

IBD OWN YOUR TREATMENT

INFORMATION FOR **PATIENTS**

This document is only intended for use by a person after their healthcare professional has made the decision to treat them with Entyvio* subcutaneous (SC)

GETTING STARTED WITH ENTYVIO® (VEDOLIZUMAB)

This booklet is for people who have recently been prescribed Entyvio® for subcutaneous (SC) injection. If you don't really know what this means, that's okay. We're about to give you an overview of what you need to know about your treatment.

Don't worry if it seems like a lot to get to grips with - we'll be here to help every step of the way.

Let's get started.



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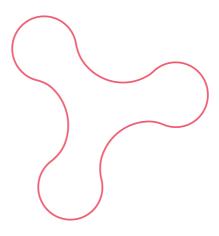
WHAT IS ENTYVIO®?

Entyvio* is a treatment for adults with moderately to severely active ulcerative colitis (UC) and Crohn's disease (CD).¹

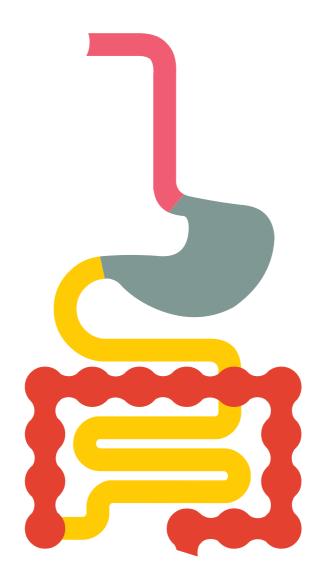
It belongs to a group of treatments called biologics. Biologics are called this because they're made through a process that involves living organisms rather than a chemical process.

Biologics have been extensively studied and accepted throughout medicine as a suitable way to treat medical conditions.²

The active ingredient in Entyvio® is vedolizumab.¹ It's designed to target specific molecules in the body that are involved in the inflammation of the gut, which leads to the symptoms of inflammatory bowel disease (IBD).¹



Your gut is the name of the tube that runs from your mouth to your anus and it includes the **oesophagus, stomach, small** and **large intestines.**³





WHY HAVE I BEEN PRESCRIBED ENTYVIO®?

Entyvio* is usually prescribed if a patient has **not responded very well**, or at all, to previous treatments, or if another treatment has **stopped working** or causes too many side effects.¹

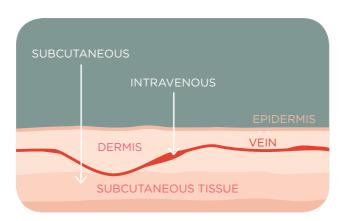
Your doctor has decided to give you Entyvio® because they think it could benefit you.





WHAT'S THE DIFFERENCE BETWEEN ENTYVIO® INTRAVENOUS (IV) AND ENTYVIO® SUBCUTANEOUS (SC)?

Entyio® is currently available in two forms, Enytvio® IV and Entyvio® SC. It's the same drug, with **the same active ingredient**. Both forms of Entyvio® have been proven to help your gut feel better.¹ The main difference between the two forms is the way the drug gets into your body.



Intravenous means it goes through a drip in one of the veins in your arm (intravenous infusion).⁴

Subcutaneous means it goes into **tissue under the skin** (subcutaneous injection).⁴





STARTING ENTYVIO®

Your first doses of Entyvio® will be given as IV infusions before you move onto Entyvio® SC. Someone on your healthcare team will be in charge of your infusions.

You will only be able to receive Entyvio® SC if you have already had your induction doses of Entyvio® IV. Either you or your caregiver will inject Entyvio® SC at home.

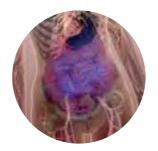
WHAT IS AN INFUSION?

In the case of Entyvio®, infusion is a way of putting the solution or liquid into your bloodstream. The solution is slowly introduced into your body through a vein.

An infusion is not the same as an injection. Injections are comparatively quick and don't always deliver their contents into a vein (you can usually receive an injection into a muscle, for example, or under the skin, which is a subcutaneous injection). Entyvio® SC is a subcutaneous injection.

HOW DOES ENTYVIO® WORK?

Before we get into the details of how Entyvio® works, we should run through the basics of IBD. We don't know yet exactly what causes IBD but we know that inflammation in the gut plays a big part in the symptoms that you experience.⁵

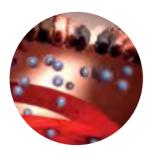


As part of your natural immune response, some white blood cells are programmed to enter and protect the gastrointestinal tract – your gut.^{1,6}



In people with IBD, too many of these white blood cells move into the gut.¹





This increases inflammation from a 'normal' protective amount to a level that causes problems – which you experience as symptoms of either UC or CD.^{1,4}



Entyvio® works by blocking white blood cells from getting into the gut.^{1,6,7}



This reduces inflammation, helps relieve your symptoms and allows the gut to heal.^{1, 6, 7}

WHAT CAN I EXPECT FROM ENTYVIO® TREATMENT?

Everyone responds differently to medications and Entyvio® is no exception.



When Entyvio® IV was tested by IBD specialists, around a third of patients responded positively to treatment by their third infusion – that's six weeks into their treatment.^{1,8}



Some people may see a sudden improvement of their symptoms when on Entyvio® – some as early as two weeks ^{1,9}



Others may improve gradually over time.¹

While some people might have total relief from their symptoms or go into remission (a period of time without symptoms), others might only improve a bit and their symptoms won't completely go away and others may not respond at all.¹



WHAT IF I DON'T RESPOND STRAIGHT AWAY?



Some people take longer than others to feel Entyvio® working; some do not respond at all. Your doctor will plan a follow up with you to check how your treatment is working.

Be patient with your treatment. It might just take some time to see results. By tracking your symptoms you may be able to see small improvements. If you don't respond as quickly as you expected, talk to your healthcare team about whether Entyvio® should be continued, or whether stopping might be the best option. Together you can decide what to do next. **Keeping to your treatment schedule** will give you the best chance of better outcomes.

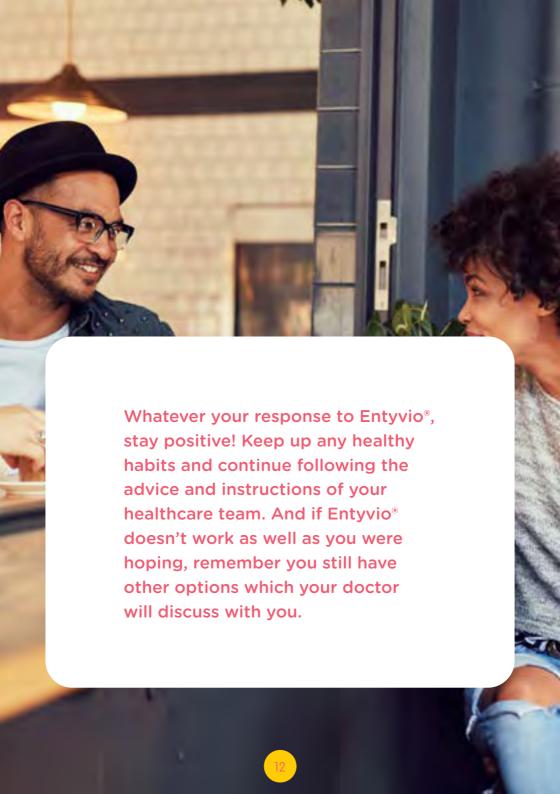
WHAT IF I LOSE RESPONSE?

If you respond to Entyvio® treatment at first but then start to lose response, please speak to your healthcare team.

Make sure you always talk to your healthcare team before changing your treatment schedule,



or if you need more information about your medicine. In any case, please do not discontinue your treatment until you have discussed this with your healthcare team



WHAT ABOUT SIDE EFFECTS?

What are side effects?

Side effects are unwanted effects caused by medical treatment. They're also called 'adverse events' or 'adverse reactions'. All medicines can cause side effects.¹⁰

DOES ENTYVIO® CAUSE SIDE EFFECTS?

As with any medication, some people may get side effects, but not everyone gets them.⁴

Your doctor might have told you that Entyvio® has a favourable safety profile. This means that when it's been studied in clinical trials, it had a low level of side effects.^{1,11}

The most common side effects (that happened in more than one in 10 people) were:1

- Headache
- · Runny nose
- Joint pain
- Tiredness



Talk to your healthcare team if you have any concerns or worries about side effects.

For a full list of side effects you can read the Entyvio[®] Patient Information Leaflet (PIL), which you can find in the packaging of your medicine.

What should I do if I get side effects?

Just remember that it isn't unusual to get side effects - it can happen with any medicine.⁴

If you notice any changes in your health that you think might be related to your medicine, talk to your healthcare team. This includes any possible side effects not listed in the PIL.⁴ You can also report side effects directly via the national reporting system listed in the PIL or via the Yellow Card Scheme. By reporting side effects you can help provide more information on the safety of Entyvio®. For more information visit www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store.

If you think the downsides of the side effects outweigh the upsides of the treatment, you should have an honest discussion with your healthcare team. They will help you decide what is right for you.

Progressive multifocal leukoencephalopathy (PML) is a rare, but serious and potentially fatal infection that can happen in people receiving certain treatments that target the same kind of molecules that Entvvio® works on.

If you display any of the following symptoms, please speak to your healthcare team immediately.

- · Blurred, loss of, or double vision
- Difficulty speaking, weakness in an arm or a leg
- A change in the way you walk or problems with your balance
- Persistent numbness, decreased sensation or loss of sensation
- Memory loss or confusion



YOUR TREATMENT SCHEDULE

Someone from your healthcare team will talk you through the dosing schedule for Entyvio® SC, but we'll recap here as well. Be sure to ask your healthcare team if you are unsure of anything about your treatment schedule.

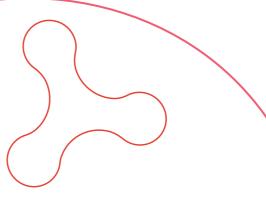
Starter doses (IV infusions)

First infusion and second infusion two weeks later

Weeks 0 2 If you are responding to Starter IV Entyvio® after at least two One SC injection Entyvio[®] IV infusions (two weeks taken at home infusions at zero apart), you can begin using every two weeks and two weeks Entyvio® SC at home Entyvio[®] Entvvio® Entvvio® 300mg 300mg 108mg Days

Before you can start injecting Entyvio® at home, you need to have at least two **starter doses** (sometimes called 'loading doses') given to you by a healthcare professional at a hospital through an **IV** infusion.

You might need more than two infusions depending on how you respond to the medicine.





Injecting at home (SC injections)

Further injections once every two weeks

If you are responding to Entyvio® after at least two infusions (two weeks apart), you can begin using Entyvio® SC at home. The recommended dose is one SC injection every two weeks.



Once you start Entyvio® SC injections at home, if you feel that you aren't responding as well as you were with the IV infusions, tell your healthcare team as they might want to change your treatment plan.

WHAT EXACTLY ARE STARTER DOSES?

Your Entyvio® treatment will begin with at least two doses given as IV infusions. If you have had infusions before, you know what to expect. If you haven't had an infusion before and want to know more about the infusion process, talk to your healthcare team. They will be happy to explain the process to you and answer any questions you may have. Check out Crohn's and Colitis UK for more information.

www.crohnsandcolitis.org.uk

Starter doses help to see if the medicine is working.

Entyvio® SC is only approved for use after you have received at least two infusions.

You will have regular contact with your healthcare team who will be able to check that you're responding to your starter doses of Entyvio® before you start managing your treatment a little more independently.

PLANNING YOUR APPOINTMENTS

Book your appointment well in advance so you can arrange time off work if you need to. If you're asking someone to come with you (not a bad idea, at least for the first time) then they can make plans too.

It might be helpful to get a list of questions ready;

things such as • "How does it feel?"

- "Will it hurt?"
- "What can I bring with me?"

HOW SHOULD I PREPARE FOR AN INFUSION?

You can eat and drink as you normally would before your infusion. It might be a good idea to bring a bottle of water to keep hydrated.



The infusion itself takes about 30 minutes. You will have to stay for a while after your infusion to be monitored in case there are any unusual signs of allergic or infusion reactions.

You may want to wear loose, comfortable clothing when having the infusion.

Take something that helps you feel calm and relaxed, like a book or your phone so you can listen to a podcast, or play a game during the infusion and observation period.



ADHERENCE TO THERAPY IS IMPORTANT

Taking your medicine exactly as prescribed (called adherence) is important for the management of your IBD. For the best chance of successful treatment, it's important that you use Entyvio® according to your healthcare team's instructions.

Don't be late with your treatment and don't miss any injections that your doctor has prescribed.

There are many ways that can help you adhere to your medicine including:

- Taking your medication at the same time with each dose
- Set up reminders/use smartphone apps
- · Create a calendar schedule
- · Plan ahead for repeat prescriptions
- Discuss your treatment plan with your family or friends
- Attend all appointments

Adherence to Entyvio® as prescribed is important at ALL times. It's particularly important when starting Entyvio® because it will enable you and your healthcare team to see if you are responding well to your medicine. Remember to maintain your treatment plan and discuss this with your healthcare team if you are having difficulties.

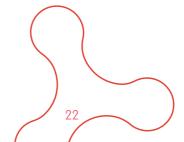


HOW CAN I PREPARE TO SELF-INJECT?

Self-injecting for the first time can be quite intimidating, but you're probably better prepared than you think. If you've had injections or infusions before you will know how to keep calm and relaxed. Even if you've never self-injected before, you will probably be familiar with the initial sharp scratch of the needle – which can be the worst bit for many people.

The other thing to keep in mind is that lots of people self-inject their medicine. Of course, that doesn't mean you'll find it easy but you can do it with a little practise.

You might want to get someone you know and trust to help you – not just with the practicalities but for emotional support too. Before you inject, you and your chosen person will be provided training on how to inject safely by a homecare nurse.



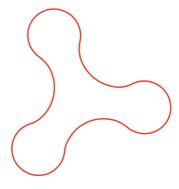


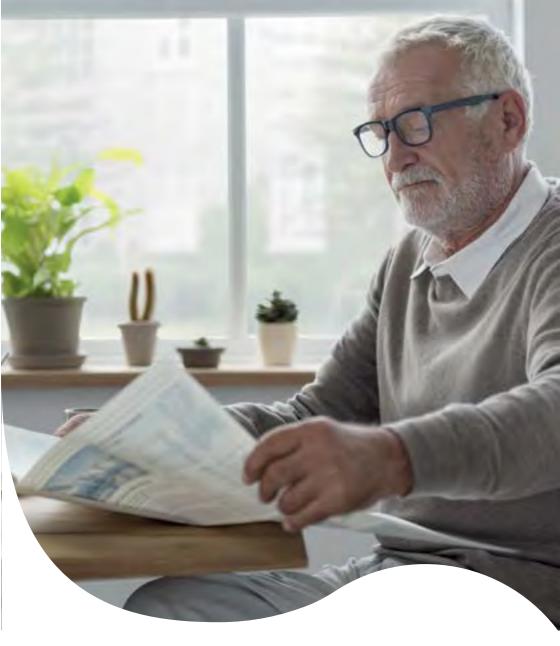
INJECTING ENTYVIO® SC

As mentioned earlier, when you get an infusion everything will be done by your healthcare team, but when you are prescribed Entyvio® SC at home you'll do it yourself (or have a person you trust do it for you).

You should have been shown how to use your Entyvio® device by someone on your healthcare team. You will receive training again with a homecare nurse after your first Entyvio® SC delivery arrives.

First of all, if you haven't had a look already, please read the PIL carefully and completely. It can be found in your Entyvio® packaging.



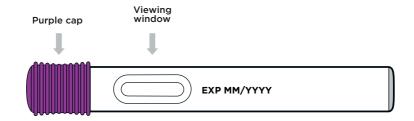


Remember to remove your Entyvio® box (pen or syringe) from the fridge **30 minutes** before use.

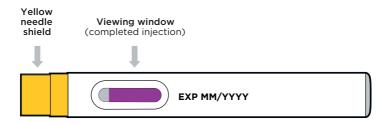


HOW DO I USE THE ENTYVIO® PEN?

Before use:



After use:





1) Get everything ready

- Find a relatively calm spot you'll want to give yourself some time and space to get things right
- Take one injection pen box from the fridge so it can start to warm up to room temperature (this takes about 30 minutes)
- Grab the other supplies you need:
 - An alcohol pad
 - · Cotton wool ball or gauze
 - Sharps disposal container



2) Check the injection pen

- Wash your hands
- Look over the injection pen for any broken or missing seals
- Check the expiry date
- Check the medicine looks clear and colourless, or light yellow
- Don't worry if there are air bubbles in the pen

 this is normal, don't shake it

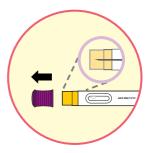


3) Pick an injection site

- Choose where you will inject front of thighs, tummy (not around the belly button) or back of the upper arm (if someone else is doing the injection)
- Make sure you inject into a different place from last time you injected, it may be useful to keep a diary
- Wipe the area you plan to inject with an alcohol pad (don't touch this area again before you inject)

4) Injecting Entyvio®

- · Pull the purple cap off the injection pen
- Hold the pen so you can see the viewing window
- Place the yellow end of the pen at 90-degrees to the area you cleaned earlier (it should be straight up and down)
- Push down on the pen as far as it will go to begin the injection
- Hold and count to 10 while pushing down as firmly as you can. This will allow all the medicine to be injected
 - You might hear two clicks, one at the start and one near the end
- Check that the viewing window is filled with purple before you stop pushing
 - It's fine if you see a small bit of grey in the window
- · Lift the pen from the injection site
- The yellow needle shield will drop down and lock over the needle
- If the viewing window isn't completely full, you might not have received your full dose – contact your healthcare team if this happens
- If you see a small amount of blood at the injection site, press on your skin with the cotton wool ball or gauze









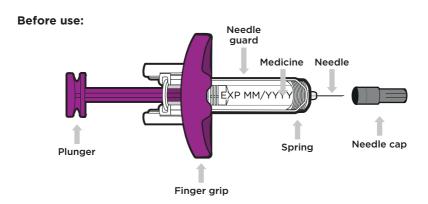


5) Clean up after yourself

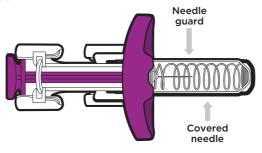
- Put the injection pen into a sharps container straight away – don't put the syringe in your normal rubbish. You should have received a sharps container with your first delivery of Entyvio® SC
- If you don't have one of those, please contact your homecare provider* immediately and use a container that:
 - Is made of heavy-duty plastic
 - Can be closed with a tight-fitting, punctureresistant lid without anything being able to come out
 - Is upright and stable during use
 - Is leak-resistant
 - Is properly labelled to warn of hazardous waste inside the container
- You can put the rest of the things (the cap, the alcohol wipe, the cotton wool ball or gauze) in your normal rubbish or in the sharps bin
- When your sharps bin is almost full, please contact your homecare provider* who will remove your sharps disposal container and provide you with a new one

^{*}Your homecare provider is the company that delivers your Entyvio® SC.

HOW DO I USE THE ENTYVIO® SYRINGE?



After use:











1) Get everything ready

- Find a relatively calm spot you'll want to give yourself some time and space to get things right
- You should take one syringe box from the fridge so it can start to warm up to room temperature (this takes about 30 minutes)
- Grab the other supplies you need:
 - An alcohol pad
 - · Cotton wool ball or gauze
 - · Sharps disposal container

2) Check the prefilled syringe

- Wash your hands
- Look over the syringe for any broken or missing seals
- Check the expiry date
- Check the medicine looks clear and colourless, or light vellow
- Don't worry if there are air bubbles in the syringe
 this is normal, don't shake it

3) Pick an injection site

- Choose where you will inject front of thighs, tummy (not around the belly button) or back of the upper arm (if someone else is doing the injection)
- Make sure you inject into a different place from last time you injected, it may be useful to keep a diary
- Wipe the area you plan to inject with an alcohol pad (don't touch this area again before you inject)

4) Injecting Entyvio®

- Lift the syringe out of the tray using its body (not the plunger) and remove the grey cap
 - Don't touch the plunger or needle
 - If absolutely anything touches the needle, use a new one
 - If the needle is bent or broken do not use it
- Hold the syringe with one hand and pinch your skin around the injection site with your other hand
 - Hold the pinch until the injection is complete
- Insert the needle at a 45-degree angle all the way into the pinched skin
- Push down on the plunger as far as it will go to inject all the medicine
- **Keep pressure** on the plunger and take the needle out of your skin
- Take your thumb off the plunger to allow the needle guard to cover the needle
- If you see a small amount of blood at the injection site, press on your skin with the cotton wool ball or gauze





5) Clean up after yourself

- Put the syringe into a sharps container straight away – don't put the syringe in your normal rubbish. You should have received a sharps container with your first delivery of Entyvio® SC
- If you don't have one, please contact your homecare provider* immediately or use a container that:
 - · Is made of heavy-duty plastic
 - Can be closed with a tight-fitting, puncture-resistant lid without anything being able to come out
 - Is upright and stable during use
 - Is leak-resistant
 - Is properly labelled to warn of hazardous waste inside the container
- You can put the rest of the things (the cap, the alcohol wipe, the cotton wool ball or gauze) in your normal rubbish or in the sharps bin
- When your sharps bin is almost full, please contact your homecare provider* who will remove your sharps disposal container and provide you with a new one

^{*}Your homecare provider is the company that delivers your Entyvio® SC.

SELF-INJECTION TIPS

You could try any of the following tips:

Preparing yourself mentally for self-injection

- Give yourself time and space to get it right
- Relax try deep breathing exercises
- Talk about it with your healthcare team, your partner and your family or friends
- Think about all the things that make injecting worth it
- Count out loud
- Give yourself a pep talk that gets you ready to inject
- Focus on something specific such as the number of seconds until you hear the sound of the click

Preparing yourself physically for self-injection

- Practise with a practice device with your healthcare team until you feel confident about injecting
- Numb the injection area with an ice cube
- Vary your injection sites

Preparing your medicine

 Let the medication warm up to room temperature and take it out of the refrigerator 30 minutes before injecting

After you inject

- Put a warm compress on the area straight after and massage it
- Reward yourself after injecting

WHY SHOULD I REHEARSE WITH A PRACTICE DEVICE?

Your healthcare team will have a practice device (pen or syringe) that you can use to familiarise yourself with self-injecting.

Practising the injection is important because it helps you get your technique right and will boost your confidence.

The more you practise, the less it will hurt and the more confident you can be that you're getting your medicine exactly as your doctor intended.

WHAT SHALL I DO WITH ENTYVIO® SC WHEN I'M NOT USING IT?

- Refrigerate at between 2°C to 8°C (36°F to 46°F)
- If needed, for example when you are travelling, the injection pen can be left in its box at room temperature up to 25°C (77°F) for up to seven days
- Do not freeze
- Keep in the outer carton to protect from sunlight



WHAT IF I DON'T LIKE NEEDLES?

First of all, don't feel like that's anything to be ashamed of.



Between 4% and 10% of people have needle phobia.¹²

There's a few things you can do to fight back against your body's response to needles, like simple breathing exercises or distraction techniques.





Applied tension¹³



Breathing exercise¹³

This is a way to get blood pressure back to normal levels so you don't faint.

Follow these steps:

- 1) Find somewhere comfortable to sit
- 2) Tense the muscles in your arms, legs and upper body
- 3) Continue tensing for 10-15 seconds or until your face starts to feel warm
- 4) Release the tension and sit normally
- 5) Wait 20-30 seconds and do it again until you have done it five times

This is a quick, five-minute exercise to help you relax and keep calm.

Follow these steps:

- Sit in a comfortable position, with your back upright but not stiff. Let your shoulders and jaw relax
- 2) Put one hand low down on your tummy
- Take a long, slow, deep, gentle breath, in through your nose and out through your mouth
- 4) Try to breathe right down into your belly, but don't force it. Just let your body breathe as deeply as is comfortable for you
- 5) Do this for five breaths

IS IT GOING TO HURT?

Well yes, it might hurt a bit. But there are things you can do to make it better.



You can make sure your medicine is at room temperature before you inject it (which is why you should take the box out of the fridge 30 minutes before you inject).

You can numb the area with an ice cube.

You can distract yourself with music or an audio book.



You can find out more about how to deal with injections from your healthcare team. They will be happy to answer any questions and they may have further helpful tips that you could try. Alternatively, visit Crohn's and Colitis UK for further information. www.crohnsandcolitis.org.uk. Get tips from someone else with IBD by joining a support group – see the Living with IBD section for more information about support groups.

FACING YOUR FEAR

One of the most effective ways psychologists have identified for overcoming phobias is creating a personalised 'fear ladder' for a specific situation. By putting a list of things that make you feel anxious in order, so that the least feared one is at the bottom and the most feared is at the top, you can put your fears in perspective and work on overcoming them one at a time, tackling the easiest ones first. 13, 14

Here's an example of a fear ladder that you might want to fill in. You can also use it as a template to make your own.

GOAL	Self-inject safely and calmly		
SITUATION		FEAR SCORE / 10	
Self-inject with injection pen			
Get used	to injection pen without needle guard		
Sit quietly	with all supplies for injection ready		



YOUR DIET

While food is not a cause of IBD, some foods may worsen your symptoms during flares.

Poor absorption and loss of appetite associated with IBD could potentially lead to malabsorption (reduced absorption of food in your gut) of essential nutrients. You may have already thought about adjusting your diet, but here are some food tips that you might want to consider during a flare up:¹⁵

- · Eat smaller meals
- · Avoid high-fibre foods
- Drink water often
- Avoid fatty/greasy/fried foods
- Avoid spicy foods
- · Limit dairy intake
- Limit intake of foods that are difficult to digest including nuts, seeds and raw fruits and vegetables
- Eat higher calorie foods (if you are suffering weight loss)
- Take food supplements (if your healthcare team thinks you might not be getting enough vitamins and minerals in your diet)
- Eat lactose-free foods (if your IBD specialist confirms that you are lactose-intolerant)



It may also be useful to keep a food journal so you can keep track of the effects of different foods on your IBD.

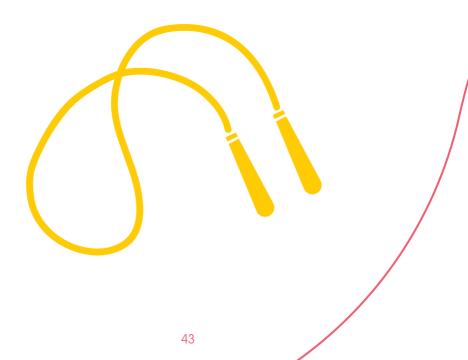


Before making any changes to your diet, you should discuss this with your doctor or a dietitian. Your healthcare team can help you with diet recommendations to ensure you get all the vitamins and nutrients that you need. This will be customised for you and is likely to be based on the type and the severity of your symptoms and personal nutritional needs.

KEEPING ACTIVE

Exercising regularly is an essential part of living a healthy life for everyone, not just those with IBD. While there is no exercise programme that can independently reduce your symptoms, exercise can help:

- Your gut to work better
- Reduce symptoms that are outside of your gut
- Increase your energy levels
- Boost your mood
- Reduce stress
- Strengthen your immune system
- Slow down natural or induced bone loss





Maintaining good overall health may help you physically and emotionally with your IBD.



You could ask your healthcare team what exercise he or she recommends for you. Before you start exercising, it is important that your symptoms are under control and that you are eating and sleeping regularly.



YOUR SUPPORT NETWORK Living with IBD can be painful or difficult in more ways than one. It can be an isolating situation but, as with many things, talking can help. Sharing your worries with other people can lift a weight from your shoulders that you might not even fully realise is there. 45



TALKING ABOUT YOUR HEALTH



Talking about your symptoms and their unpredictability might be difficult and embarrassing.

However, once other people know about them, it may be less stressful for you.

Talk to your healthcare team about any worries and share your experiences with other people on the many online forums available, such as HealthUnlocked. You can also contact Crohn's & Colitis UK's helpline and they can put you in contact with a volunteer that you can talk to.

If you'd like someone in your life to understand a bit more about your IBD, you could recommend that they download the App 'In My Shoes' from the Apple App Store or Google Play.

TALKING WITH...





... your partner

Sitting down for a chat about your IBD might not seem like much of a romantic proposition.

But starting an open and honest conversation about how your chronic condition can affect your lives is a good way to show you're committed to having a trusting and truthful relationship.

If you're not sure how to handle the conversation, try these tips:

- · Be honest
- · Communicate any worries about sex or intimacy
- Don't be afraid to ask for some private time or a bit of space
- Acknowledge when your partner is trying to help even if it's something small
- · Ask questions about how they're feeling

... your family

Getting the right support at home will not only allow you to rest or take time out when you need to, it may also help reduce any feelings of guilt or anxiety when your condition does prevent you from doing certain things.¹⁶

Here's a few examples of how to help the conversation along:

- · Go into detail only when you feel comfortable
- Ask your family members to come with you to medical appointments
- Encourage your family members to ask questions
- Try to explain how physical symptoms can affect you emotionally
- · Thank them for their support
- · Be honest
- · Ask for space when you need it







... your friends

When it comes to telling your friends, it can be hard to know who to tell and what to say.

If you're close, you might want to tell them some details about your diagnosis so they can support you. If you're not that close, it might just be a few choice words that explain why you've cancelled plans or rescheduled a date.

Obviously 'toilet talk' is not anyone's go-to conversation starter so you might not know how to begin the conversation. We can help you out:

- Tell them you have a chronic gut condition and outline your symptoms
- It's also a good idea to mention that even though you don't look ill, you can still be in pain or feel extremely tired
- Most people won't know much about IBD so you might want to mention that it's not an infectious disease
- If you don't want to go into more detail, just share a few links to helpful websites like Crohn's and Colitis UK and apps such as 'In My Shoes'

... your employer

It's up to you whether you want to tell your boss or colleagues about your condition, but it will probably be a good move. Having an open and understanding conversation will mean that you don't have to stress about hiding your condition or the effect it can have on you.

If you decide you want to talk to your boss, we've got a few pointers:

- Book a meeting so you have plenty of time to talk in confidence
- · Think about getting a letter from your doctor
- Tell them your condition is chronic and relapsing. You can't predict when it might become a problem and you might feel unwell without looking unwell
- You might want to explain that you're taking medicine to help with the symptoms
- Explain how your condition might affect your work – e.g. you might need time off for medical appointments or more bathroom breaks than other people and it may impact your travel





... your healthcare team

Having a good relationship with your healthcare team is an important part of successfully managing your disease.¹⁷

If you're just beginning a different treatment, you will probably be in regular contact with your healthcare team - make sure you keep in touch even when you've been on treatment for a while and are feeling well.

- Keep track of your symptoms and treatment so you can feed back on how it's working
- Tell your healthcare team if anything major changes in your life as this might affect your treatment
- Don't be afraid to say how you really feel your healthcare team are experts in IBD, but nobody knows your body better than you

... other people with IBD

Connecting with other people who live with IBD can be really helpful. You might be surprised at how much of a difference it can make to talk to people who really understand what you're going through.

Get in touch with some local support groups. Find out more on www.crohnsandcolitis.org.uk

You don't have to attend a group in person – plenty of organisations have active online communities or phone lines. Here's one example: www.healthunlocked.com/crohns-colitis-support

That's pretty much the basics covered. Hopefully, you now feel like you're a little more prepared to self-inject Entyvio®. Keep this booklet handy in case you want to refer back to it. And just remember, lots of people have been in your situation. You might not be able to imagine self-injecting right now, but after a while it becomes just another part of your routine.





GLOSSARY

WORD	PRONUNCIATION	DEFINITION		
Biologic	by-oh-lodge-ick	Biologic is a general term for any drug or medicine made from living organisms rather than a chemical process like most drugs are. It's a very modern way of treating diseases.		
Chronic	kronik	An illness or disease that goes on for a long time; the opposite of an acute disease, which appears suddenly and doesn't come back.		
Colitis	coll-ite-iss	Simply put: inflammation of the colon. You'll be unsurprised to hear that people with ulcerative colitis have colitis, but so do some people with Crohn's disease. There are also other forms of colitis unrelated to IBD.		
Crohn's disease (CD)	kr-oh-n-s dee-zeas	Named after American gut doctor Burrill Bernard Crohn, this type of IBD is distinguished from UC in that it can affect any part of the gastrointestinal tract, from mouth to anus.		
Flare	flair	A flare, or flare-up, is an acute return or worsening of the symptoms of UC or CD that isn't controlled by regular medication. Stress, infections, or changes in medication can all trigger flares, but they are also simply part of a chronic disease.		
Gastrointestinal (GI) tract	gass-tro-in-test-in-al track-t	The GI tract is made up of the mouth, oesophagus, stomach, small intestine, large intestine and anus.		
Immune system	im-mew-n sis-tem	The body's defence system against illness.		
Inflammation	in-flamm-a-shun	A reaction of the body's tissues causing redness, heat, pain and swelling. If left uncontrolled, it can lead to permenant damage.		
Inflammatory bowel disease (IBD)	inn-flamm-at-tory b-ow-ell di-zeas	IBD is a group of conditions including UC or CD. IBD is an autoimmune disease, meaning the body's own immune system is the cause of the chronic inflammation.		
Infusion	inn-few-shun	The process of getting a liquid or solution into the bloodstream via a needle. Unlike an injection, an infusion is inserted into a vein and is done over a long period of time.		
Intravenous (IV)	inn-tra-veen-us	While an injection can be intravenous, a lot of people refer to their infusions as IVs. Intravenous means it goes into one of the veins in your arm.		
Oesophagus	uh-soff-ah-guss	A tube that connects your mouth with your stomach.		
Organism	or-gan-iz-um	A living thing.		
Relapse	ree-laps	When symptoms return after a period of not having them.		
Remission	ree-mish-un	A period of time during which a disease is not active and you don't get symptoms. As wonderful as remission is, it's important to remember that it's not necessarily permanent: a disease like UC or CD can still cause problems in-between periods of prolonged remission.		
Subcutaneous	sub-cue-tain-ee-us	A form of medication which is situated or applied under the skin.		
Ulcerative colitis (UC)	uls-ur-ah-tiv coh- lite-us	A type of IBD distinguished from CD in that it only affects the colon (large intestine) and rectum. The main symptoms are recurring diarrhoea, which may contain blood and mucus, and abdominal pain.		

NOTES

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