guide, you'll find references to our other free publications. You can order them by calling **0800 319 6789**, or by visiting **independentage.org/publications**.



Long-term health conditions vary in severity and affect people differently. I myself have long-term health conditions so fully understand how it feels – how frightening it is, how frustrating it is, how unfair it is! BUT knowledge is power!

The key is to live as well as possible with the conditions you have. Self care, help from your GP and other healthcare professionals, emotional support, and access to good information can all help.

Long-term conditions can be related to your physical or mental health, and they may overlap. If you've just been diagnosed with a physical health condition, the effects could be more wide-ranging than you expect.

For example, your condition might affect:

- your mobility
- your confidence
- your mood
- your mental health
- your diet
- your lifestyle
- your daily routine.

What you can do

However you're affected, there are things you can do to help yourself and improve your quality of life. For example:

- talk about it family, friends, healthcare professionals and support groups can help
- ask for help if you need it there's a lot of help out there, but your GP or other healthcare professionals may not know what you need if you don't ask
- look after yourself sticking to a healthy diet and lifestyle, and making sure you get the support you need can help. Ask your healthcare team for advice on this
- follow advice it's not always easy but try to follow medical advice on things like diet, exercise and medication. If you're unsure or have questions about the advice you've been given, speak to your GP.

I think sometimes it is mind over matter. You get up and you think, oh I can hardly walk, but then you do.

If this seems daunting, it can help to break changes down into achievable steps. For example, rather than setting yourself the aim of finding support, you could say "This week I will contact two local support groups to see if they are right for me".

Chapters 5–6 have more information on things you can do to live well with a long-term health condition.

2. How you might be feeling

Finding out you have a long-term health condition might leave you feeling unsettled. Everyone will react differently, but learning to accept the situation can help you to adjust and make any changes you need to.

If you're feeling very low or anxious, talk to people you trust and seek help. For example, your local NHS and some charities may offer self-management courses for people with specific conditions. These often cover coming to terms with your condition and how to deal with any stresses and worries.

I had a heart attack nine years ago. I think when you have something like that it knocks your selfconfidence because you think you are invincible until it happens and then you suddenly think, whoa!

Some things you might be worried about

It's normal to feel worried if you have a long-term condition and you might find that it knocks your confidence. You might be concerned about:

- how you'll cope with your condition, both practically and emotionally
- what might happen in the future for example, fear of your health getting worse or of dying
- how you'll manage if you live alone
- how you'll care for anyone who relies on you
 for example, if you're a carer for your partner
- whether you should have done something differently to prevent the condition, such as having a different diet.

Where you can find support

If you're worried about anything or just want someone to talk to, there are places that can help – for example, local or online support groups for people in a similar situation. Read **chapter 5** for more information and contact details. If you haven't been offered any support but think you'd find it helpful, ask your GP what's available.

Living with a long-term condition can affect your mental health. If you've been feeling depressed or anxious for a while, or it's having a big impact on your life, speak to your GP.

Our guides **Dealing with depression** and **Managing anxiety** have more information.

Talk about it

Talking therapies, such as counselling or group therapy, can be very effective and they help you find your own ways to cope. Your GP can refer you through the NHS. There may be a waiting list for these services. In England, you can refer yourself at **nhs.uk/service-search/find-a-psychological-therapies-service**. In Scotland, you can call NHS 24 on **111** and select the option for mental health services (**nhsinform.scot/ illnesses-and-conditions/mental-health/mentalhealth-support/mental-health-services-at-nhs-24**).

If you're feeling distressed and want someone to talk to, you can call Samaritans on **116 123**. You can talk to them about whatever is troubling you. Other free helplines include:

- Breathing Space (Scotland) 0800 838587
- C.A.L.L. (Wales) 0800 132 737
- Samaritans Welsh Language Line **0808 164 0123**.

Private therapy

You could also look for a private therapist. Make sure they're accredited by a professional body, such as the British Association for Counselling and Psychotherapy (BACP). The cost can vary a lot, so compare a few services. Your GP should be able to help you find one.

You can also search online at **bacp.co.uk/search/ therapists**. For services in Scotland, visit **cosca.org.uk/our-services/find-counsellor/ find-a-counsellor**.



3. Coping with challenges

The impact your condition has on you will be personal to you. Everyone will cope differently, but it can be reassuring to know that other people have similar concerns and frustrations. Here are a few of the things people have told us they find difficult.

Managing pain

If you're in pain, it can be hard to think of anything else. This can have an impact on your mental health too. You might feel anxious or irritable, or feel isolated if you can't get out so much.

Your GP or other healthcare professional should be able to suggest treatments such as medicines, tailored exercise programmes and diet changes. They may be able to refer you to an occupational therapy or physiotherapy service.

You could ask if the NHS offers pain management services in your area. These could include pain clinics or Pain Management Programmes. You may use techniques like talking therapies or mindfulness to reduce stress.

When you're in pain it affects everything: your mood, your relationships, everything. The hospital gave me a pain management support worker and she has been amazing. If I was in pain I just kept going. She said, 'Why don't you sit down for five minutes and do it afterwards?' She made me stop and look at how I manage everything. It's brilliant.

Organisations that deal with your condition may be able to give you more specific help and may have support groups – see **chapter 5**. You can also get self-help resources at:

- The British Pain Society (020 7269 7840, britishpainsociety.org)
- the online Pain Toolkit a collection of selfmanagement tips by someone with long-term pain (paintoolkit.org)
- NHS Inform (nhsinform.scot/illnesses-andconditions/mental-health/mental-health-selfhelp-guides/chronic-pain-self-help-guide).

Managing fatigue

Fatigue is more than tiredness. It's a feeling of exhaustion that isn't helped by sleep or rest. It can affect your mood and how much you're able to do. Fatigue is common in many conditions.

Regular light exercise can help and there may be other things you can do to manage your fatigue – such as pacing yourself, planning ahead and setting goals. For certain conditions, your GP may be able to refer you to a fatigue clinic.

You could also contact support organisations for your condition to ask about help with managing fatigue – see **chapter 5**.



Managing medication

Keeping track of medication can be tricky, particularly if you have to take several kinds or take them at particular times of day. Changes to your medication or to your routine might confuse you even if you usually remember what to take and when. Many people find it helps to keep their medication somewhere visible and take it at the same time each day – you could even set an alarm.

There are also apps (applications you can download from the internet onto your smartphone or tablet) that can remind you to take medication. For example, in England the free NHS-recommended app Echo lets you order repeat prescriptions, as well as reminding you to take medicines.

You might want to get an automatic pill dispenser that releases the right number of tablets at the right time. The Disabled Living Foundation has information on these (0300 999 0004, livingmadeeasy.org.uk/ category/health-and-personal-care/personalhealth-aids/medication-alarms-and-reminders).

Coping with changes to your medication

If you're taking a lot of medication or think you already know how to take it, it can be tempting to skip reading the pamphlet that comes with your tablets, but it's important to read it. There might be uncommon interactions or side effects you weren't aware of, as the following story shows.

I'd been taking tablets for 18 months and I just didn't feel right. The doctor asked about my diet. I told him and he said, 'Didn't you read the booklet? You're not meant to have grapefruit with that.' I'd been having half of one every morning. So it does pay to read it. That was an eye-opener for me.

Be aware that certain medications or taking four or more medications can increase your risk of falls.

If you're unsure about anything, ask your GP or pharmacist. You can also arrange a medicines use review with your pharmacist to discuss your medication.

3. Coping with challenges



They changed my blood pressure pills so they didn't have the days of the week on them anymore. I asked the pharmacist about it and he found me a brand that did have them. It's always worth asking.

Managing multiple conditions

Having more than one long-term health condition can mean that you'll see more than one healthcare professional. You might worry that your conditions are being treated separately and no one is considering your overall health.

The National Institute for Health and Care Excellence (NICE) has produced guidelines for treating people with multiple conditions. These state that healthcare professionals should:

- know if you have more than one condition and take this into account when delivering care
- give you a chance to discuss your personal values, priorities and goals as much as possible
- make sure you know who's responsible for coordinating your care
- discuss with you whether any of your treatments could be stopped or changed when reviewing your medication.

Speak to your GP if this doesn't seem to be happening. You could also ask whether you have a care plan – read **chapter 4** for more information.

I was told I should exercise because of my diabetes, but then I can't always exercise because of my fibromyalgia. What can you do?

Managing conflicting advice

If you have more than one condition, you might find that different medications interact, you're given conflicting dietary advice, or one condition makes another one worse.

Make sure you tell anyone prescribing you something about any medication or treatment you're already having. They will be able to tell you about possible interactions and may suggest ways to balance conflicting needs.



If you drive

You need to tell the DVLA and your insurance provider if you develop any medical conditions that could affect your ability to drive safely. You must also tell them if an existing condition has got worse.

You can find out which conditions you need to report at **gov.uk/health-conditions-and-driving** or ask your healthcare team for advice. You may be able to use the online service to tell the DVLA or contact DVLA Medical Enquiries (**0300 790 6806**).



4. Getting the most out of medical appointments

Planning, booking and getting to medical appointments can be frustrating and time consuming. It might be particularly difficult if you're seeing different healthcare professionals in different places for different conditions. Here are some tips for getting the most out of your medical appointments.

Make a list of questions you want to ask

This will help you to be clear about what you want to say and make sure you don't forget anything. Start with the questions or concerns that are most important to you.

When you're older there are often quite a few things going on with your health. So if you go to the doctor you think, where am I actually starting with this? You feel you want to say everything but then they wouldn't take anything seriously.

Make a list of your current medications and treatment

This should include prescription and nonprescription medication. Your healthcare professionals need to know everything you're taking to keep an overview and make sure nothing interacts badly.

Also take a record of any home test results you have, such as blood sugar levels. Make sure you also write down any complementary therapies you're using or thinking of trying, such as acupuncture and homeopathy.



Ask if anything is unclear

Make sure you understand what you've been told and what you need to do next. For example, do you need to book any follow-up appointments or will your GP refer you? Don't be afraid to ask if anything is unclear.

The same goes for test results. If they haven't been explained to you, ask what they mean. You may worry about taking up the GP's time, but it's important that you leave feeling confident about what is happening and what you need to do.

Consider taking notes or recording appointments

It can be hard to take in everything you're told and remember it, especially if you're given a lot of information or feel anxious. You might find it helpful to take notes. You can bring a friend or relative to appointments and they might be willing to do this for you.

You also have the right to record your appointments – use something like a smartphone or Dictaphone. It's best to let your GP know you'll be doing this.

Find a GP you trust

Seeing a GP who knows you and you feel comfortable talking to can make a big difference. You have the right to ask to see a specific GP when you book your appointment, although it might mean a longer wait. Occasionally, this might not be possible – for example, if you need to see a GP with a particular specialism.

In England, if your GP is referring you, you also have the right to choose the hospital or service you'd like. The NHS website has more information about how this works (**nhs.uk/using-the-nhs/about-the-nhs/ your-choices-in-the-nhs**) or you can ask your GP.

I think it's very important that you find one GP you can rely on or trust. And sometimes you have to go through two or three. You need to find the GP at the surgery who you feel at home with.

Care plans

A care plan is a written record of the overall plan for your care, including what support and treatment you'll receive, and your personal goals.

If you're interested in having a care plan, discuss this with your GP. They'll be able to help you set goals and give you a written copy of your plan to share with other health or social care professionals involved in your care.

Having a care plan that accurately reflects what you want and need should help if you're seeing several different doctors or other professionals.

Think about your priorities

Make sure healthcare professionals know which conditions are having a big impact on your life, particularly if you have more than one condition. For example, you might be finding it straightforward to manage your diabetes, but not your depression.

If you have a care plan, make sure your priorities are recorded there.

I always ask my patients, 'What are you hoping I can do for you today?' Think about what you want to gain from the appointment and your expectations of your GP, so that both of you can be satisfied your needs have been met. Dr Emma Poyner, GP

Make sure you have enough time

If you know you have something complex to discuss or want to ask about more than one thing, try to book a double appointment slot or an appointment at the end of the day when the GP may be less rushed.

You might also be able to arrange a follow-up telephone consultation rather than going to the surgery again.

Getting to appointments

If getting to appointments is difficult, for example because you have limited mobility or you're caring for someone else, see if you can arrange telephone or online consultations. If you need to arrange multiple appointments – for example, GP and nurse – ask whether you can book them next to each other to save you making more than one trip.

Patient transport services provide free nonemergency transport to and from appointments for people who are unable to make their own way. Speak to a healthcare professional to find out if you qualify.

Be honest about how you're feeling

Don't feel embarrassed or worry that you're wasting the GP's time. They want to help you, but they won't necessarily know how your condition's affecting you unless you say. Don't feel you can only mention physical health concerns. For example, if your anxiety about your health is hard to manage, mention this. You know your own body. Sometimes you have to say 'I'm the patient. I know how I feel.'

Become an expert patient

Ask if there is a local Expert Patient course. These are self-management courses for people with long-term health conditions. They cover topics like healthy eating, dealing with pain, and telling others about your condition. There may also be courses for self-management of specific conditions.

Questions to ask

Don't be afraid to ask questions. The following template includes some examples of things you might want to ask at an appointment if you're asking about a particular concern.

Try filling in the template or creating your own. You might want to ask different questions if your appointment is for something else, such as test results, a medication review or a routine check-up.

Medical appointment planner

Time and date of appointment:

Name of GP/healthcare professional:

What I want to discuss:

How long it has been affecting me:

The impact this is having on me:

Medication I am taking:

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Any other treatment I am having:

Notes on the appointment

Do I need any follow-up appointments?

Are there any tests to book?

Am I being prescribed any new medication or treatment?

Do you have any written information for me?

Is there anything I can do to help myself?

Who should I contact if there's a problem (eg GP or hospital)?

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Consider the alternatives

Your pharmacist or GP practice nurse may be able to help with some problems. For example, in England, if you've been prescribed certain medicines for the first time, you can get free support from your pharmacist through the NHS New Medicine Service. In Scotland, you may be able to get support with your medication from the Medicines, Care and Review Service. Ask your pharmacist for details.

Telehealth can monitor certain long-term health conditions remotely. For example, if you have diabetes and take insulin, a telehealth device can check your blood sugar levels and let you know if they get too low or high so you can adjust your insulin dosage.

A telehealth device is usually provided by a healthcare professional, who will show you how to use it and explain how it will help them to support you. Speak to your GP to find out what's available in your area.



Read our factsheet **Technology to help you at home** for more information. If you're considering complementary or alternative therapies, such as acupuncture and homeopathy, you should always speak to your GP before trying any. The NHS has more information at **nhs.uk/conditions/ complementary-and-alternative-medicine**.





5. Where to get support

There is a range of support available to help you live well with long-term health conditions. People are not always aware of the help they can get or may be offered support at a time when they can't take in what they're being told. This chapter looks at some of the main sources of help.

Your GP and other health services

Your GP will probably be your first point of contact. They may refer you to specialist consultants or other services. For example, if you've had a heart attack, a number of healthcare professionals might be involved in your care, including nurses, physiotherapists, dieticians and exercise specialists.

Ask your GP or practice nurse about any services you're interested in or for suggestions of services that could help. For example, are there charities, local support groups or tailored exercise classes that could help you?

I went to cardiac rehabilitation for six weeks. They were very good. You hear people say if you've had a heart attack don't run, don't do this or that, but you've got to! If you don't use your heart, it's like any muscle: use it or lose it.

Your local council

If you need some help to look after yourself, contact your local council to arrange a free care needs assessment. This looks at your needs and how they might be met. For example, do you need help to wash or dress, or get out and about?

The type of support suggested will depend on your needs, but might include things like adaptations to your home, disability equipment or visits from care workers.

Even if you don't qualify for support from the council, it can still be helpful to get an assessment to help identify your needs and the best support for you.

For more information, read our factsheet **First steps in getting help with your care needs**.

Charities

Charities offer a variety of support. They might:

- produce information to help you learn about and manage your condition
- run helplines offering you advice some also have condition specialists
- run courses on how to manage conditions
- organise support groups where you can talk to people with the same or similar conditions and share your experiences. These might be face-toface or online. Talking to other people about your condition and how you're feeling can be very helpful.

Look for charities that help people with long-term conditions or the specific conditions you have – ask your GP or pharmacist, or try searching online.



Patient support services

In England and Wales, Patient Advice and Liaison Services (PALS) support patients and their families. You can find PALS officers in your local hospital. They can help with health-related queries and give you information about support groups inside and outside the NHS. PALS vary so see what they offer in your area (**nhs.uk/Service-Search/Patient-advice-andliaison-services-(PALS)/LocationSearch/363**).

NHS patients in Scotland can contact the Patient Advice and Support Service (**0800 917 2127**, **cas.org.uk/pass**).

You could also contact:

- England Healthwatch (03000 683 000, healthwatch.co.uk/your-local-healthwatch/list).
- Scotland Healthcare Improvement Scotland (0131 623 4342, healthcareimprovementscotland.org)
- Wales the Board of Community Health Councils (02920 235558, boardchc.nhs.wales).

It's worth checking what else is available near you. For example, ask what services your local pharmacist offers and which organisations run support groups locally. If a hospital, care home or hospice is involved in your care, they may also offer services to support you.



PALS are amazingly good. People think they just do complaints but if you go to PALS and say I'm really confused, I don't know what to do, they'll advocate on your behalf with consultants. They're brilliant.

If you're unhappy with your care

If you're unhappy with the care you've received from your GP or other NHS staff, you may wish to make a complaint.



For more information, read our factsheet **Complaints about health services** or call our Helpline on **0800 319 6789** to arrange to speak to an adviser.

An independent advocate could support you if you need help to express your views and wishes.



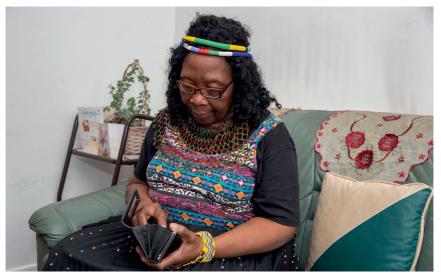
Read our factsheet **Helping you get your voice heard: Independent Advocacy** for more information.

Help with extra costs

You might find you have some extra costs, such as the cost of travelling to appointments or hospital.

For information on help that might be available, read our **Moneywise** guide.

If you need help with your personal care because of your condition, you may qualify for a disability benefit such as Attendance Allowance. Contact our Helpline to arrange to speak to an adviser (**0800 319 6789**).





6. Ways to help yourself

Living well with a long-term condition is about finding ways to manage conditions, rather than cure them. This means there is a lot you can do to help yourself. Here are some suggestions.

Stay informed

Many people find that staying informed about their condition can help them to feel in control and be more involved with managing their own health. However, there are so many possible sources of information, it can be overwhelming trying to find what you need in the right format, at the right time.

It's important to make sure you can trust the information you're reading. If you're uncertain about something you've read, check it with your healthcare professionals. For more information, read our online guide to finding reliable information on the internet (**independentage.org/finding-health-information-online**).

I think all the information is there if you want to find it. It's online, or it's in a leaflet, or it's at your doctor's. It's there. You just need to be trained to find it. Good sources of online information are the NHS website (**nhs.uk/about-the-nhs-website**) or the websites of charities for different conditions, such as those mentioned in **chapter 5**. You could also look at:

- Health Unlocked (healthunlocked.com), a social network where people can talk about their conditions. It's moderated by patient organisations and charities to make sure patients are sharing the best information.
- **Healthtalk.org**, which offers information based on people's real-life experiences. It includes videos where they talk about their experiences.

I get Heart Matters delivered every month. It keeps me informed on a lot of things, like diets. You can subscribe or pick it up from your doctors. It's produced by the British Heart Foundation.

Self-help guides and tools

You can find online resources, such as tools to help you manage stress and anxiety at **nhs.uk/mentalhealth/self-help/guides-tools-and-activities**.

If you're looking for printed information, ask your GP or look in your local library. For example, Reading Well books on prescription are recommended by healthcare professionals. They can help you manage your condition (**reading-well.org.uk/books/bookson-prescription**).

Some charities also have newsletters you can subscribe to, or ask about their printed information.

Make sure you're getting information in a form that suits you. If you don't use computers, ask your GP or healthcare team if they have any printed information. This also means you'll have something to refer back to easily. You have a right to receive information in an accessible format – for example, large print, audio or Braille.

Getting support at the right time

Sometimes, you may be offered information or services at a time when you can't take it in. Don't feel embarrassed about asking again when you feel more able to absorb the information. For example, you might only feel ready to think about support groups or counselling once the shock of a diagnosis has passed or treatment is over.

I had cancer, and we didn't get any counselling afterwards. It was a very difficult time for my wife and family. I think the GP mentioned counselling once, but that was it. When you're under stress and trauma, it doesn't go in.



Making changes

It's important to listen to medical advice about changes you might need to make to your lifestyle, including diet and exercise, and any medication you need to take.

There are also changes you might be able to make to help yourself. For example, if you know that your condition causes you more pain in the mornings, you might want to replan your activity around that. See **chapter 3** for advice on managing pain.

Staying active

Whether or not you've been prescribed an exercise plan, you might want to consider ways to become more active. As well as improving your physical health, this can boost your mood and help you sleep better.

Speak to your GP if you're unsure what forms of exercise are right for you. They can help you to find a personalised exercise programme that takes account of the symptoms of your condition.

Be kind to yourself if you don't always manage to achieve what you want to. It can help to set yourself short, realistic goals. For example, rather than saying you will exercise every day this week, you might set yourself the goal of completing stretching exercises on three days and going for two short walks.

I walk with a friend. That helps a bit, just having that. We walk at our pace, not anybody else's. It does you the world of good. And you laugh and you talk and you potter as you go. And you don't realise how far you've gone. And you feel so much better.

Planning ahead

If you find that you worry about dying, it can help to think about the kind of care you want to receive at the end of your life. Making decisions in advance can give you peace of mind.

Read our guide **Planning for the end of life** for more information.

The charity Compassion In Dying has a Peer Navigator Service. They can help you come to terms with your diagnosis and work out your next steps (0800 999 2434, compassionindying.org.uk/ services).



It was 2004 when I started finding it difficult to see and I'm now registered blind. Ten years later I was diagnosed with diabetes. This means I have to be very careful what I eat, even at Christmas. I stick to the advice from the doctor.

Some people feel that long-term health conditions are a big disadvantage, but I try to be positive. Everyone has something in their life they don't like. Even though my eyesight is bad I can manage to watch some TV. I'm always active and that's what keeps me going. I go to church and to day centres.

I know how important it is to ask for help and I've been very lucky with the help I've had. I find you only have to ask.

My experience with getting support from Independent Age has helped to show me that there are people always willing to help and this has changed my life completely.

About Independent Age

No one should face financial hardship in later life.

Independent Age is a national charity providing support for older people facing financial hardship. We offer free impartial advice and information on what matters most: money, housing and care.

We financially support local community organisations across the UK through our grants programme. We campaign for change for older people struggling with their finances.

You can call us on freephone **0800 319 6789** (Monday to Friday, 8.30am to 5.30pm) or email **helpline@independentage.org** to arrange to speak to one of our advisers.

To donate or help support our work, please visit **independentage.org/support-us**.





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