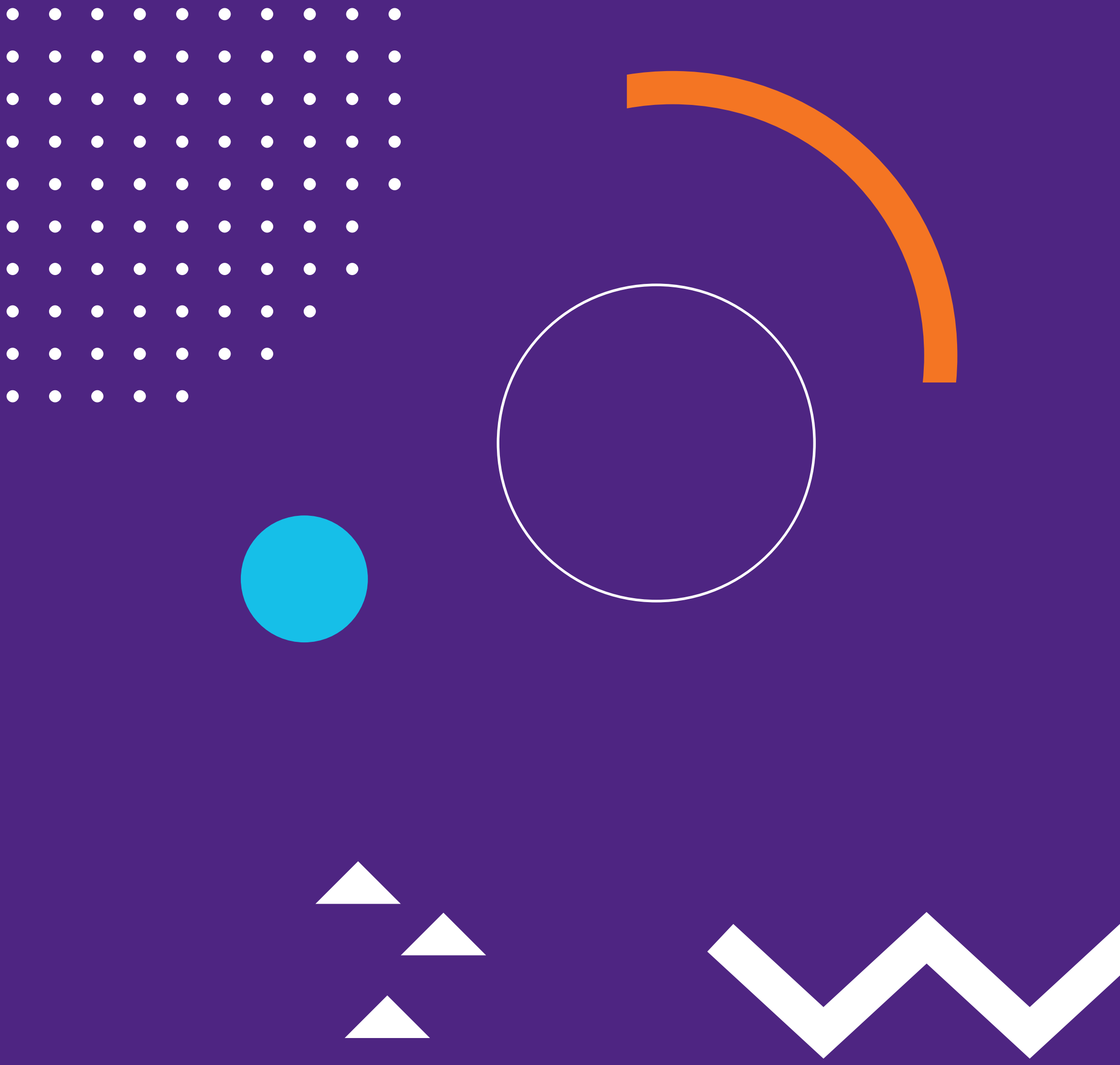
CROHN'S & COLITIS UK

My appointments journal



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Crohn's & Colitis UK. Charity registered in England and Wales
Number 1117148. Scotland Number SC038632

This guide belongs to:

Important numbers:

Crohn's & Colitis UK Helpline	**0300 222 5700**

> “Make a list of questions, make a list of symptoms and frequency and take pictures if needed!”

Tom, living with Crohn’s

Contents

About this Journal

Tools to help

Making the most of your appointments

Health appointments can be daunting when you have Crohn’s or Colitis – no matter how many you’ve attended before.

What do you want to get out of the appointment?
What should you ask?
How can you make sure you’re being listened to?
What will your doctor or nurse want to know?

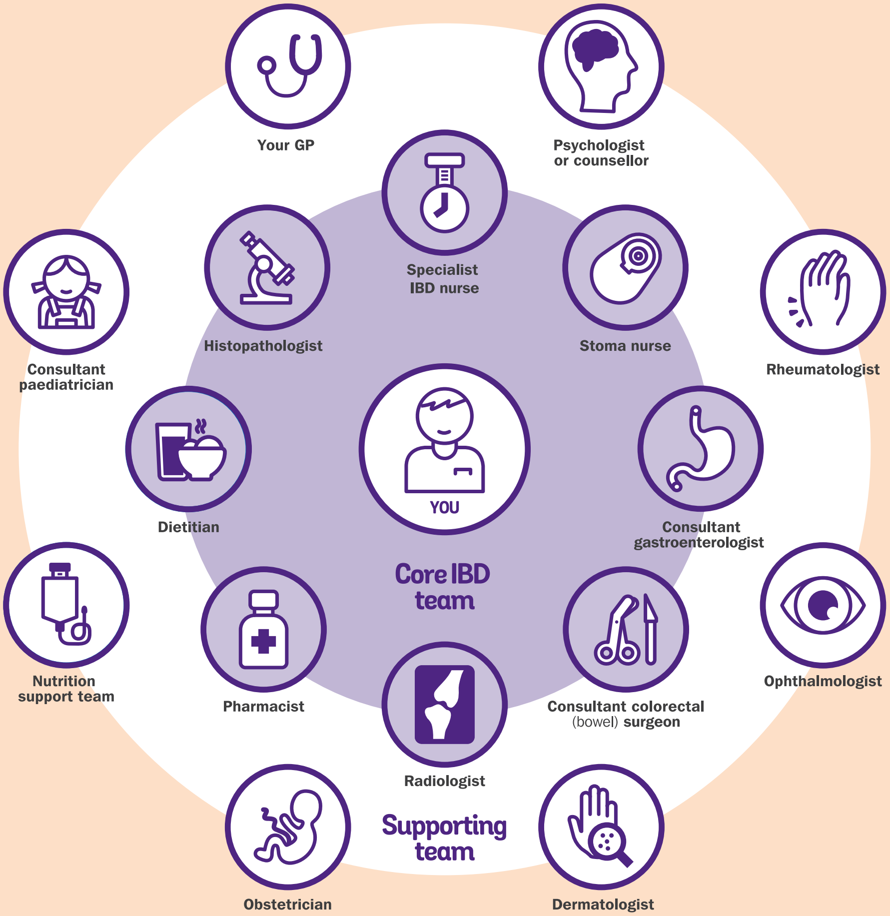
There’s a lot to think about.
But you’re not on your own.

This journal will help you get the most out of your time with health professionals, help you take note of how you’re feeling in between appointments, and keep everything neatly in one place. Most importantly, it will make sure that you focus on **what matters to you.**

Be honest when filling it out, and make sure you keep it somewhere safe. Don’t forget that the Crohn’s & Colitis UK website may answer any questions you have – visit **crohnsandcolitis.org.uk**

> “Don’t worry about looking bad – if you’ve been really busy, forgotten to take your medicine, haven’t been tracking your symptoms, or cancelled your dietician appointment, make sure you’re open about it.”

Jaya, living with
Ulcerative Colitis


Your GP
Psychologist or counsellor
Specialist IBD nurse
Consultant paediatrician
Histopathologist
Stoma nurse
Rheumatologist
Dietitian
YOU
Consultant gastroenterologist
Core IBD team
Nutrition support team
Pharmacist
Consultant colorectal (bowel) surgeon
Ophthalmologist
Radiologist
Supporting team
Obstetrician
Dermatologist

Who you'll see

Not everyone's IBD care teams look the same – but whoever you see, they're all working to help keep you as healthy as they can.

Here's a list of who you might see.

- **Your GP** – can provide blood tests, faecal calprotectin tests, and prescriptions. They organise your referrals and take a holistic approach to your health.
- **IBD Clinical Nurse Specialist** – will facilitate communication with the IBD team to enabling shared decision-making, support your care plan, manage medicines and offer practical and emotional support.
- **Consultant Gastroenterologist** – a named gastroenterologist should lead your care and be responsible for the management of your condition.

Remember that there may be another health professional who can help you reach a specific goal.

For example, you could ask if there's anyone who can support you with diet or nutrition, looking after your mental health, or alternative approaches to living with your condition.

If you want to, you can ask for a second opinion.

We've helped create guidelines on what quality care should look like.

Visit **ibduk.org/ibd-standards** to find out more.

Don't forget you can bring a friend or family member along with you – you don't need to remember everything on your own!

Your team

Use this page to list your personal IBD team.

Name
What they do
Location
Contact

Name
What they do
Location
Contact

Name
What they do
Location
Contact

Name
What they do
Location
Contact

About you

When you were diagnosed:

Medicines you're taking now:

Medicines you've tried:

Allergies to medicines:

Tests/surgeries you've had:

About you

Your Annual Review :

Where Crohn's or Colitis is in your gut:

Other conditions you have:

Notes:

Talking about how you're feeling

There's no right or wrong way to say how you feel, or describe symptoms. But, to give you a steer, here are some words and phrases that might be helpful.

Pain:

- aching
- biting
- blunt
- burning

Fatigue:

- brain fog
- a big black hole
- being woozy or fuzzy
- heaviness
- shattered

Bowel problems:

- urgency
- having an accident
- fear of not getting to the loo in time
- gas, flatulence or wind.

Describing your poo:

- explosive diarrhoea
- like toothpaste
- like a cowpat
- like droppings

The Poo Chart on page 86 can help

Attention-grabbing phrases:

Don't be afraid to use emotive language to say how bad things are for you.

- "I'm worried about"
- "I can't...
- "I'm struggling to/with...
- "I'm not coping with...
- "My quality of life has got worse"
- "I'm not happy with how well my

A great resource for finding the right words is the Crohn's & Colitis UK It Takes Guts website, at **ittakesguts.org.uk**

Understanding you

Your triggers

Use this space to note down things that trigger symptoms for you. Maybe it's stress, certain foods - making notes will help you understand more about what you should (if you can!) avoid.

What helps you in a flare?

Make a note here of tried and tested ways you can feel better. Have a plan of action that you've developed with your doctor or IBD nurse around what to do in a flare. Does your IBD service have a flare card?

Understanding you

Your goals

Your health professionals probably won’t know what your priorities are. So setting goals for what you want out of your treatment is really useful for staying focussed.

What’s your normal?

Let your health professional know what‘s usual for you - it’s easy to get used to living with symptoms that you shouldn’t.

What matters to you?

Crohn's and Colitis affect more than just guts. Tick off what's bothering you and let your health professionals know.

Understanding my condition

- How will Crohn's or Colitis affect me ☐
- Bowel cancer risk (including surveillance colonoscopy) ☐

Symptoms

- Sleep problems ☐
- Unintended weight loss or gain ☐
- Bones and joints ☐

Work, education and training

- Staying in work/education ☐
- Reasonable adjustments ☐
- Working when you shouldn't ☐

Feelings

- Feeling at odds with my culture, beliefs or values ☐
- Anger, loss or frustration ☐
- Sadness or depression ☐
- Confidence knocked/low self esteem ☐

Relationships

- Loneliness or isolation ☐
- Others struggling to accept my condition ☐
- Sex and intimacy ☐

Life

- Exercise and activity ☐
- Pregnancy ☐
- Food and eating ☐
- Complementary therapy ☐
- Challenges performing daily tasks ☐

Tips on talking

Communication is key to a successful appointment, but when you're under pressure it's not always easy. Here you'll find top tips on what to say, and how to say it.

If you don't understand something, say so!
Don't be afraid to ask your doctor to explain.

Try phrases like:

- "Can you help me understand..."
- "So, you mean..." and repeat back what you've understood.

See if your health professional can draw a diagram to help show things like:

- Where your Crohn's or Colitis is most active.
- What will happen in a surgical procedure.
- How and when to take your medicines, such as the best way to insert an enema.

It takes guts to be assertive with your doctor. But being clear about your needs is the best way to get the most out of your time, so don't be afraid to ask questions about **what matters to you.**

Your feelings and symptoms are valid. Health professionals see a variety of people, some of whom are very ill. But don't let what you're going through be dismissed. Needing the toilet 5 times a day may seem less serious in comparrison to others, but it doesn't mean it's not having a huge impact on your life.

What happens next?

Before you leave your appointment, check that you know what will happen next.

These questions can help clear up any uncertainty.

- What should I do if I think I'm having a flare?
- What should I do if I'm having an urgent problem?
- How long will it take for new medication to kick in and are there any side effects to look out for?
- When will I get my test results?
- How long will it take for my referral to come through?
- Where can I find out more information?
- Who can I contact for help? What are their full contact details?

Be assertive

You might feel rushed or that your question hasn't been answered. But don't be afraid to ask more questions about what matters to you.

Imagine you're developing a flare, but you're worried about taking steroids again.

Your doctor says: "From what you are telling me, I had better put you on a course of steroids."

How you might respond:

- "Before we can do that, can I ask about the pros and cons of this medication?"
- "I am worried about this as it will be my third lot in 18 months. Can I make another appointment next week, in case the symptoms die down and I don't need them?"
- "I would like more time to discuss the medication with you."

Handy questions

Not sure what to ask at your appointment? Not to worry – we've put together a useful list of questions that people with Crohn's or Colitis often want to know.

Pick the ones that are most relevant to you. You don't need to ask everything at once – if you think of something later, you could send an email, or call.

About your condition

☐ Why do you think this is Crohn's/Colitis?
☐ Which parts of my bowel are affected?
☐ How does that affect how the disease is treated?
☐ Are there any reasons why you think I may have a more difficult time in the future?
☐ Are there any things I can do to reduce my risks of flaring?
☐ How do I know if I'm in remission?
☐ How do I know if I'm having a flare?
☐ Might my children also develop the condition?

About available support

☐ Are there any support organisations in my local area?
☐ Could I have written information?
☐ Are there any patient education sessions?

Find support and information at **crohnsandcolitis.org.uk**

About your lifestyle

☐ Would it help my condition if I made some changes to my lifestyle, such as giving up smoking or changing my diet?
☐ Will I be able to work full time?

About medicines

☐ Why have you decided to offer me this medicine?
☐ What are the pros and cons of this treatment?
☐ How will it help me?
☐ What effect will it have on my symptoms and everyday life?
☐ How long will it take to have an effect?
☐ Are there any alternative treatment options?
☐ Are there any potential side effects with this medicine?
☐ What should I do if I get any side effects?
☐ Are there any long-term effects of having this treatment?
☐ Why do I need regular blood tests when taking this medicine?
☐ How might steroid treatment affect my bones?

About medicine side effects

☐ What should I do if I get a specific side effect?
☐ What monitoring do I need to look for side effects?
☐ Are there any long-term effects of taking this treatment?

About surgery

☐ How do you think having surgery will help me?
☐ What are the risks associated with this surgery?
☐ What will the operation involve?
☐ What improvements can I expect?
☐ Please give me more information about having a stoma.
☐ How long will I need to stay in hospital after the operation?
☐ Could I talk to someone who has had the operation?
☐ Is there any information on the surgeon who will be doing the operation?
☐ How long will it be before I can get back to my usual activities?
☐ Will surgery affect my sex life? Will it affect future fertility or how a baby might be delivered?

Notes

Notes

Using your journal

This next section of the journal will really help you make the most of your appointments. It will make you think about what you want to get out of it before you meet your health professional, and then reflect on how it went afterwards.

Fill out the left hand side before you go to each appointment. Spend some time thinking about your symptoms, how you'd describe them, and what you'd like to ask.

After your appointment, or during if it helps, fill out the right hand page. Think about how you felt, whether you have any other questions you need to follow up on, and if there are any important things to remember, like test results.

At the end of the book you'll see 'handy reference' pages. These will give you the language to help you describe things like your pain and fatigue levels and communicate how you've been feeling.

We've filled in the first Journal entry with the help of people living with Crohn's and Colitis as an example to get you started.

You'll also find some stories of other people like you who've shared their thoughts and feelings - **you're not alone.**

Time in appointments is limited, so think whether your questions could be answered with a call to your IBD Nurse, or on the Crohn's & Colitis UK website

> “My consultant asked me for a goal and I said it was to stand in a field with no toilets around. For a long time toilets were like a security blanket – I always had to know where the nearest one was.
>
> So, the idea of going to Peru and doing the Inca trail –it felt like an impossible journey. But that’s where we’ve just gone on holiday. I’m not worried at all now”

Paul, living with
Ulcerative Colitis

Before your appointment: Example

Who you're seeing: My Gastroenterologist

When: Tuesday 2pm

Where: Hospital – gastro outpatients

My main worries:

I don't think my medicine is working anymore because I've been in a lot more pain, and going to the toilet a lot more. It's making me really worried about leaving the house. More and more foods set me off now so I've been limiting what I eat. It's starting to make me feel really down as I don't have anyone to talk to who understands.

My mental health – I've felt

😁 🙂 😐 [✓ 🙁] 😦

←→

💩 **Poo:**

6 times a day

⚡ **Pain:** Around 7 on the pain scale on page 87

💤 **Fatigue:** Around 5 on the fatigue scale on page 87

What are your goals for this appointment?

Discuss an alternative treatment option ☐

Get advice about what to eat ☐

Information on support groups ☐

☐

After your appointment

How did it go?

My blood test results look normal so I'll have to have an endoscopy to check. Dr gave me a prescription for some enemas for now to see if that helps. She gave me some information sheets on other medicines I could try next, so I'll book in an appointment next month to discuss these if the enemas don't help. She also said Crohn's & Colitis UK have a Local Network in the area where I can meet others with Crohn's and Colitis.

What needs to happen next?

- **My health professional has agreed to :**

Refer me to the hospital dietician and counselling service

Arrange an urgent colonoscopy with the Endoscopy deptartment

- **I've agreed to:**

- Start reading about the other medicines I may try next
- Try the enemas every night
- Arrange an appointment with my doctor for next month
- Join the Crohn's & Colitis Local Network

Weight:

Test results:

Bloods all normal

Before your appointment: ___/___/___

Who you're seeing:

When : **Where:**

My main worries:

My mental health – I've felt:

💩 Poo:

⚡ Pain:

Zz Fatigue:

What do you hope to get out of this appointment?

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After your appointment

How did it go?

What needs to happen next?

- My health professional has agreed to :

- I've agreed to:

KG **Weight:**

Test results:

Before your appointment: ___/___/___

Who you're seeing:

When : **Where:**

My main worries:

My mental health – I've felt:

😃 🙂 🙁 😐 😧

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💩 Poo:

⚡ Pain:

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After your appointment

How did it go?

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- My health professional has agreed to :
- I've agreed to:

KG Weight:

Test results:

Waiting for your appointment and got a pen handy? Get creative.

You can spend a lot of time in waiting rooms – so there are pages in the journal for you to doodle the time away. Researchers believe you're able to retain more information following a good doodle session, so grab a pen!

Before your appointment: __/__/__

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😃 🙂 🙁 😐 😧

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Pain:

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- I’ve agreed to:

Weight:

Test results:

Charlie's story

Need a bit of encouragement to open up? Here's what Charlie has to say…

"I've had so many conversations about my Colitis that it's almost become one of my opening lines.

But a time that stands out most is when I went on a date with my now-wife. We'd met on a night bus on the way home from town and arranged a meet up over text in a local bar.

On our first date I told her that I might keep disappearing off to the loo due to my Colitis. She took it in her stride, with a sip of her wine. Despite my regular visits to the WC she didn't seem to mind! I told her then it's part of me and a big part of my life. If she didn't like it, I would have known then that it wasn't going any further.

I've never been afraid to share my condition with others, but it was incredible to know this woman that I really fancied was accepting of it. My advice? Just be open and honest."

Charlie, living with Ulcerative Colitis

Waiting for your appointment and got a pen handy? Get creative.

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When : **Where:**

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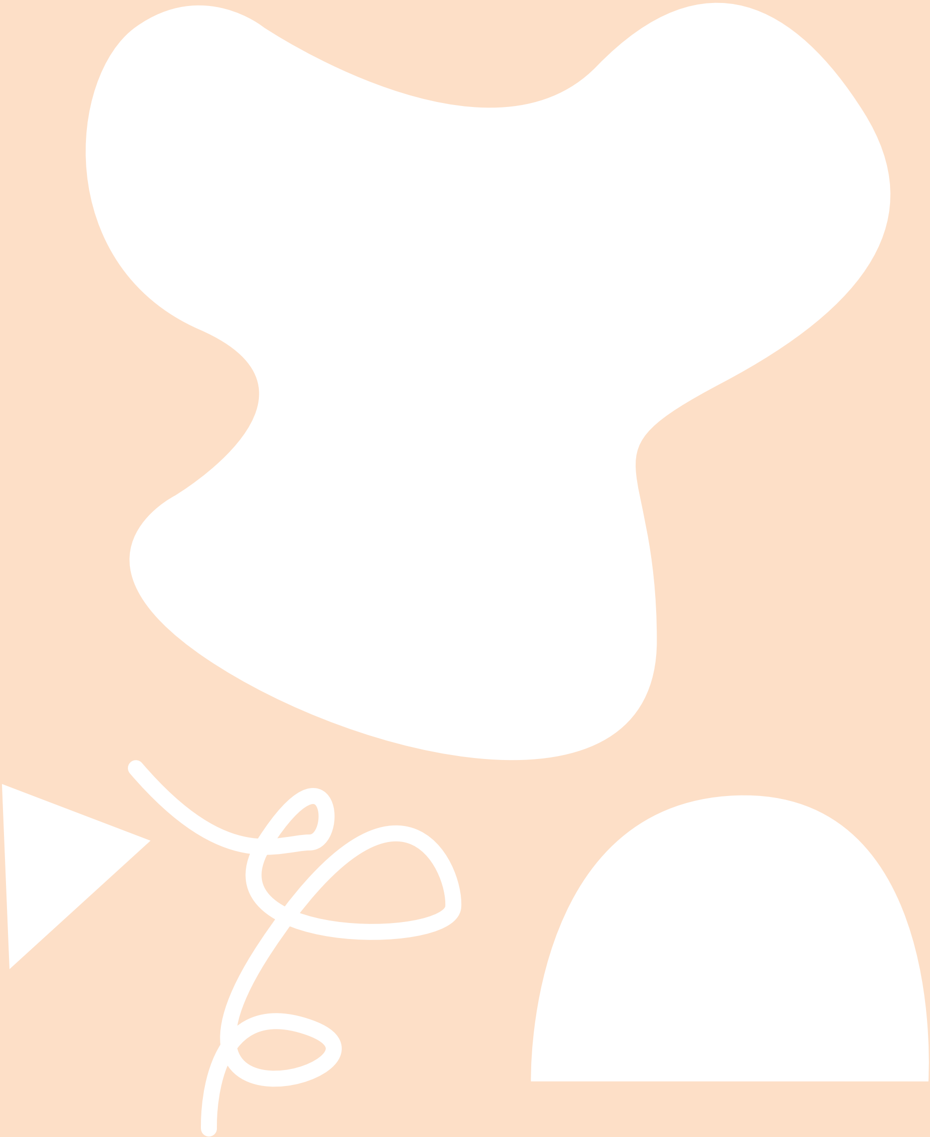

Tips to stay calm

- Breathe. Take a few deep breaths and focus on them fully.
- Tackle your to-do list. Ticking tasks off can help you feel better if you're overwhelmed.
- Write down how you're feeling. There are notes pages in this journal for you to capture your thoughts.

Before your appointment: ___/___/___

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Test results:

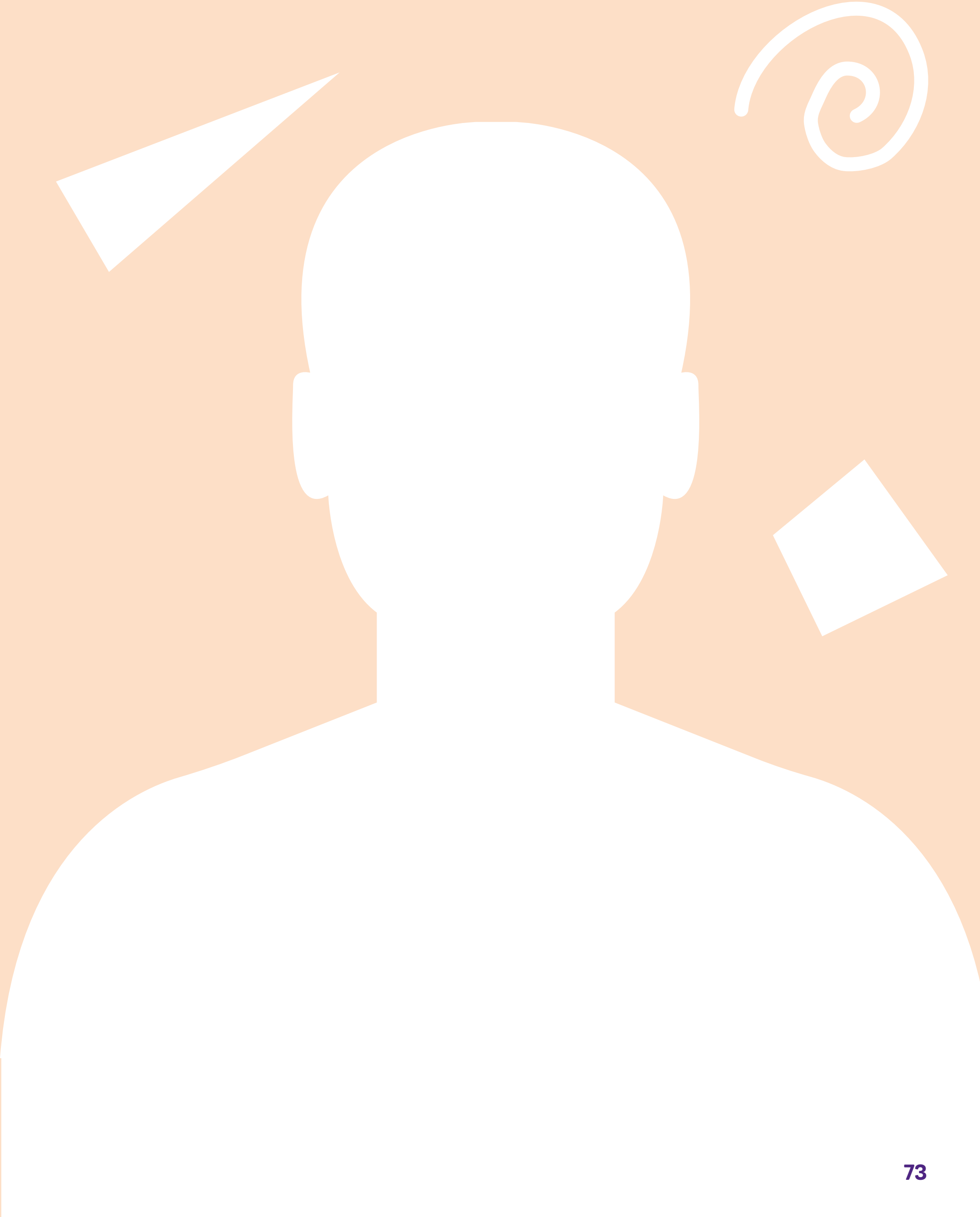
Becky's story

Got two minutes before your appointment?
Read Becky's story of opening up at work.

> "I started a new job and decided to tell my whole team about my Ulcerative Colitis. It turned out one of the other girls on my team also had it!
>
> She was the first person I met who had the same disease as me, and it ended up being a great way of starting a tricky conversation. There are still times when I don't feel completely understood but every conversation helps chip away at the stigma around bowel diseases!
>
> I felt more comfortable at work, and like I could tell my team if I was feeling particularly unwell or fatigued.
>
> My tip? Use the Crohn's & Colitis UK website for facts and useful information that can help other people understand what you're going through. It might feel awkward at first, but people are more understanding of things when they are more informed."

Becky, living with Ulcerative Colitis

Waiting for your appointment and got a pen handy? Get creative.



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After your appointment

How did it go?

What needs to happen next?

- My health professional has agreed to :

- I’ve agreed to:

Weight:

Test results:

Before your appointment: __/__/__

Who you're seeing:

When : **Where:**

My main worries:

My mental health – I've felt:

😃 🙂 🙁 😐 😧

↔

💩 **Poo:**

⚡ **Pain:**

Zz **Fatigue:**

What do you hope to get out of this appointment?

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The first step

By Anne Ayres

Winner of the Crohn's & Colitis UK It Takes Guts short story competition.

Jane sat in the hospital corridor trying not to read the posters on the wall. On either side of her a row of people were busy reading books, or scrolling through their phones. She had left Jack in the waiting room - she hadn't wanted him to see how nervous she was.

A young man appeared. "Amelia Roberts?"

Everyone looked around but nobody moved. "Amelia Roberts?" he called again, this time with just a hint of impatience.

"Sorry, that's me." Jane stood up, feeling flustered. "You see, Amelia is my first name and..."

The man had disappeared through a door. Jane followed him, feeling wrong-footed. He indicated a chair by the side of his desk. "I'm Mike," he said. "I'm the gastroenterologist." He smiled encouragingly at her and then started reading a file.

Jack's advice ran through her head. "Tell him everything. Tell him about the pain and always having to look for loos." But she couldn't find the words to tell Mike any of these things, he was too young. He was probably younger than her son. She felt herself flush with embarrassment.

"So, how are you feeling today?" Mike asked.
"Good, thank you."
Mike picked up a pen and started writing. He paused waiting for her to continue. He looked very tired.
"It's just that, every so often,"
Jane's tongue seemed to swell in her mouth.
"Yes?"
"It's just that,"

Mike started writing again. He looked like a diligent schoolboy doing his homework. She found herself burbling something. She imagined he was writing ‘time-waster’ and she missed the next bit of the conversation.

“So, what do you think?” he asked. “Shall I arrange that?”
“I’ll think about it.”

Jane was too embarrassed to admit she hadn’t been listening. Jack’s anxious face floated across her vision. He was such a patient man. He never complained about spoiled holidays and difficult days out or just not being able to leave the house at all. Somehow she must find the courage to explain, for Jack’s sake. She took a deep breath.

“I’m sorry,” she said. “Can we start again?”

Mike gave a quick glance at his watch and Jane started talking quickly about her fears that things were more serious than she had admitted to Jack or to herself. She found it easier to talk to the picture on the wall above Mike’s head, but she didn’t think he minded.

Then suddenly it was over and she was being ushered to the door. Mike was saying “I’ll be writing to you shortly setting out a plan.”

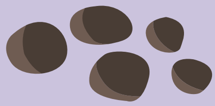
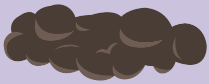
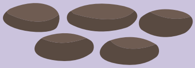
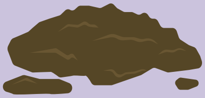
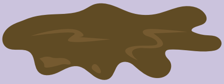
When she got back to the waiting room Jack was reading his newspaper.
“Well, love, how did it go?”
“The doctor is going to write.”
Jack looked so disappointed that she reached out to him.
“It’s all right,” she said. “I told him everything and it was such a relief.”

They smiled at each other. It was the first step.

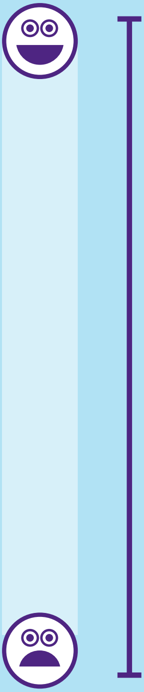
Handy references

From what's going on in the toilet, to feeling fatigued – it can be hard to know how to explain your symptoms. Use these pages to help.

Poo chart – Bristol Stool Chart, your health professionals will be familiar with this.

	**Type 1**	Separate hard lumps	**Severe constipation**
	**Type 2**	Lumpy and sausage like	**Mild constipation**
	**Type 3**	A sausage shape with cracks in the surface	**Normal**
	**Type 4**	Like a smooth, soft sausage or snake	**Normal**
	**Type 5**	Soft blobs with clear-cut edges	**Lacking Fibre**
	**Type 6**	Mushy consistency with ragged edges	**Mild diarrhoea**
	**Type 7**	Liquid consistency with no solid pieces	**Severe diarrhoea**

Pain scale



0	**No pain**
1	**Very mild**– very minor annoyance
2	**Discomforting** – minor annoyance
3	**Tolerable** – anoying enough to distracting
4	**Distressing** – distracting but can ignore
5	**Very Distressing**– can't be ingored for more than 30 mins
6	**Intense** – but you can still do other activities
7	**Very intense** – hard to concentrate
8	**Utterly horrible** – physical activity limited
9	**Excruciating** – unable to speak
10	**Unimaginable**– can make you pass out

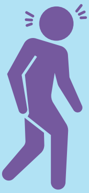
Fatigue scale

0

No fatigue – able to do all normal activities.

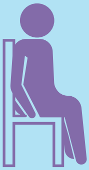
1 2 3

Mild fatigue – able to do most normal activities.



4 5 6

Moderate fatigue – able to do some activities but need rest.



7 8 9

Severe fatigue – difficulty walking or doing everyday activities.

10

Extreme fatigue – needing to sleep or rest all day.

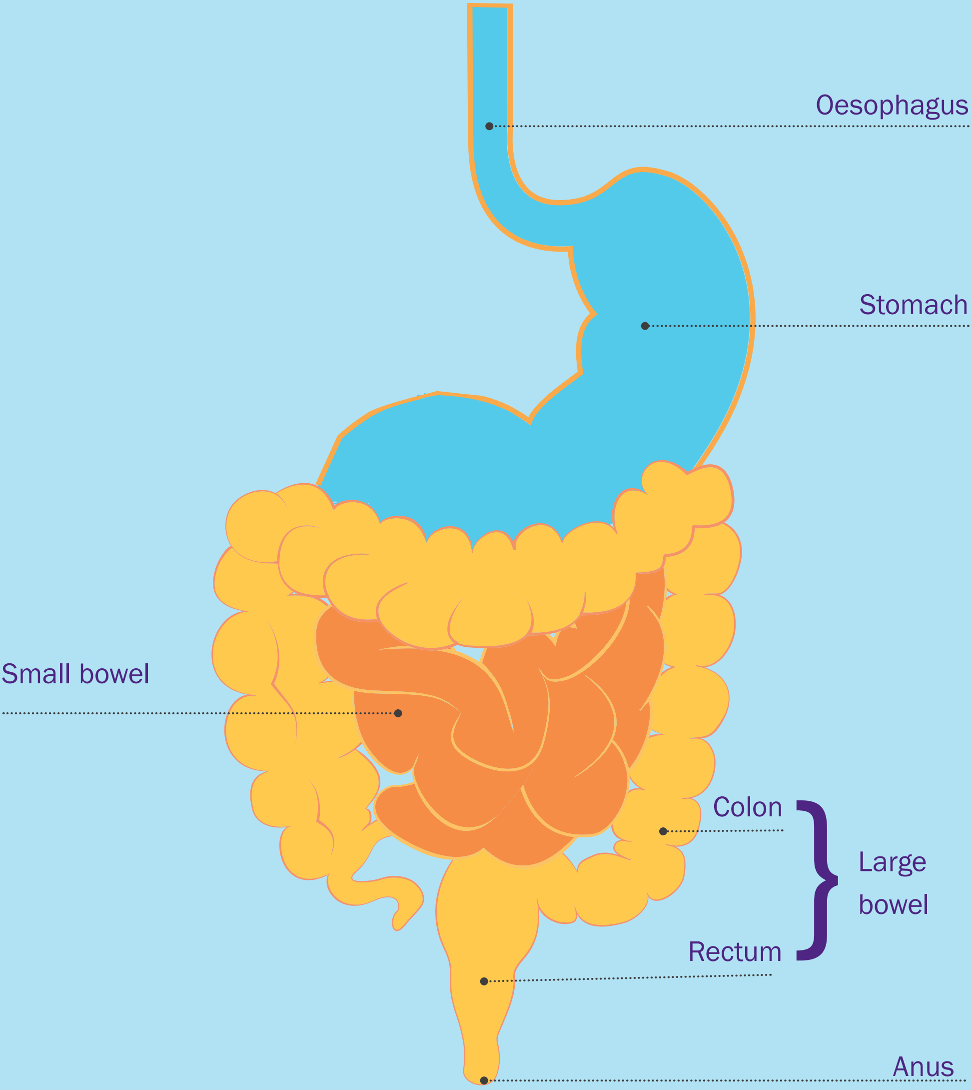
Things your healthcare professional may say

If you hear a word you don’t understand, make sure you ask what it is - remember our tips on being assertive.

Diarrhoea	Going to the toilet a lot, with loose or watery poo
Chronic condition	Lifelong, ongoing disease or illness
Fatigue	Extreme tiredeness
Relapse, flare-up, active disease	When you feel unwell
Remission, inactive disease	When you feel better
Ulcerated	To have sore wounds: ulcers
Opening bowels	Poo, bowel movement, stool, faeces
Personalised care	You have choice and control over the way your care is planned and delivered

The Gut

Ask your health professional to show you on this diagram where they're referencing when they're talking about your condition.



Symptom tracker

Date	Time	Food, medicine, or activity	Symptoms
Example	3pm	Ibuprofen	Abdominal pain

Symptom tracker

Date	Time	Food, medicine, or activity	Symptoms

Symptom tracker

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Symptom tracker

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Notes

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HELP FROM CROHN'S & COLITIS UK

We're the UK's leading charity for Crohn's and Colitis. We want improved lives today and a world free from Crohn's and Colitis tomorrow.

We work to improve diagnosis and treatment, and to fund research into a cure; to raise awareness and give people hope, comfort and confidence to live freer, fuller lives.

We're here for everyone affected by Crohn's and Coltis

Crohn's & Colitis UK received funding from Pfizer and AbbVie, who had no input into the content or design of this guide.

it takes
guts

to talk about
Crohn's
and Colitis

crohnsandcolitis.org.uk