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# MY CROHN'S AND COLITIS CARE YOUR GUIDE



“

Sometimes living with IBD is frustrating but having the right information and support has helped me to feel more in control of my life. ”

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**Melissa, 44**  
Diagnosed with  
Crohn's Disease in 2000

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# ABOUT THIS GUIDE

The aim of this guide is to help you to get the best out of your healthcare service by working in partnership with those supporting you. It should apply to you whatever your age. Each section focuses on a different one of the top 10 essentials that make up a good Inflammatory Bowel Disease (IBD) service and outlines how you can work most effectively with your local health service to manage your condition and care. It may also be helpful for your family and carers to read **My Crohn's and Colitis Care** so they can support you as you make decisions about your treatment and care.

**My Crohn's and Colitis Care** draws on the **IBD Standards** (see page 4), which were developed by Crohn's and Colitis UK and a wide range of health professional organisations, with significant input from people living with IBD and their families. Services vary and not every service will currently provide the same level of care and support, although most will be working towards the **IBD Standards**.

In developing **My Crohn's and Colitis Care**, we have sought the views and opinions of a range of people living with IBD, as well as doctors, nurses and others who provide care and support to people with IBD. We are very grateful to all those who have been involved. See inside back cover for supporting organisations.

# TOP 10 ESSENTIALS OF A GOOD INFLAMMATORY BOWEL DISEASE SERVICE:

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### WHAT IS INFLAMMATORY BOWEL DISEASE?

The two main forms of Inflammatory Bowel Disease (IBD) are Crohn's Disease and Ulcerative Colitis (UC). In both Crohn's and UC, parts of the digestive system, usually the intestines (also known as the bowels), become swollen, inflamed and sore.

Common symptoms can include pain, diarrhoea (sometimes with blood), weight loss and tiredness. Some people develop anaemia or have problems with their joints, skin or eyes. Both Crohn's and UC are chronic (long-term) conditions that can flare-up unpredictably, although you may also have periods of good health (remission). There is no cure at present.

### THE IBD STANDARDS

The **IBD Standards** were developed in 2009 by patient associations and a wide range of professional organisations working together. The Standards set out what a good quality IBD service should look like. The aim of the **IBD Standards** is to ensure that people with IBD receive consistent, high quality care wherever they live in the UK.

The **IBD Standards** were produced following the first UK IBD Audit in 2006, which collected information about IBD services and care and found wide variation in quality. Further audits have shown significant improvements, but also highlighted the changes that still need to be made.

The **IBD Standards** were updated in 2013 and continue to provide a benchmark for healthcare services. They have been used to inform the development of a NICE quality standard for Inflammatory Bowel Disease.

1

I AM SUPPORTED BY A  
TEAM OF IBD SPECIALISTS  
WHO HELP ME MANAGE MY  
CONDITION

WHY DOES THIS MATTER?

Living with a fluctuating condition such as Inflammatory Bowel Disease (IBD) means you may need the support of a number of different healthcare professionals over time. Each person you deal with should have a specialist knowledge of IBD, and between them, this team should be able to support you with every aspect of your IBD care. This will range from initial assessment and diagnosis, to disease and treatment management, rapid care during flare-ups, nutritional support, and surgery if and when required.

Members of the IBD team must establish a collaborative approach to the provision of care for IBD patients.

IBD Standards  
Standard A1

WHAT DOES THIS MEAN FOR ME?

Every local area should have a dedicated IBD team. This may cover one or more hospitals. This team, working well together and with you, is a central element of the **IBD Standards**. It is vital for ensuring that you get the type and continuity of care you need. Every team should have one person with overall responsibility for the IBD service and you should be told who they are.

Every IBD service should be working towards having a full IBD team in place, although some may not have achieved this yet.

## WHO IS PART OF MY IBD TEAM?



“  
Having a specialist IBD team has helped me immensely, both physically and mentally, to cope with IBD. It is reassuring to know that there is somebody that understands the condition and how to deal with it promptly and efficiently.”

**Melissa, 44**  
Diagnosed with  
Crohn's Disease in 2000

Your first point of contact for advice or support in relation to your IBD may be an IBD specialist nurse, gastroenterologist or GP. These are the people you are likely to see most regularly. Most IBD services will have an IBD nurse, who will work with you and the other members of your team to coordinate your treatment and care. They are also there to advise you during flare-ups and provide you with the information and support you need to help you keep your IBD under control. Most IBD nurses can be contacted through a helpline or dedicated email address.

The **IBD Standards** outline that you should have access to a **core IBD team**, who should all have a special interest in IBD or gastroenterology, and should include:

- Specialist IBD nurses (often called clinical nurse specialists)
- Stoma nurses
- Consultant gastroenterologists
- Consultant colorectal (bowel) surgeons
- A radiologist (who uses imaging to diagnose and inform treatment)
- A pharmacist
- A dietitian
- A histopathologist (who looks at cells and tissue samples to diagnose and inform treatment)

Additionally, there are healthcare professionals who should work alongside the core IBD team and also have an interest in IBD. These should cover a number of essential supporting services and include:

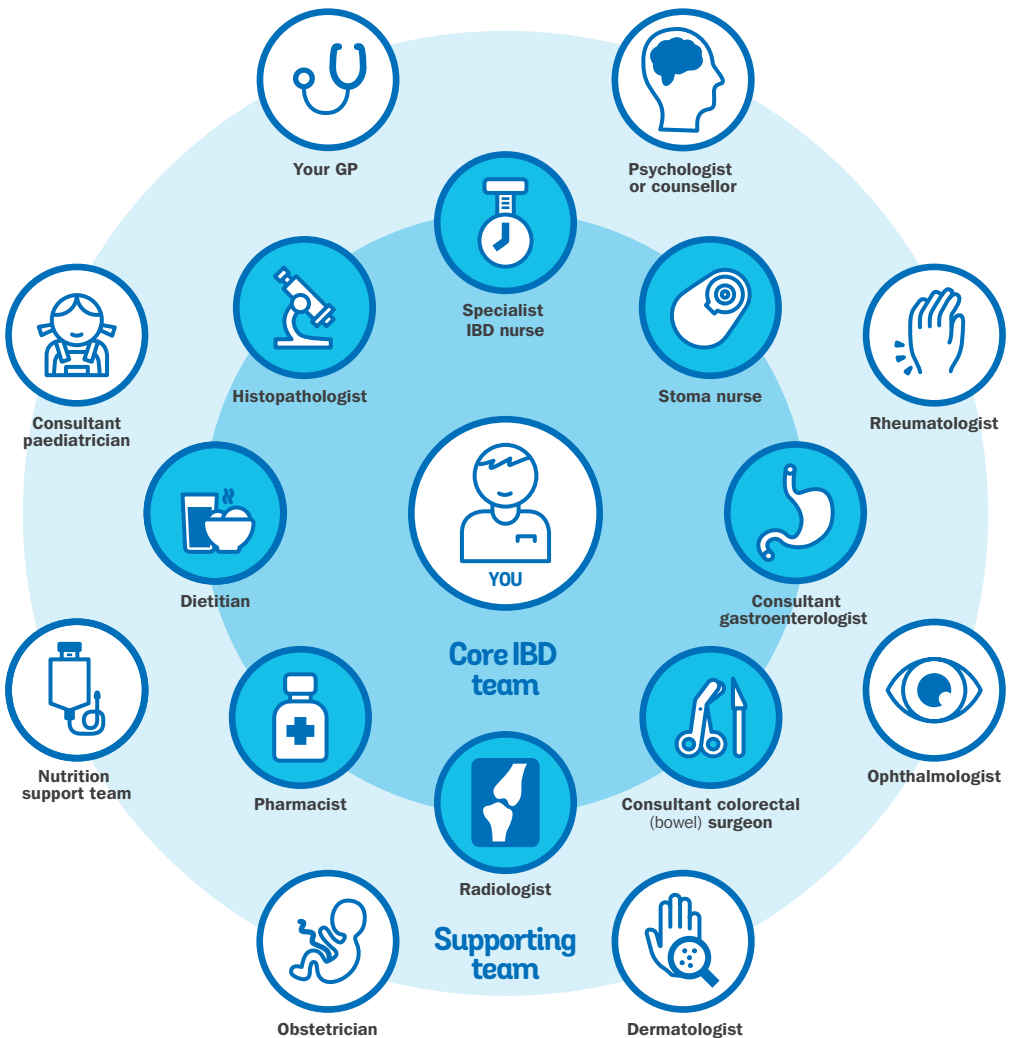
- A psychologist or counsellor
- A rheumatologist (a specialist in diagnosing and treating arthritis and related conditions)
- An ophthalmologist (a specialist in medical and surgical eye problems)

## MY IBD TEAM

- A dermatologist (a skin specialist)
- An obstetrician (a pregnancy and childbirth specialist)
- A nutrition support team
- A consultant paediatrician

Your GP is also likely to play a role in some elements of your care, and should be aware of and in contact with your IBD team.

## YOUR IBD TEAM



**The professionals involved in providing IBD care must have specialist knowledge about IBD and its impact. A multidisciplinary approach [which brings together a range of healthcare professionals] is essential to achieving the best care for patients.**

**IBD Standards**  
Standard A Rationale

Your IBD team should be able to support you with all aspects of your IBD. There should be regular communication between members of the team and with you. Even if they work in different parts of the NHS, members of the IBD team should work together to help you manage your condition.

Members of the IBD team should always introduce themselves to you and explain their role.

**WHAT CAN I DO?**

- Find out who is in your IBD team and who leads the team
- Ask if there is a leaflet describing your IBD service
- Find out what supporting services are available to you, for example, a dietitian or psychologist
- Learn about your condition – see below for details of where to find more information



**HELP AND  
SUPPORT  
FROM  
CROHN'S &  
COLITIS UK**

Crohn's and Colitis UK produce a number of publications on IBD, and living with Crohn's Disease and Ulcerative Colitis. These are available to download for free on the Crohn's and Colitis UK website: [www.crohnsandcolitis.org.uk/quick-list](http://www.crohnsandcolitis.org.uk/quick-list)



## 2

# I KNOW WHO TO CONTACT QUICKLY IF I NEED ADVICE OR IF MY CONDITION CHANGES

## WHY DOES THIS MATTER?

The unpredictable nature of Inflammatory Bowel Disease (IBD) means that speedy access to specialist advice and support, when needed, is essential.

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## WHAT DOES THIS MEAN FOR ME?

Your IBD service should have a system in place to ensure that they can quickly respond to any questions or concerns you may have about your condition. A member of your IBD team should provide you with details for all the ways you can contact them, and explain how quickly you should receive a reply.

The **IBD Standards** say that:

- All IBD patients should have access to a dedicated telephone service (IBD Helpline)
- Calls should either be answered or answerphone messages should be responded to by the end of the next working day
- Ideally, there should be a choice of telephone and email contact

There should be a clear process for patients to obtain access to specialist advice and support from a relevant member of the IBD team by the end of the next working day.

**IBD Standards**  
Standard C3

## SOMEONE TO CONTACT

You should feel confident about making use of this service even if you have experienced only a small change in your condition or you are not sure how best to manage a new symptom. You may need to have a specialist review, so should not put off contacting your IBD team to alert them to your changing condition.

— Patients experiencing a possible relapse [flare-up] of their IBD should have access to a specialist review within a maximum of five working days.

**IBD Standards**  
Standard A11

## WHAT CAN I DO?

- Ask for the details of your IBD helpline or email address, or alternative point of contact
- Talk to your healthcare professionals about the sorts of changes that should prompt you to get in touch
- Find out who you can contact should a need arise out of office hours
- Ensure you understand about the potential side effects of any new treatment you are starting

The healthcare professionals involved in your care will have details of your condition and treatment plan, so are the best people to contact in relation to any changes.



## HELP AND SUPPORT FROM CROHN'S & COLITIS UK

Our helpline is a confidential service providing information and support to anyone affected by IBD. It is staffed by a team of trained Information Officers who provide callers with clear and balanced information on a wide range of issues relating to IBD. While they are not able to give individual advice, they can answer questions about IBD, and living with Crohn's Disease and Ulcerative Colitis. You can contact them on:

**0300 222 5700** or email **[info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk)**

You can find more information on the range of helplines available through Crohn's and Colitis UK by visiting the website: **[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)**

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MY CARE IS APPROPRIATE  
FOR ME AND TAKES ACCOUNT  
OF MY AGE, PREFERENCES,  
PERSONAL VALUES AND GOALS

WHY DOES THIS MATTER?

People of all ages live with Inflammatory Bowel Disease (IBD), including an increasing number of children and young people. Whatever your age, the care provided by your IBD service should be personalised to you and work for all aspects of your whole life, not just the management of your condition. Your care should take account of your age, views and beliefs and the things that are important to you, including studying, working, socialising, having a family and family life.

Patient-centred care  
should be responsive  
to individual needs.

IBD Standards  
Standard C

WHAT DOES THIS MEAN FOR ME?

You should feel confident to talk to your IBD team about the broader aspects of your life and how these may affect your decisions about your own care choices.

Treatment and care should be appropriate to your age. It should take account of how your condition impacts on your life, and look for ways to help you do as much as you can in all areas of your life. Your family should also be given information to understand how best to support you.



“

**The doctors and nurses are really kind and always talk to me as well as to my Mum and Dad. ”**

**Ahad, 13**

Diagnosed with Ulcerative Colitis in 2015

**Children and young people with IBD should have the choice of being managed in an age-appropriate environment.**

### **IBD Standards**

Standard A12

It can be daunting to move from children's services to adult services, but your IBD team should have a clear process in place to make this as easy for you and your family as possible. One member of the team, who you know and can contact, should manage your transition between children's and adult services.

You should feel able to ask questions about anything that may be concerning you. As a young person with IBD, these might include:

- How your condition may impact on your life at school, college or university
- Any concerns you may have around body image or how others might respond to your condition
- The best ways to keep yourself well
- How your condition might impact on growth and puberty, as well as fertility and sexual relationships where appropriate
- What happens when it is time for you to move to the adult IBD service, whether you feel ready for this transition, and what will be different

As an adult living with IBD, you might seek support with some of the following:

- Understanding how your condition may impact on your work
- Information on how best to keep yourself well
- How your condition may affect fertility, maternity care and raising a family
- How to explain your IBD when you need to see other healthcare professionals for reasons unrelated to your Crohn's Disease or Ulcerative Colitis and how to ensure that your care is joined-up

## WHAT CAN I DO?

- Think about what your personal goals are and what is important to you in your life and share these with the healthcare professionals supporting you
- Take advantage of any opportunities that you have to ask questions – you may find it helpful to write down your thoughts before calling a helpline or attending an appointment
- Ask about the process for moving from children's to adult services if this is relevant to you or a family member
- Find additional information about managing your condition alongside other aspects of your life (see below)



### HELP AND SUPPORT FROM CROHN'S & COLITIS UK

You may find the following Crohn's and Colitis UK publications on living with IBD and the transition to adult care helpful:

- **IBD in Children: a parent's guide**
- **Students with IBD: a guide for students**
- **Fertility and IBD**
- **Pregnancy and IBD**
- **Employment and IBD: a guide for employees**
- **Transition: moving to adult care**

For further information, see the Crohn's and Colitis UK website: [www.crohnsandcolitis.org.uk/quick-list](http://www.crohnsandcolitis.org.uk/quick-list)

# 4

## MY CARE IS COORDINATED BETWEEN THE DIFFERENT HEALTH PROFESSIONALS INVOLVED

The arrangements and scope for shared care (with the GP) and the circumstances in which the patient should be referred back to hospital care, must be clearly defined between the hospital staff and the GP.

**IBD Standards**  
Standard B1

### WHY DOES THIS MATTER?

It is likely that the nature of your Inflammatory Bowel Disease (IBD) will mean that you will interact with a variety of healthcare professionals at different times. As well as your IBD team and your GP, you may come into contact with people who can help you with issues relating to psychology, rheumatology, ophthalmology, dermatology and obstetrics.

Given the range of people you may be dealing with, it is important that your care is effectively coordinated by the different healthcare professionals involved. Your GP should also have clear and agreed arrangements with your hospital-based IBD team regarding any involvement they have that may affect your IBD care.

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### WHAT DOES THIS MEAN FOR ME?

All parties, including you and your family, should know the circumstances in which your GP might refer you back to hospital care. This information should be clearly explained to you both in person and in writing.



“

I get so much more out of my appointments when everyone knows my history. ”

Tom, 27

Diagnosed with Crohn's Disease in 2011

There should be an agreed system for sharing information between your GP and IBD team through written communication, IT or your own patient-held records. This will mean that everyone involved in your IBD care – including you – is told when you get test results or your treatment changes.

You should experience a joined-up service between your GP, IBD team and the wider range of healthcare professionals that you may need to see over time. The aspiration of each person involved in your care should be to share information with you, your IBD team and your GP, in a clear and accessible way.

You are entitled to see your health records, although there may be a fee for doing so. You can make an informal request during a consultation or by phoning your GP, surgery or hospital to arrange a time to see them. You can also make a formal request in writing to a registered healthcare professional.

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## WHAT CAN I DO?

- Ask how the healthcare professionals supporting you will be working together and ensure you know who should be your point of contact
- Find out what systems are in place for sharing information about your test results and any treatment changes
- Ask for copies of letters that are exchanged between your IBD team and GP
- Make a note of current prescriptions and recent symptoms so that you can take this information with you to appointments or hospital

# 5

## I AM OFFERED DIFFERENT OPTIONS FOR MY TREATMENT AND CARE SO THAT I CAN UNDERSTAND AND CHOOSE WHAT IS RIGHT FOR ME

### WHY DOES THIS MATTER?

Over time, the way that your Inflammatory Bowel Disease (IBD) affects you is likely to change or fluctuate. As it does, you and your IBD team may need to consider different approaches to your treatment and care, for example, dietary therapy, a new drug treatment or surgery.

In order to help you choose the best approach for you, you should be given every opportunity to understand the different treatment options available, including the benefits and risks of each. You should always have the right to accept or turn down a treatment offered to you, and your choices should be respected and supported by your IBD team.

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**All patients should be offered appropriate information about their care and treatment options at all stages of their illness. This should be delivered by an identified member of the IBD team.**

**IBD Standards**  
Standard D1



WHAT DOES THIS MEAN FOR ME?



“Empowering yourself with the right advice and knowledge about IBD is so important to your health and well-being, both physically and mentally.”

Zaine, 22  
Diagnosed with Crohn’s Disease in 2010

Patients should be offered choice between their treatments, after receiving the necessary support and information.

IBD Standards  
Standard C3

By having access to clear information from your IBD team about the treatment options available, you should be able to make an informed choice about what would work best for you and your life.

This information should be appropriate for your age and be accessible in a range of different languages and formats, such as leaflets, DVDs and web-based resources. If you are considering pouch surgery or a permanent ileostomy, your IBD team may be able to put you in contact with someone who could help by talking about their experience. See the next page for where to find more information about surgery.

As your condition changes, you should feel comfortable asking your IBD team questions about the possible treatments, or seeking clarity or further information about different options that have been suggested. You do not have to agree to a treatment that you are not comfortable with, but you should always feel that you are able to make as informed a decision as possible.

NHS Choices produce a checklist to help if you are not sure what questions to ask your doctor or healthcare professional in an appointment. See the *Other resources* section of this guide for further details.

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## WHAT CAN I DO?

- Discuss the different care and treatment options that may be available to you and agree an approach. This may need to change over time
- Ask for information about, and the opportunity to discuss, the benefits and risks of the different treatment options available
- You may find it helpful to write down some questions you would like to ask. You may wish to involve a family member, carer or friend to help you make your decision



### HELP AND SUPPORT FROM CROHN'S & COLITIS UK

Crohn's and Colitis UK produce a number of publications on options for treatment. These include a number of information sheets on individual drugs. There are also two information sheets on surgery – one for Crohn's Disease, and one for Ulcerative Colitis.

The Information Officers on the Crohn's and Colitis UK helpline are able to answer general questions about treatment.

You can contact them on: **0300 222 5700** or email [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk)

For details of the Crohn's and Colitis UK publications and helplines, visit the website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

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I AM FULLY INVOLVED IN ALL DECISIONS ABOUT MY CARE AND, IF I WISH TO, AM ABLE TO INCLUDE A FAMILY MEMBER, CARER OR FRIEND IN MY DECISION-MAKING

WHY DOES THIS MATTER?

As your condition may change over time, you should expect to be fully involved in your care, making decisions in partnership with your IBD team and GP. This should help to ensure that you are as knowledgeable and comfortable as possible with the approach being taken for your treatment and care, both when your condition is stable and when it changes.



Patients’ preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.

IBD Standards  
Standard C

WHAT DOES THIS MEAN FOR ME?

Only you can know how your condition affects you, what treatments have worked well and how different approaches to care impact on your life more broadly. Your IBD team play an important role in supporting you, but you should be involved in every decision about your treatment and care.

This does not mean that you have to always have a view or lead the discussion. However, your IBD team should invite, value and respect your input whenever you want to give it, and seek to work alongside you

as you jointly plan and review your care. You should actively participate in your relationship with the IBD team, taking responsibility for your role in your IBD management. This should also help you to feel more in control of your condition.

You may also want a partner, family member or carer to be involved in supporting your decision-making. This may mean that you want information shared with them when you change your treatment, or that you want them to be actively involved in the decision-making process about your care. Your IBD team should respect and support your wish to involve someone else.

You should also be told how to raise specific concerns for discussion at a regular IBD team meeting and how to request a second opinion.

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**Patients are actively involved in shared decision-making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.**

**IBD Standards**  
Standard C

## WHAT CAN I DO?

- Ask questions if you are unclear about any aspect of your treatment or care
- Explain to your doctors how your treatment has been working for you and your life
- Consider whether you would like a family member, carer or friend to be involved in your appointments or decision-making process

# 7

## I WORK WITH MY IBD TEAM TO AGREE A PLAN FOR MY CARE AND HAVE REGULAR REVIEWS WITH A MEMBER OF THE TEAM TO MONITOR MY HEALTH AND WELL-BEING

### WHY DOES THIS MATTER?

For the majority of people, Inflammatory Bowel Disease (IBD) is a lifelong condition that can fluctuate over time. As a result, you might need different types of care at different times. You should be supported at every stage of your condition, including when you are not experiencing any symptoms.

Patients should have written information explaining clearly what arrangements have been made with them for their care.

**IBD Standards**  
Standard C4

### WHAT DOES THIS MEAN FOR ME?

You should have a clearly agreed plan for your care, which will mean that you, your IBD team and your GP all know how your care will be managed. This might involve:

- Attending hospital as an outpatient
- Supported self-management with access to more support when you need it
- Care from your GP with links to your IBD team

The approach that you agree with your IBD team should be written down in a clear and accessible format and shared with you.

## A CLEAR PLAN

You should also have regular reviews of your care, at least once a year. This should be carried out either in hospital, a community clinic or by telephone, by an appropriate healthcare professional.

**All patients who are not under immediate or ongoing care, including those in remission [not experiencing any symptoms], should have an annual review and basic information recorded.**

**IBD Standards**  
Standard A11

You may not need to contact your IBD team while your condition is stable and under control. However, having an annual review of your condition means that you can maintain contact with the medical team, and make sure that your details are up to date. This will also give you the opportunity to ask for advice or further information about your condition or broader health and well-being. It will also ensure that your long-term health needs are being monitored.

## WHAT CAN I DO?

- Talk to your healthcare team about what might work best to help you manage your care
- Ask for written information about what arrangements have been made for you and your care
- Discuss plans for reviews of your care and agree how and by whom these should be undertaken



### HELP AND SUPPORT FROM CROHN'S & COLITIS UK

You may find the **Staying Well with IBD** information sheet useful for ideas about how to keep well as much as possible.

For further information, see the Crohn's and Colitis UK website: [www.crohnsandcolitis.org.uk/quick-list](http://www.crohnsandcolitis.org.uk/quick-list)

# 8

## I AM GIVEN INFORMATION AND OFFERED ONGOING SUPPORT TO UNDERSTAND AND MANAGE MY LIFE WITH IBD

The IBD service should provide educational opportunities for patients and their families.

**IBD Standards**  
Standard D2

All patients should be provided with contact information for the relevant patient organisations.

**IBD Standards**  
Standard D3

### WHY DOES THIS MATTER?

Information and understanding about how best to manage your life with Inflammatory Bowel Disease (IBD) should empower you to improve your emotional and physical health and well-being. It should also reduce the fear of the unknown and give you the confidence to achieve your personal goals.

### WHAT DOES THIS MEAN FOR ME?

Your IBD team should help to educate people about all aspects of IBD, including care and treatment options, but also broader issues relating to managing life with IBD. They should look for ways to provide educational opportunities for you and your family about IBD, treatment and self-management strategies.

Your IBD team should also be able to provide you with details of patient organisations that can give you more support, advice or opportunities to meet and engage with other people living with IBD.

“

Crohn's & Colitis UK is a lifeline and link to find out information and turn fears and uncertainty into positive action. ”

Bev, 47

Diagnosed with  
Ulcerative Colitis in 1980

## WHAT CAN I DO?

- Ask your IBD team what educational opportunities are available to help you understand and manage your life with IBD
- Take advantage of opportunities to participate in educational sessions that are offered and encourage your family to do so too
- Explore further information and opportunities offered by local and national patient organisations that may increase your understanding and provide support



## HELP AND SUPPORT FROM CROHN'S & COLITIS UK

There are two booklets produced by Crohn's and Colitis UK which cover basic information about IBD, and ways to live with the conditions. These are:

- **Understanding IBD – Ulcerative Colitis and Crohn's Disease**
- **Living with IBD**

You might also find it beneficial to speak to other people who understand what it is like to live with IBD.

The Crohn's and Colitis UK Forum on Facebook is a closed-group community for everyone affected by IBD. You can share your experiences and get support from others at:

 [www.facebook.com/groups/CCUKforum](https://www.facebook.com/groups/CCUKforum)

You may also find it helpful to get in touch with the charity's local network of volunteers. See the Crohn's and Colitis UK website for further details: [www.crohnsandcolitis.org.uk/volunteering](https://www.crohnsandcolitis.org.uk/volunteering)



# 9

## MY IBD TEAM ARE INFORMED IF I AM ADMITTED TO HOSPITAL

### WHY DOES THIS MATTER?

It is important that your Inflammatory Bowel Disease (IBD) is properly assessed and treated by specialists in an appropriate environment if you are admitted to hospital.

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### WHAT DOES THIS MEAN FOR ME?

The **IBD Standards** define the specific essentials that should be followed by inpatient services, including:

- Clear arrangements for admitting IBD patients onto gastroenterology wards
- Transfer to the care of a consultant gastroenterologist and/or colorectal (bowel) surgeon within 24 hours of admission for patients with known or suspected IBD
- IBD specialist nurses should be notified when an IBD patient is admitted

These protocols should ensure that you are cared for by specialists in IBD as soon as possible, and that your IBD team is kept informed about all aspects of your care.

Defined arrangements should exist for admitting IBD patients directly to the specialist gastroenterology ward or area.

**IBD Standards**  
Standard A10

**All IBD patients admitted should be notified to the IBD specialist nurses.**

**IBD Standards**  
Standard A10

If you are admitted to hospital for another reason, but your IBD has not been discussed, you should tell the medical team caring for you about your Crohn's Disease or Ulcerative Colitis and ask for your IBD team to be told that you are in hospital.

If you are unsure about how your treatment might impact on your IBD, you should ask to speak to someone from your IBD team or call the IBD helpline.

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## WHAT CAN I DO?

**Patients admitted with known or suspected IBD should be discussed with and normally transferred to the care of a consultant gastroenterologist and/or colorectal (bowel) surgeon within 24 hours of admission.**

**IBD Standards**  
Standard A10

- Ask whether your IBD team has been told that you have been admitted to hospital
- Request to be admitted or transferred onto a gastroenterology ward, if appropriate
- Check if the details about your time in hospital have been included in your records and that it has been discussed with you after you have been discharged

10

I AM ASKED FOR FEEDBACK ON MY EXPERIENCE OF CARE AND I AM ABLE TO PLAY A ROLE IN IMPROVING MY SERVICE

Patients should have a voice and direct involvement in the development of the IBD service. The service must be able to demonstrate that mechanisms are in place to obtain and respond to patient feedback.

IBD Standards  
Standard C5

WHY DOES THIS MATTER?

Feedback is important to help your IBD team identify ways that the IBD service could improve in the future. Getting involved in any discussions about how the service is working, and any plans for change, should help to ensure that your views are reflected in any developments.

WHAT DOES THIS MEAN FOR ME?

Every IBD service should actively look for ways to ensure that people using the service know how to give their views – both positive and negative – and should respond to the feedback when it is given.

As someone with practical experience of using your local IBD service, you should also be given the opportunity to contribute to the future development of the service.

Your IBD service should provide you with information about the different ways you can give your feedback about the service and the team.

These may include:

- Patient experience surveys or comment cards
- Regular meetings with people who use the service to talk about how the service could be improved, such as IBD patient panels
- Open days for people to talk to the IBD team about the service
- Involving people who use the service in project planning/service development groups

Your feedback should be valued and respected by your service. When the service is being reviewed, you should be approached for your thoughts and opinions to help shape this.

## WHAT CAN I DO?

- Find out about and take advantage of opportunities to give feedback about your care
- Ask about and consider getting involved with local service development activities – for example, project planning groups or a patient panel



### HELP AND SUPPORT FROM CROHN'S & COLITIS UK

There are a number of IBD patient panels at hospitals around the UK, which are supported by Crohn's and Colitis UK. An IBD patient panel is a group of people who have IBD, using the same IBD service at their local hospital. Their overall aim is to improve the experience of those who use the IBD service. For more information about patient panels, visit: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

To find out if there is a patient panel in your area, email: [ppr@crohnsandcolitis.org.uk](mailto:ppr@crohnsandcolitis.org.uk) or ask your IBD team.

## WHAT SHOULD I DO IF I AM NOT HAPPY WITH MY CARE OR TREATMENT?

If you have concerns about your care or treatment, the lead person responsible for your IBD service, or your own IBD nurse specialist, if you have one, is a good person to raise your concerns with in the first instance. Your feedback should always be welcomed and taken seriously.

If you do not feel that your concerns are being addressed, you could try speaking to other members of your healthcare team. Wherever possible, it is more constructive to resolve any issues informally.



### HELP AND SUPPORT ACROSS THE UK

If you would like help or advice with raising concerns or possible next steps, you can contact the relevant organisations below, depending on where you live in the UK.

- **England:** Patient Advice and Liaison Services (PALS) – based in each hospital
- **Scotland:** Patient Advice and Support Services – accessed through any Scottish citizens advice bureau and the Scottish Health Council:  
[www.scottishhealthcouncil.org/home.aspx](http://www.scottishhealthcouncil.org/home.aspx)
- **Northern Ireland:** Patient and Client Council:  
[www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)
- **Wales:** Community Health Councils – cover each Local Health Board:  
[www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils](http://www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils)

## RESOURCES

The documents referred to in this guide may be helpful to you. They include:

- **The IBD Standards** which define what is required to provide safe, effective, patient-centred, high quality and joined-up IBD services for the people who need them. You can see the latest version of the **IBD Standards** at: [www.crohnsandcolitis.org.uk/improving-care-services/health-services](http://www.crohnsandcolitis.org.uk/improving-care-services/health-services)
- **The IBD Audit** sets out how local services are performing against the **IBD Standards**. The audit is managed by the Royal College of Physicians and you can find the latest audit findings, which include some key results for every local service that took part, at: [www.rcplondon.ac.uk/ibd](http://www.rcplondon.ac.uk/ibd)

A summary booklet has been produced with some of the main overall findings and can be found at: [www.crohnsandcolitis.org.uk/improving-care-services/health-services](http://www.crohnsandcolitis.org.uk/improving-care-services/health-services)

- **NICE quality standards** are designed to improve the quality of care in a particular condition area. A NICE quality standard for IBD has been developed for England, identifying four ‘quality statements’ that service providers should aim to achieve. The quality standard mirrors many of the expectations outlined in the **IBD Standards** and **My Crohn’s and Colitis Care**, and can be viewed on the NICE website: [www.nice.org.uk/guidance/qs81](http://www.nice.org.uk/guidance/qs81)

## OTHER RESOURCES

- **NHS Choices** produce a checklist of questions to ask your doctor. This is available from their website: [www.nhs.uk/nhsengland/aboutnhsservices/questionstoask](http://www.nhs.uk/nhsengland/aboutnhsservices/questionstoask)
- **NHS Inform** is Scotland’s health information service and provides information about local and national health support services in Scotland. Visit [www.nhsinform.co.uk](http://www.nhsinform.co.uk) or call **0800 22 44 88**

Information and links about these resources are available on our website at: [www.crohnsandcolitis.org.uk/improving-care-services/health-services](http://www.crohnsandcolitis.org.uk/improving-care-services/health-services)

## CROHN'S AND COLITIS UK

We lead the battle against Crohn's Disease and Ulcerative Colitis and we won't stop until we've won.

We actively work across four different areas:

- We give emotional and practical support and information to help people manage their conditions – we want people to live their lives to the fullest
- We create greater awareness of the conditions and their impacts to tackle the stigma, fear and isolation they cause – we want people to be heard and understood
- We work with the UK health sector to improve diagnosis, treatment and management – we want everyone with the conditions to have access to the best specialist services
- We support crucial research to increase knowledge of the causes and the best treatments – we want to improve lives now and, ultimately, find a cure

By uniting the strength and passion of everyone affected by Crohn's or Colitis, we are creating a powerful community with positive impacts across the UK.

“

I have found Crohn's and Colitis UK to be very supportive as a charity and their information is invaluable. Becoming a member is one of the best things I have done since being diagnosed. ”

**Vicky, 31**

Diagnosed with  
Ulcerative Colitis in 2011

### MY CROHN'S AND COLITIS CARE IS SUPPORTED BY:



The Association of  
Coloproctology of  
Great Britain and Ireland



The Association  
of UK Dietitians



BRITISH SOCIETY OF  
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# CROHN'S & COLITIS UK SUPPORTING YOU TO MANAGE YOUR CONDITION

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## HOW WE CAN HELP YOU

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### Follow us



/crohnsandcolitisuk



@CrohnsColitisUK



@crohnsandcolitisuk

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

Contact us by telephone on **0300 222 5700** or email **[info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk)**

See our website for WebChat (Live Online)  
**[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)**

**CROHN'S &  
COLITIS UK**

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FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

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