

# Looking after your well-being

A guide for people with acromegaly

# "one of our greatest freedoms is how we react to things"

(harlie Mackesy



Nobody ever chooses to get acromegaly. Or, if it happens to you, to feel utterly exhausted or get potentially excruciating headaches or any of the other life-altering symptoms that can be associated with acromegaly.

It's common, and completely understandable, to feel overwhelmed by acromegaly and its symptoms. But you can choose how you respond to it. Treatment and support, from both a physical and emotional perspective, are vital to dealing with the condition.

When you feel ready, focusing on your well-being in general can be another important way to help you feel in better control of your life.

Here you'll find suggestions of different ways to take charge of your mind and body. You might find it best to think of this as a resource to dip in and out of whenever you need a boost, rather than rushing to try everything right away. Remember, improving your well-being is something that will take time and little steps.

# (ontents

Moving	4
Discover new opportunities to release extra feel-good hits of endorphins into your life.	
Nutrition	12
Realistic ways to improve the quality of what you put into your body.	
(onnecting with others	18
It's easy to feel alone with acromegaly—but you don't have to.	
Sleep	20
Tips to help improve the quality and quantity of your sleep.	
Mindfulness	24
Being more conscious of your thoughts can add a new dimension of control to your life.	
Relaxation	26
Discover a less-considered meaning to relaxation and ways to make it work for you.	
Breathing	28
Suggestions of ways to open up your airways—and your mind—to a deeper sense of calm.	
What could work for you?	29
Three charts for you to fill out to help you discover what possible changes you might want to prioritize and what might prevent or motivate you to implement them into your life in a lasting way.	

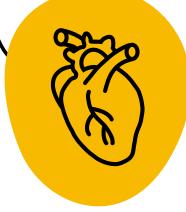


# Moving

As you read through each of the suggestions in this guide, consider thoroughly evaluating whether and how each of them could work for you. Doing so could help you to think through any potential barriers before they arise so you feel more able to overcome them and to implement positive and lasting changes in your life in a way that will work for you and your friends or family. See page 30 for help with this.

# What are the benefits?

Alongside the life-altering symptoms acromegaly itself can cause is a higher risk of developing conditions like diabetes and heart problems. Regular movement can help to reduce the risk and impact of these conditions on your long-term health. It can also help improve your body's ability to heal itself, manage the experience of pain, improve your sleep quality, increase confidence, and help you feel better about your self-image day to day. Find some suggestions on other ways to improve the way you feel about yourself in the Self-image guide.



# What is it about?

Exercise—raising your blood flow or heart rate by contracting and releasing your muscles—can carry negative connotations, especially if you never enjoyed the "exercise" elements of your earlier years and you've spent your life avoiding it, or if your body is crying out in pain most of the time and exercise or a sport you used to love seem to make it worse. If either applies, it might be better to think about whether there are other forms of movement and physical activity that you could fit into your daily schedule. There are so many different things you can try.

# How do I do it?

You probably know moving is good for you, but how could you fit more into your daily schedule? Especially when it feels that your life is already filled with managing your acromegaly and everything else and possibly hampered by fatigue. Could you consider what's making things difficult for you? On the next 2 spreads you'll find some common barriers and suggestions of ways to overcome them.

# Common barrier It makes my body ache

### Suggestion

If you're suffering from carpal tunnel syndrome, chronic pain, or an injury, the normal things you do to get out and about—like walking—can be painful in themselves. It's especially important to get your healthcare team's advice in this instance, but there are many activities that people who experience pain can benefit from. Try doing activities in the water (for example, swimming or water aerobics). Our buoyancy in the water takes pressure off our joints and helps to relieve pain. If you can find a pool at a warmer temperature for therapeutic exercises, this will help even more. There are also specialized yoga classes that focus on relieving pain and increasing blood flow throughout the body.

If you're somebody who has always benefited from moving and keeping fit, then the barrier of pain can be particularly demoralizing, especially if you feel you need to give up on a sport you have had a deep relationship with. If this is the case, could becoming a coach be an option?



# Common barrier I don't have the time or energy

### **Suggestion**

Start small.

- Could you try using the stairs instead of the elevator, starting with just 1 floor?
- Could you get off the bus or train 1 stop early and enjoy a little fresh air?
- Could you try 2 minutes of moving where you are right now?
- ~ See the resources on page 19 for things you could do with just 2 minutes. If the thing you choose works for you, try building up to 3 minutes tomorrow, 4 the next day, and so on
- ~ If it doesn't work for you, think about why it didn't work—is there something else you could try that could help to overcome that barrier?
- Congratulate yourself for every moment you spend moving—and if you can, track your progress with a smartphone app or a step counter, or even a handwritten diary or exercise log. Seeing your progress in this way can be a great motivator until (and beyond) the point when you start physically feeling the progress and benefits to your body and health

# Common barrier 1 get out of breath too quickly

### Suggestion

Start small and gentle—you could do intervals of 2 minutes on, 2 minutes off. Or you could try moving with resistance, such as lifting small weights or stretch bands rather than something that gets you out of breath. In people with diabetes, resistance training has been shown to be just as effective at improving health outcomes as aerobic exercise.

# Common barrier I don't like anything

### **Suggestion**

Try to find something new, something you don't consider a chore—how about dance, Pilates, tai chi, or aqua aerobics? You can find further information and tutorials on all of these online, or consider joining a group class in your local area if you can. Many people find group activities more enjoyable as the social component helps us feel connected and motivated. If you feel unsure about this, perhaps you could take a trusted friend along with you?

# PLEASE REMEMBER



Check with your healthcare team before trying anything new that could impact your health and treatment plan.

# Common barrier I can't afford it

### **Suggestion**

You don't have to join a gym or invest in classes (though these can help with boosting your motivation and accountability). All you need are some comfortable shoes and comfortable clothes. See if you can fit in an extra (free) walk, turn the music up and dance around your living room, play with your kids, or try a free workout video online.

# Common barrier | feel self-conscious

### Suggestion

No one has to know—you can exercise in the privacy of your own home, or disguise it as a normal walk in the park or around the block. Overcoming worries about exercising in public can take time—be easy on yourself and remember, this is for you. Why not get a friend to come with you and/or support you?

# Common barrier I can't—I have to look after my children

### **Suggestion**

Can they come with you? Could you explore different activities together until you find one you all like? If not, can you try some home exercises after they've gone to bed?

# Common barrier I'm just not made for exercise

### Suggestion

- Perhaps you could try visualization—seeing yourself actually doing some kind of movement or physical activity and visualizing how you might feel afterward could be that little push you need to get you going
- Ask friends or family to help motivate you
- ▶ Take some time to consider what you do enjoy doing—for example, listening to music or being outside. Could you find a way to incorporate physical activity into that?

Once you've chosen some suggestions to try—and obtained your healthcare team's approval for them if necessary—it might also help to put in place some SMART goals (see the "What could work for you?" section at the end of this booklet for support with this) to help ensure what you're setting out to do is actually possible and prevent you from giving up on it before you've given yourself enough of a chance.

Hopefully there is something in here that could help you incorporate more movement into your day-to-day life—and start or reignite your ability to feel the benefits for yourself.

Remember, it's common to feel anxious or worried about setting new goals for physical activity. Try to be easy on yourself and your body, and take your time. When you set your goals, consider breaking them down into the smallest steps possible that you can build on. For example, if your goal is to try a new exercise class but you haven't engaged in formal physical activity for a while, you could consider starting off with a 10-minute walk outside, then 15 minutes, then 20 minutes, then 20 minutes with a friend, then 20 minutes with a walking group, working up to 60 minutes...and then trying out the new exercise class that was your original goal.

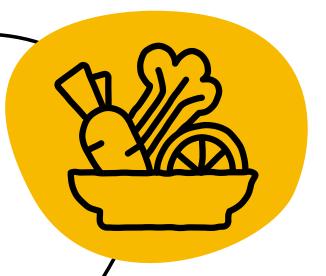
# Nutrition

# What is it about?

Because acromegaly can adversely impact the way your body processes sugar and make you more susceptible to diabetes and heart conditions, it's important to explore ways to get pleasure from eating and drinking beyond a bakery, your usual restaurant food choices, or alcohol. Of course, that isn't completely realistic for most people—there's pressure from friends and peers, the convenience factor, plus the underlying pressure of having acromegaly...doing what we know is best for our bodies is hard. This section isn't about giving things up (unless you've been prescribed a particular diet by your healthcare team). It's about trying to be a little more mindful about what we eat and drink, trying to savor it for longer, and hopefully feeling better about ourselves along the way.

# What are the benefits?

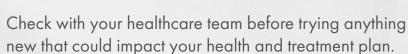
It's highly likely that your healthcare team has discussed the benefits of eating well (plenty of vegetables and fruit) and cutting down on fats, sugar, and alcohol at some point. There's a lot of evidence to support the effects of different types of diets and calorie restriction on health outcomes—in general, people who eat a balanced and varied diet and maintain a healthy weight tend to suffer less from diabetes, heart conditions, and their associated complications.



# How do I do it?

Think about what influences your food and drink choices—the advertisements you see, the restaurants you go to, the way you're feeling as you walk around the supermarket or shop online, the recipes and eating habits you've picked up from family and those around you as you were growing up. There are so many reasons why we eat what we do. Do you think your diet could use an overhaul? Or are there small, manageable changes you could try?

# PLEASE REMEMBER &



If you'd like to start yourself on a healthier eating and drinking track, consider the following ideas...



# Be clear about your goals

It's much harder to stick to something that's a bit vague, like planning to eat a little healthier. Try setting yourself concrete (and realistic) targets, such as having 3 to 4 portions of vegetables every day.





# Find a buddy

Let a friend or family member know what you're doing, and ask them for support. It's much easier to stick to something if you know someone's there to keep you going.



Why are you making these changes? Of course, your new nutrition plan could help with some of the symptoms and conditions associated with acromegaly. But perhaps you also want to look and feel better, perhaps you want to look after your health for the sake of your family and loved ones. Write your reason down (or print a photo of it), and put it somewhere you'll see it every day, such as next to your toothbrush or on the fridge. By doing this, you can directly link your behaviors around food with the values you hold dear—which can make you more likely to reach for the apple instead of the chocolate, for example.



# Tell your healthcare team

In addition to giving approval for any substantial changes to diet, your healthcare team can offer professional advice and support, or perhaps even refer you to a nutritionist. Knowing you'll report back to a professional can help provide that extra motivator you need to achieve your goals.



# Start small

Focus on only the next thing you'll eat. How can you make that thing the right thing to eat, and when do you really need to eat it? Then congratulate yourself for having made that healthy choice. And then, plan the next one.

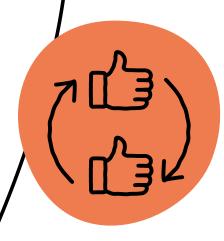
# Plan in advance

If you can, make meals for the week ahead (some of them transportable if your days will involve being away from home) in 1 batch cooking session. That way, you're much less likely to falter from your nutrition plan when you're stressed, out and about, or feel like you have no time to cook.



# Discover new foods

Healthy nutrition doesn't have to be boring or bland. There are so many recipes and food types you could try that you might not even have heard of before. How about swapping potatoes for white sweet potatoes (almost identical but with a slower energy release)? Or perhaps instead of that glass of Sauvignon blanc you try a nonalcoholic kombucha (a slightly sparkling fermented yeast tea drink that can do wonders for your digestive health)?

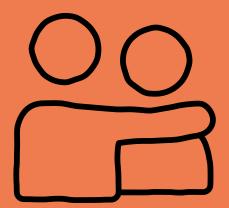


# Start a positive feedback loop

The more informed you are about why it's important to make changes, the more likely you are to follow them. And the more you follow them, the better you'll feel. And the better you feel, the more you'll be able to stick to your plan. So start the cycle of positivity today. Be kind to yourself and your body. Over and over again.

Of course, all of this will be a case of trial and error and finding out what works for you. It's also good to remember there's no point beating yourself up if you slip up and stray from your plans. Healthy eating isn't all or nothing—it's little changes that we can make every day, starting right now. And, of course, before you make any extreme changes to your diet, please remember to ask your healthcare team for advice, as these changes could affect your health in general and any medications you're taking.

# (onnecting with others



# What is it about?

Given that acromegaly is quite a rare condition that not many people know much about—and you could possibly go your whole life without meeting anyone else with the condition—it's easy to feel alone. While friends and family members may try to be empathetic to what you're going through, it can be difficult for them to fully understand your perspective. This can result in feelings of isolation even if you aren't physically alone. But this makes it even more important to seek support and connections from a variety of places.

Help your friends and family members help you better by encouraging them to read **Supporting people with acromegaly**, another guide in the Acroline<sup>™</sup> series.

# What are the benefits?

Decades of research have shown that social connection and support are cornerstones of both good mental and physical health and well-being—and that the belief that you are supported can be even more important than the support itself. Feeling adequately supported can improve both your physical and mental ability to face day-to-day stressors, such as acromegaly symptoms or upcoming operations or treatments.

# How do I do it?

There are several groups and websites available that may help you feel more connected. See the links below for more information.



# Acromegaly communities and resources

# Acromegaly Community acromegaly community.org

This is a support network run by patients for people touched by acromegaly. It offers information on issues such as surgery, medication, radiation, and postdiagnosis support. In addition, it provides a network of emotional support for acromegaly patients, as well as their friends and family.

# The Pituitary Society

pituitarysociety.org

This website presents articles on pituitary diseases, information about International Pituitary Congress programs, the Pituitary Society Newsletter, and tables of contents from back issues of the society's journal, *Pituitary*.

# Pituitary Network Association (PNA)

pituitary.org

Founded by a group of patients with acromegaly, this is the website of an international nonprofit organization. The PNA is the world's largest patient advocacy organization for people with pituitary tumors and disorders.

### Hormone Health Network

hormone.org

This is the public education affiliate of the Endocrine Society. Its mission is to be a resource for the public by promoting the prevention, treatment, and cure of hormone-related conditions.

# Pituitary World News (PWN)

pituitaryworldnews.org

PWN connects thought leaders to patients and brings up-to-date information on health-related matters of importance to those with pituitary tumors and other pituitary disorders.

These websites are neither owned nor controlled by Pfizer.
Pfizer does not endorse and is not responsible for the content or services of these sites.

# Sleep



### What is it about?

Are you getting the recommended 7 to 9 hours of sleep a night your brain and body need to rest, recover, and develop? Does this feel like enough for you?

With acromegaly, it's common to feel absolutely exhausted all the time, despite getting plenty of sleep. This could be due to the impact of the condition itself, but it's also important to note that up to 8 in 10 patients with acromegaly will also have or develop sleep apnea. This is a condition caused by changes in the structure of your airways that can impair sleep quality and/or quantity. It's a treatable condition that, if unchecked, could lead to impaired quality of life and a higher risk of life-altering accidents, so it's important to be aware of the symptoms of sleep apnea and get tested for it if you think it might affect you. Read more about sleep apnea in the Acromegaly and health guide.

In addition to treating your acromegaly and sleep apnea, if you have it, there are some other ways you can potentially improve your sleep habits, and we'll focus on those here.

# What are the benefits?

Getting enough sleep, of good enough quality, can have a positive impact on your mood, energy levels, mental sharpness, and ability to handle tough situations or stress.

# How do I do it?

Good sleep hygiene can help improve the quality and quantity of your sleep—and can involve different things for different people. Here are some suggestions that could improve your sleep quality or quantity.



## Schedule

Try to set and stick to a regular sleep schedule—respecting your biological clock can help ensure your body is ready to go to sleep and wake up when you need to. A sleep schedule involves keeping to a fixed bedtime and wake-up time every day, including weekends.



Check with your healthcare team before trying anything new that could impact your health and treatment plan.

# **Exercise**

Build exercise or movement into your day—how much you need will vary, but for most people a minimum of 30 minutes of activity can help improve sleep quality. Aim to keep any high-energy moving to at least 4 hours before your bedtime, if possible.

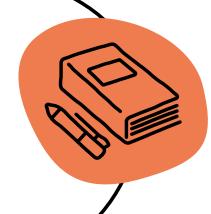


# **Nutrition**

Be mindful of your eating and drinking—caffeine, alcohol, and highsugar foods too close to bedtime (or after midday for some people) can all impair sleep, as can eating heavy meals or drinking too much fluid just before you go to bed.

# Calm

If the stress of the day and your to-do list are stopping you from getting to sleep or keeping you up if you wake during the night, consider ways of managing these better, such as by keeping a daily journal, jotting them down to handle in the morning, or getting further psychological support on ways to manage them.



# **Environment**

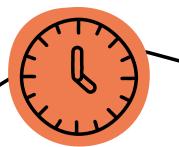
Darkness, quiet, and cool temperatures are all important sleep-promoting conditions. Could you consider installing black-out blinds or curtains, wearing a sleep mask or earplugs, using a white noise machine, and/or keeping any pets out of the sleep environment?

# **Comfort**

Make sure your sheets are cleaned regularly and that your mattress is supportive. You could consider a specialized supportive mattress or pillow to help with any particular joint or back pains you're suffering from.

# **Routine**

Create a calming bedtime routine for yourself to help you wind down. Avoid TV, computer, and phone screens before bed; take a bath; read with a dim light; try gentle stretching exercises or yoga relaxation techniques; or use a sleep meditation exercise.



# How will I know it's working?

You may find you are feeling and functioning better throughout the day, but a sleep tracker, such as a smartwatch, can also help you monitor your progress. And remember, if your sleep amount or quality is still not meeting your needs, or if you're concerned about it at any time, please contact your healthcare team for advice and support, as your acromegaly or sleep apnea status might have changed and therefore could benefit from further professional attention.

# Mindfulness

The exercises discussed here could be particularly useful if you're about to have MRI/CT scans, surgery, radiotherapy, or injections.



# What is it about?

24

Think about the way your mind works for a minute. Do your thoughts wander from one to the next, sometimes randomly jumping around? Do you go through the day on a kind of autopilot, moving from one thing to the next? When you do stop to reflect on things, do you find your thoughts become filled with self-criticism or worry?

Thinking like this is natural, and most of us think this way sometimes.

Mindfulness aims to focus our attention on our experience in the present moment (our sensations, thoughts, bodily states, consciousness, and the environment), noticing it with an attitude of openness, acceptance, and curiosity. It's about developing a more compassionate and empowered relationship with our self.

# What are the benefits?

Although still a developing area of research, there is a wealth of evidence to support health benefits of practicing mindfulness. It has been shown to help reduce symptoms of fatigue, persistent pain, sleep disturbance, stress, depression, and anxiety, and to improve general well-being. In some cases, practicing mindfulness can be just as beneficial as other forms of therapy, such as cognitive-behavioral therapy (CBT).

# How do I do it?

From dedicated courses involving weekly face-to-face classes, daily practice, and mindfulness retreats, to smartphone apps that give you 2 minutes of mindfulness practice a day, there are many different ways to practice mindfulness. They all involve setting an intention to focus on a specific object or activity happening in the present moment and gently redirecting attention back to it whenever the mind wanders.

Once you've learned how to practice mindfulness, you can incorporate it into your day (for example, by mindfully focusing on an activity like walking, eating, or even taking medication). Or you can take time out of your day to focus on mindfulness, such as through a guided meditation. Yoga can also incorporate elements of mindfulness.

Mindfulness is about being aware of our attention and thoughts in a nonjudgmental way.

# Relaxation

This approach could be especially useful if you're about to have MRI/CT scans, surgery, radiotherapy, or injections.

Anything that helps you to focus on a single thing and eliminate all other thoughts can bring relaxation.

# What is it about?

Relaxation in the context of improving your well-being is about more than investing in monthly massages (or the persuasive effort required to get them from friends or family), though that possibly wouldn't hurt. A bit like mindfulness, relaxation is about focusing your thoughts and attention onto a single point or activity. However, unlike mindfulness, relaxation aims to eliminate all other thoughts, promoting a sense of calm in potentially stressful situations (whereas mindfulness is about training your mind to accept all kinds of thoughts, even discomforting ones).

# What are the benefits?

Relaxation aims to lower your blood pressure and heart and breathing rates, giving your body and mind a period of dedicated time to restore and heal. Across a number of different clinical settings, relaxation practice has been shown to improve general well-being and reduce symptoms of stress, depression, pain, insomnia, and anxiety. It can also help reduce anxiety related to medical procedures like injections or operations.

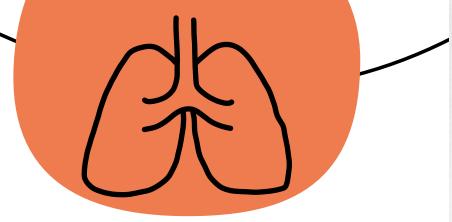


# How do I do it?

The way you can achieve total mind and body relaxation will be unique to you and your individual preferences.

This includes types of relaxation meditation such as deep-breathing exercises, but also activities like gardening, cooking, cleaning, reading, and elements of yoga (savasana). It's also good to note that relaxation isn't for everyone—some people can feel disconcerted by relaxation techniques, in which case a mindfulness approach might work better.

# Breathing



### What is it about?

Hopefully you already know how to breathe! But do you know how to breathe with intent, with focus, in a way that can improve your well-being? This section is a reminder that taking a few moments out of your day (especially during a time when things might be starting to overwhelm you) and focusing on your breath can give you a little positive mental and physical boost just when you need it the most. The exercises we describe here can either fit with a mindfulness or relaxation approach to well-being or straddle the two.

# How do I do it?

Try to make sure you're sitting in a comfortable, upright position. If you can, find a quiet place or wear headphones or earplugs to block out any background noise or disturbance. Focus your attention on your breath. Take a deep breath over the count of 4 seconds, inhaling through your stomach more than your rib cage. Then gently exhale, noticing any tension in your body release as you do so. Then repeat for 5 more deep breaths with your eyes closed.

There are all sorts of audio guides and apps available to help you with breathing exercises like this.

# What are the benefits?

28

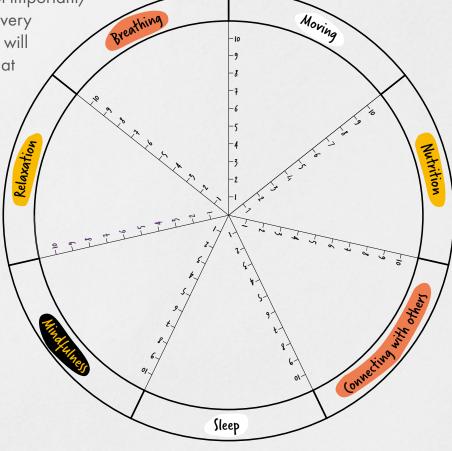
As with mindfulness and relaxation, breathing exercises can help reduce symptoms of fatigue, persistent pain, stress, depression, and anxiety and can improve general well-being and help you get to sleep at night or fall back asleep if you've woken in the middle of the night.

# What could work for you?

# What would benefit you most?

Think about each of the different ways of improving your well-being, and rank them from 1 to 10 based on what appeals to you and how easily you could incorporate each technique into your life (fill in the chart twice, using a different colored pen to rank what's important to you vs what's easy

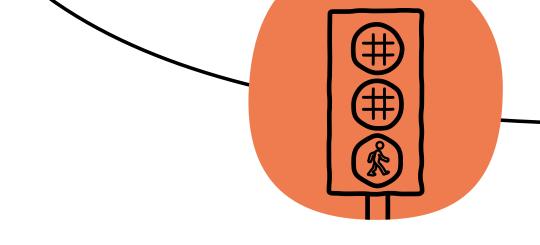
for you to change, where 1 = not important/
too difficult to change and 10 = very
important/easy to change). This will
give you a visual target as to what
areas you might find it helpful to
focus on—you could consider
sharing this with friends or
family and getting their
thoughts, too.



# What's motivating you?

A guided exercise to help you set SMART goals that will give you the best chance of incorporating and sustaining well-being improvements in your life

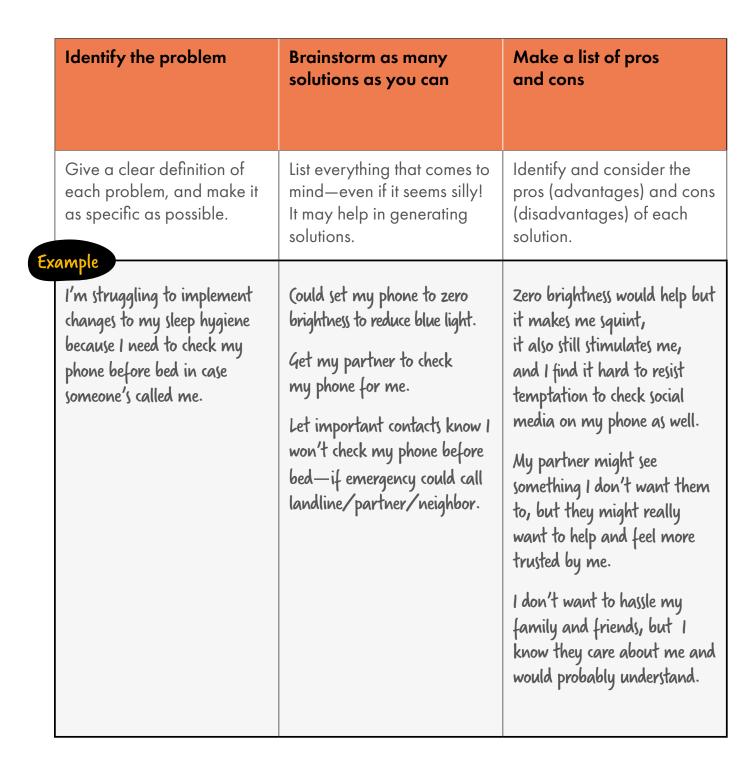
S Be Specific	Make it Measurable	A Is it Attainable?
Write down what exactly you aim to achieve.	How will you know you've achieved it?	Given your medical history, how is it possible to achieve this goal (and do you need to discuss it with your healthcare team)?
Have the confidence to get through my upcoming surgery, scheduled for 2 weeks from now.	Doctor will confirm!	Yes—it's scheduled and the healthcare team says I'm fit enough for the surgery.

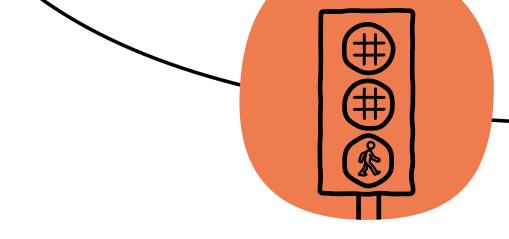


R Is it Realistic?	Is it Time Bound?
Do you think you have the willpower and support network that you need to be able to achieve it? Do you need anything you don't currently have?	When will you check your progress, and when do you aim to have completed it?
Need to tell my boss and arrange time off work.	Have just set a meeting with boss for 3 days from now.
Would be good to make time to focus on relaxing and learning breathing exercises beforehand, will arrange this with work and family also.	In I week from now, I aim to have downloaded a breathing/meditation app and spent 10 minutes a day using it.

# What's stopping you?

A guided problem-solving exercise to help you incorporate well-being improvements into your life

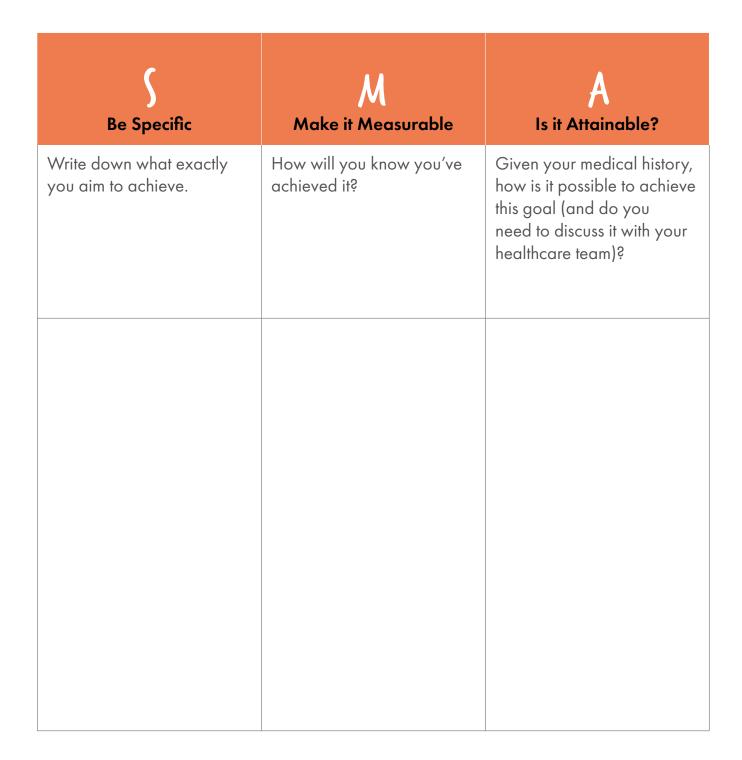


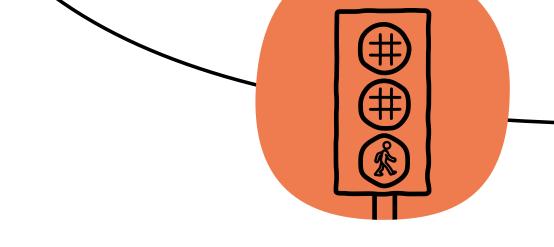


Pick a solution or a combination of solutions that will solve the problem.  Create a detailed plan to implement it	Reflect on the plan
Think about whether you have all the necessary resources—do you know exactly what needs to be done and when you will do it?	Review how that option went. Is there anything you should alter or try differently?
I'm going to try letting key contacts know my plan to stop checking my phone before bed (and why I'm doing it) and giving them another way to contact me, just in case.  If I know an important message might come in late at night, I'll ask my partner to help alert me to it and read it to me.	Family and friends seem (mostly!) to understand, and I've noticed they often message me earlier than they used to.  It's just a small thing, but I feel closer to my partner for working through this together.  I've noticed an improvement in the time it takes me to get to sleep—now just need to work on how to get back to sleep if I wake during the night!

# What's motivating you?

Here is a blank table to set some SMART goals for yourself



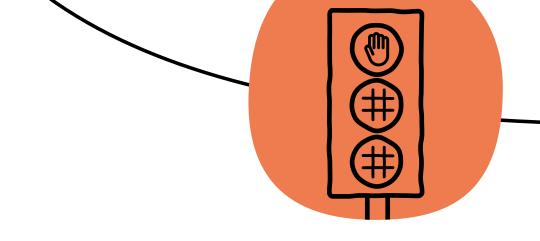


R Is it Realistic?	Is it Time Bound?
Do you think you have the willpower and support network that you need to be able to achieve it? Do you need anything you don't currently have?	When will you check your progress, and when do you aim to have completed it?

# What's stopping you?

Here is a blank table to allow you to develop a solution plan to some of the problems you might be faced with

Identify the problem	Brainstorm as many solutions as you can	Make a list of pros and cons
Give a clear definition of each problem, and make it as specific as possible.	List everything that comes to mind—even if it seems silly! It may help in generating solutions.	Identify and consider the pros (advantages) and cons (disadvantages) of each solution.



Pick a solution or a combination of solutions that will solve the problem.  Create a detailed plan to implement it	Reflect on the plan
Think about whether you have all the necessary resources—do you know exactly what needs to be done and when you will do it?	Review how that option went. Is there anything you should alter or try differently?

Notes	Notes



Created in collaboration with an international panel of people with acromegaly, acromegaly support groups, and health psychologists, Acroline<sup>TM</sup> is a series of supportive guides and tools designed to help you keep your life on track and live well with acromegaly.

### Related titles include:

- ▶ Self-image
- Supporting people with acromegaly
- > Acromegaly and health

To view related brochures for more information, please click here or visit acromegaly.pfizerpro.com.

