

# MY PARTNER IN CARE



Managing Crohn's disease  
and ulcerative colitis together

# 1 WHO'S ON MY TEAM?

Life with Crohn's disease or ulcerative colitis can be complex. It affects every individual in a different way and your needs may change over time.

Multiple healthcare professionals work together with you and each other to take care of your overall health and wellbeing. This team is known as your inflammatory bowel disease (IBD) team.

## An IBD team should include you and:

### General practitioner (GP)

A doctor in your local community who works closely with your specialists

### Specialist IBD nurse

Educated and informed of the latest developments in IBD care

### Psychologist

Supports you through any psychological distress and adjustment to living with IBD

### Stomal therapist

Helps care for those with an ostomy (bag) due to IBD related surgery

### Telephone IBD helpline

Pharmacist  
With an IBD interest and expertise

### Gastroenterologist

Specialises in the treatment of the gastrointestinal tract and liver

### Accredited practising dietitian

Helps make a dietary plan for you

### Colorectal surgeon

Specialises in the surgical treatment of the lower digestive tract



## Does every hospital have an IBD team?

Not all hospitals or clinics in Australia have all of these services available. If you live somewhere with a small hospital, you can speak with your team about linking you with specialised services. A nominated local clinician should help coordinate your care.

If you see a private specialist you can be referred to other healthcare professionals to create your own team.

## What if I'm not 18?

Anyone under the age of 16 should be cared for by paediatric gastroenterologists, with access to specialist nursing and dietetic support.

Your team should develop a plan for transition to adult care when you are 15 or 16. If you're 17 or 18, you may be treated by paediatric or adult services. For more information on living with IBD from childhood please visit: [rch.org.au/kidsinfo/fact\\_sheets/Inflammatory\\_bowel\\_disease/](http://rch.org.au/kidsinfo/fact_sheets/Inflammatory_bowel_disease/)

## YOU MAY WANT TO ASK

Who is on my IBD team?

I would like to see a dietitian.

Who is my main contact person on the team?

I would like to see a psychologist.



## 2 HOW WILL I BE CARED FOR?

Your IBD team will work closely with you to determine the best course of action. Although there is no cure for Crohn's or colitis, they can be managed through several treatment options.

### Medical therapies

The aim of these steroid, immunomodulator and biological therapies is to get you feeling well again (remission). While they are generally initiated and managed by a specialist, General Practitioners (GPs) and pharmacists should also be involved.

### Specialist surgical care

If you need any surgery it should be carried out by recognised colorectal surgeons who are core members of the IBD team. The hospital where you receive surgery should have the necessary IBD team support services available.

### Nutritional support

From dietary advice to specific instructions, nutritional support plays an important role in your care. You should have access to an accredited practising dietitian.

### General practice care

You should have access to ongoing general practice services. Your GP should be updated on your progress and management plan. They may also coordinate other aspects of your care with members of your team.

### Psychological care

Psychological care can be important to help you adjust to living with a chronic disease like Crohn's or colitis. IBD can trigger anxiety and depression, especially when it's active. All patients should be screened by their IBD team and treated for any psychological distress.



My advice to others with IBD is: take your condition seriously, learn the possibilities, but don't let it rule your life.

Jill, diagnosed in 2008



### WHERE CAN I LEARN MORE?

For more information on **medical therapies** visit: [crohnsandcolitishub.com.au/medication-for-ibd](https://crohnsandcolitishub.com.au/medication-for-ibd)

For more information on **surgical care** visit: [crohnsandcolitishub.com.au/surgery](https://crohnsandcolitishub.com.au/surgery)

You can download the **Wellbeing Toolkit** on the Crohn's and Colitis Hub e-Books section: [crohnsandcolitishub.com.au](https://crohnsandcolitishub.com.au)

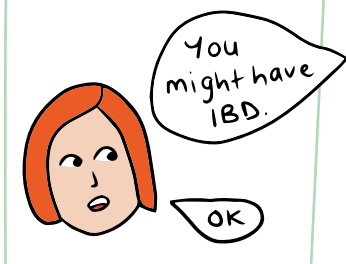
For information on **psychological therapy** visit: [fameyourgut.com](https://fameyourgut.com)

# 3 HOW DO I GET WHAT I NEED ON TIME?

Crohn's disease and ulcerative colitis symptoms can be unpredictable. They occur when the disease is in an active inflammation state, often referred to as a "flare". Standards are in place to ensure your needs are met quickly. That's the best way to minimise the effect on your health and wellbeing.

The Australian IBD Standards have recommended timeframes in place for different scenarios including:

4 weeks



## Newly suspected IBD patients

Your first point of contact will likely be with your GP or an emergency department. There are guidelines in place to help them identify and refer anyone suspected of having IBD. You should be seen by the appropriate specialist within 4 weeks or earlier if necessary.

Feel free to share this helpful resource with your GP: [gesa.org.au/resources/clinical-guidelines-and-updates/inflammatory-bowel-disease/](https://gesa.org.au/resources/clinical-guidelines-and-updates/inflammatory-bowel-disease/)

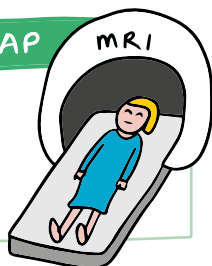
24 hours



## Hospital admission

If you are admitted to hospital and are suspected of having IBD you should be placed under the care of a gastroenterologist or colorectal surgeon within 24 hours.

ASAP



## Access to diagnostic services

There are guidelines in place to make sure ultrasound imaging, MRI, CT scans, contrast studies, endoscopic assessment and biopsies are promptly available.

## 4 WHAT'S AN IBD HELPLINE?

You should have access to a dedicated phone service, usually provided by your IBD team, for any questions or concerns you have about your condition. Calls or emails should either be answered or messages responded to by the end of the next working day.

**For those without access to an IBD team helpline, try Crohn's and Colitis Helpline/ NurseLine: 1800 138 029**

### YOU MAY WANT TO ASK

What happens next?

What are my choices?

When will I have the results?

How do I find out my results?

Will you give my GP/IBD team a copy of the results?

What phone number should I call if anything changes?

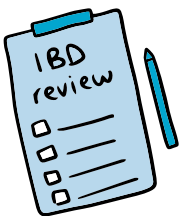


## 5 WHAT WILL MY HOSPITAL STAY INVOLVE?

If you need to be in hospital, you should be admitted into a specialist gastroenterology ward or area. Rooms and toilet facilities should ensure you have the privacy required. Processes and protocols should be in place to make sure you are assessed, diagnosed and treated quickly.

### After you leave hospital

You should receive information about follow-up care before you are discharged. Even if you're in remission, there are several lines of support that will remain open to you after you leave hospital.



**An annual review of your IBD.**



**An IBD helpline which offers a response by the end of the next working day.**



**Specialist review within five working days of suspected relapse or flare.**



**A choice of outpatient care.**

# 6 WHAT ARE MY CHOICES IN THE CARE I RECEIVE?

You should be offered a choice about the care you receive. This is both during treatment and the follow-up. Your choices should always be clearly communicated to you. You should be clear on who to go to if your condition changes.

## Different types of care to choose from

Hospital outpatient or private practice

GP-based shared care

Self-managed with support

## Things that impact your choice

The complexity and severity of your disease

Local facilities

Personal preferences

## How do I choose which treatment to have?

You may be offered a choice in treatments and should receive support and information to help you decide. For example, many children have the choice between drug treatment and dietary therapy for Crohn's disease. The benefits and risks of each should be discussed.

You should be given the opportunity to participate in clinical trials for suitable IBD medications and treatments currently in development.

## How do I give my consent?

Sometimes you will need to give written consent for a treatment or procedure. It should be written in clear, simple language and a team member should be sure you understand before signing.

## How do I find out more about surgery?

If you are being considered for surgery, you should be offered written, audiovisual or web-based information. You may also get the opportunity to talk with those who have had pouch surgery or a permanent ileostomy, if relevant. You should get information about postoperative care before discharge.

## Can I use any alternative or complementary therapies?

Some IBD patients use complementary and alternative medicines or therapies. All IBD treatments, including complementary therapies, should be reviewed with your IBD team for benefits and possible side effects.

## YOU MAY WANT TO ASK

What options for treatment do I have?

What are the risks and benefits of each?

Can I have some written information on the proposed treatment?

Are there any clinical trials I could participate in?

Can I speak to someone who's had the surgery?

For more questions visit: [healthdirect.gov.au/questions-to-ask-your-doctor](https://www.healthdirect.gov.au/questions-to-ask-your-doctor)

Or this tool can help you prepare your own questions:

[healthdirect.gov.au/question-builder](https://www.healthdirect.gov.au/question-builder)

For more information to guide your healthcare choices:

[chf.org.au/be-health-aware](https://www.chf.org.au/be-health-aware)



## 7 HOW DO I FIND OUT MORE?

The more well informed you are the greater chance you have of achieving the best quality of life. These tools are a great place to start: [crohnsandcolitis.com.au/find-support/clinical-insights-tools/](http://crohnsandcolitis.com.au/find-support/clinical-insights-tools/)

There are provisions in place to make sure you are well informed at every stage of your illness.

### Information you receive should be:

Relevant to your care and treatment options.

Delivered by an identified member of the team.

Appropriate to your age, understanding and communication needs.

Available in outpatient clinics, wards, endoscopy and day-care areas.

Available in languages other than English, if required.

In a variety of formats including written, audiovisual or web-based.



Knowing that I can email the IBD nurse and get an answer quickly is great. They are just so super friendly and approachable and give me the information I need.

Meredith 31,  
diagnosed  
with UC  
at 26 years



## 8 HOW DO I PROVIDE FEEDBACK ON THE CARE I RECEIVE?

Sharing your experiences can help improve the service provided to those affected by IBD. Reach out to your IBD team or Crohn's & Colitis Australia (CCA) to find out how.

# ABOUT THIS BOOKLET

This booklet is designed to help people living with Crohn's disease and ulcerative colitis, together known as IBD, their families, carers and other support people get the most out of their care.

It is a condensed version of the Australian IBD Standards, focussing on your direct care and the services available to you. **You can find the full document and more information at: [crohnsandcolitis.com.au/ibdqoc](http://crohnsandcolitis.com.au/ibdqoc)**

This document was written together with people living with and affected by IBD and incorporates aspects of their care experience.

The information provided can be used in discussion with your doctor and healthcare professionals. This includes nurses, pharmacists, specialists, allied health, mental health workers and GPs.

This booklet does not replace the advice of healthcare professionals. Always consult with a doctor or healthcare provider for a better understanding of IBD care.

Health services in Australia vary and not every service will currently provide the same level of care and support, although most will be working towards the Australian IBD Standards.

This booklet has been produced by CCA, the peak national body representing approximately 85 000 Australians with IBD.

## Published by Crohn's & Colitis Australia

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