# CROHN'S & COLITIS UK



### STEROIDS (CORTICOSTEROIDS)

#### **INTRODUCTION**

If you've started or are considering treatment with steroids, you're not alone. Steroids, also called corticosteroids, are a common medicine for Crohn's and Colitis, with 4 out of 5 people with the conditions taking them at some point.

Our information can support you to make an informed decision about treatment that's right for you. It looks at:

- how steroids work
- what you can expect from treatment

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- possible side effects
- stopping or changing treatment

#### **99** CONTENTS

Other names for this medicine	2
Why you've been offered steroids	2
How steroids work	3
How effective steroids are in Crohn's and Colitis	3
Budesonide: Why it's different from other steroids	. 3
How long steroids take to work	. 3
How to take steroids	4
Dosage information	. 5
How long you'll take steroids for	. 5
Special precautions	. 5
Checks you'll need before starting steroids	. 6
Ongoing checks	. 6
Side effects	7
Pregnancy and fertility	. 8
Breastfeeding	. 9
Taking other medicines or vaccinations	. 9
Drinking alcohol	10
Alternatives to steroids	
Who to talk to if you're worried	. 11
Help and support from Crohn's & Colitis UK	. 11

#### 66

Once your IBD is under control (with steroids) life quickly returns to normal. You realise how much the steroids can help you to get your life back.

Barry, age 41 living with Crohn's Colitis

#### **OTHER NAMES FOR THIS MEDICINE?**

There are many different types of steroids (also known as corticosteroids) which can be taken in different ways. The type of steroids you'll be given will depend on how severe your Crohn's or Colitis is, and where it is in your gut.

**Oral steroids** are taken by mouth and swallowed. They include:

- prednisolone (brand names Deltacortril®, Deltastab® and Dilacort®)
- prednisone
- hydrocortisone (Plenadren®)
- methylprednisolone (Medrone®)
- beclometasone dipropionate (Clipper®)
- budesonide (Entocort® and Budenofalk®)
- budesonide-MMX (Multi-Matrix system) (Cortiment®)

Intravenous steroids are given directly into a vein (in hospital). They include:

- hydrocortisone
- methylprednisolone

**Topical steroids** are given directly at the site of inflammation. Rectal steroids (suppositories, foam or liquid enemas) are a type of topical steroid. Steroids that come as a mouthwash (for treating mouth ulcers) are another type of topical steroid. Topical steroids include:

- hydrocortisone (Colifoam®)
- prednisolone (Predfoam®)
- budesonide (Budenofalk®)

#### WHY YOU'VE BEEN OFFERED STEROIDS

When you're in a flare-up and feel unwell, steroids can help to quickly reduce the inflammation in your gut to help you feel better (known as remission). But they have a high risk of side effects and can't control your Crohn's or Colitis long-term.

4 in every 5 people with Crohn's or Colitis will be treated with steroids at some point. Sometimes you might take steroids while also taking other medicines (in combination with other medicines).

#### If you have Crohn's Disease

Intravenous, oral or topical steroids may be used to treat adults and children with Crohn's when you're first diagnosed, or if you're having a flare-up.

#### If you have Ulcerative Colitis

Oral or rectal steroids may be used to treat adults and children with Ulcerative Colitis if you're having a flare-up but you don't need to stay in hospital. You may also be given steroids if you're having a flare up but aminosalicylates (5-ASAs) aren't right for you.

#### Acute Severe Ulcerative Colitis (ASUC)

Acute Severe Ulcerative Colitis (ASUC) is a serious condition. You'll first be treated with intravenous steroids in hospital. Intravenous steroids work quickly, so you should start to feel better within a few days. If you're not any better after three days, your IBD team will discuss other possible treatment options with you.

#### If you have Microscopic Colitis

Oral budesonide is used as a first treatment in adults with Microscopic Colitis (Collagenous Colitis and Lymphocytic Colitis).

#### 2

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We're funding research led by Dr Sree Subramanian to better understand how to treat patients with ASUC to avoid surgery. 99

#### HOW STEROIDS WORK

Steroids are hormones (chemicals) that are produced naturally in your body. Steroids used to treat Crohn's and Colitis are man-made versions of these hormones, but they are taken in higher doses than your body makes naturally. In these high doses, steroids reduce inflammation by decreasing the activity of the immune system.

The steroids used to treat Crohn's and Colitis are not the same as the anabolic steroids used by athletes to improve their performance.

#### HOW EFFECTIVE STEROIDS ARE IN CROHN'S AND COLITIS

Steroids are effective as a short-term treatment during a flare-up to bring you into remission.

Taking steroids for long periods of time or repeatedly will not help to control your Crohn's or Ulcerative Colitis and can cause unwanted side effects. Once in remission, your steroid treatment will gradually reduce and stop and you'll be offered a different treatment to keep your symptoms under control. If you have Crohn's or Ulcerative Colitis, you may be offered 5-ASAs, an immunosuppressant, or a biologic medicine. See our other **drug treatment sheets** for more information.

You shouldn't have more than two courses of steroids in a year. If your GP has prescribed you a course of steroids, make sure you let your IBD team know at your next appointment.

Some research suggests that if you have Collagenous Colitis, ongoing treatment with a low dose of oral budesonide may be helpful in keeping you in remission.

#### BUDESONIDE: WHY IT'S DIFFERENT FROM OTHER STEROIDS

Conventional oral steroids (such as prednisolone or prednisone) cause a range of side effects because they can affect the whole body. Budesonide is different because it works directly in the small bowel (small intestine) and colon (part of the large bowel). This means there is very little budesonide in the bloodstream and so the risk of side effects is lower than with other steroids. Budesonide-MMX® is a new type of capsule that releases budesonide throughout the entire colon and is usually used to treat Ulcerative Colitis.

#### How effective is budesonide?

Studies show that budesonide causes fewer side effects than conventional oral steroids, but it's generally not as good at treating flare-ups.

HOW LONG STEROIDS TAKE TO WORK

Everyone responds differently when taking a new medicine.

If you're taking oral steroids, you may start to feel better within a week, but it could take up to a month after starting treatment. You'll usually feel better after a week

3

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#### 66

Once your IBD is under control (with steroids) life quickly returns to normal. You realise how much the steroids can help you to get your life back.

Barry, age 41 living with Crohn's Colitis or two if you're taking rectal steroids. If you're taking intravenous steroids, you may feel better after few days, but it can take up to 10 days after starting treatment.

You may experience side effects much sooner, see the section below on **Side** effects.

Steroids don't work for everyone. Around 1 in 5 people don't respond to steroid treatment – this known as being steroid refractory. Speak to your IBD team if your condition isn't improving.

#### HOW TO TAKE STEROIDS

How you take steroids will depend on the severity and location of your Crohn's or Colitis.

#### **Oral steroids**

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Steroids are most commonly taken by mouth (orally). These could be tablets, capsules or granules, or they may be available as a dissolvable or liquid version.

Take your oral steroids in the morning to help reduce side effects. If you've been prescribed budesonide capsules or granules (or any other delayed-release or enteric coated steroids), you should swallow these whole with a glass of water around half an hour before food in the morning. Do not chew budesonide capsules or granules because this may stop them working.

#### **Intravenous steroids**

For severe flare-ups, steroids are injected into a vein (intravenously) to give the quickest response. This only takes place in hospital. You may then be switched to oral steroids.

#### **Topical/rectal steroids**

For Crohn's or Colitis affecting the lower part of the colon and rectum, steroids can be applied directly to the affected area by enemas or suppositories (rectally). Enemas use a specially designed applicator (containing the drug as a liquid or foam) that is inserted into the anus and reaches into the colon. Suppositories are small 'bullet-like' capsules of drug inserted into the rectum through the anus. There are fewer side effects as these steroids directly target the inflamed area.

Taking rectal steroids may seem daunting, but there are a few things you can try to make it easier:

- Take your steroids at night you're likely to have more time and this will help you stay relaxed.
- Read the instructions that come with your steroids they'll explain the best way to take the steroids and often have pictures to help.
- Go to the toilet just before taking your steroids.
- Try lying on your left side (on a towel) while inserting the applicator into your anus. Extra lubricant on the applicator might help. Stay lying on your left side or on your tummy for 20-30 minutes after to give the steroids time to work. After this time you can go to the toilet to release the remaining liquid or foam.

Don't worry if you don't quite get it right the first few times, or if you spill some. It'll soon become another part of your routine.

It took me a few goes to reduce my steroid dose as the symptoms kept coming back and I had to return to the starting dose. But each time I was able to get telephone advice from my IBD nurse.

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Lucy, age 45 living with Crohn's Disease

#### **DOSAGE INFORMATION**

Your dosage will depend on the type of steroid prescribed, your condition and your weight. Your IBD team will advise you on this.

For example:

**Mild to moderate flare-up of Crohn's or Colitis** – you may start on oral prednisolone 40 mg (eight tablets a day), taken as a single dose in the morning. But there can be differences – your IBD team will give you the dose that's right for you.

**Severe flare-up of Crohn's or Colitis** – if you're admitted to hospital, you may be given intravenous steroids such as hydrocortisone 100 mg four times daily or methylprednisolone 60 mg every 24 hours.

Microscopic Colitis - you may be given 9mg budesonide daily.

Talk to your IBD team before making any changes to your dosage or how you take it.

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#### HOW LONG YOU'LL TAKE STEROIDS FOR

Steroids are usually only used for a short time to help you get into remission or while longer-term treatments, such as azathioprine, start to work.

You must complete your full course of steroids – you'll usually be prescribed steroids for 8 weeks with the dose reducing over this time. You must **NOT** suddenly stop taking steroids, even if you feel better. See **Side effects** to find out why.

#### SPECIAL PRECAUTIONS

**Carry a steroid card.** Your pharmacist or doctor may give you a blue steroid card with details of your steroid treatment, including the dose and how long you'll be taking steroids. Always carry this and show it to any healthcare professional treating you, even if you're being treated for something not related to your Crohn's or Colitis, such as by your dentist. You could also consider wearing a wear an emergency bracelet, like the ones made by MedicAlert. See **Other organisations** at the end of this leaflet for more information.

**Speak to your doctor if you think you have an infection.** Steroids affect the way your immune system works so you may be more likely to get infections. Even a mild infection such as a cold or sore throat could develop into something more serious. Tell your doctor or hospital if you feel unwell and think you might have an infection.

**Avoid close contact with people who have infections.** This includes viruses and bacteria that cause chickenpox and shingles, measles, tuberculosis and pneumococcal disease. You could become seriously ill from these illnesses. Tell your doctor if you come into contact with anyone who has these infections.

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#### CHECKS YOU'LL NEED BEFORE STARTING STEROIDS

You'll need some checks before you start treatment to make sure steroids are right for you. Let your IBD team know if you have:

- Infections. This includes any past infections (such as tuberculosis) or if you currently have an infection, or if you're generally feeling unwell or feverish. Your treatment with steroids may have to be postponed until your infection has cleared. This is because steroids can mask the symptoms of infections and make them worse.
- Liver problems. The levels of steroids in your blood may be increased if your liver isn't working properly.
- Mental health disorders. This includes psychosis, severe depression or bipolar disorder, or if someone in your family has had mental health problems.
- **Wounds.** If you have wounds from recent surgery or are going to have surgery soon, as steroids may delay wound healing.
- Pre-existing conditions, including heart failure, a recent heart attack, high blood pressure, diabetes, epilepsy, cataracts, glaucoma, an underactive thyroid, osteoporosis, obesity, stomach ulcers or systemic sclerosis. Steroids can make some conditions worse so your medical team may need to monitor your condition more closely.

And tell your IBD team if:

- you're pregnant, planning to get pregnant or breastfeeding.
- you're taking any other medicines.
- you've had any vaccinations recently, or plan to have any vaccinations.
- you've had surgery recently, or plan to have surgery.
- you've ever had chicken pox or not. If you've not had chicken pox, you may be able to have the vaccine before you start steroids.

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#### **ONGOING CHECKS**

You'll usually only be taking steroids short-term, so you may not see your IBD team during this time – however, you should contact your IBD team if you experience any side effects or if steroid treatment isn't working for you.

Your doctor may want to monitor you if you're at risk of developing weak bones (osteoporosis). See the section below, **Protecting your bones.** 

If you're taking steroids longer-term, your doctor will also check for secondary adrenal suppression. For more information on this, see **Side effects.** 

#### **Protecting your bones**

6

Taking steroids can weaken your bones, so you may be given vitamin D and calcium supplements to help keep them strong. Your doctor will assess your risk of bone fractures and, if you're considered to be at a high risk, you may have a bone density scan (also known as a DEXA scan). You may also be given another type of drug called a bisphosphonate to help keep your bones strong. If you're pregnant, or wanting to become pregnant, speak to your doctor before starting bisphosphonate treatment as it may not be suitable for you. Steroids taken rectally (in enemas or suppositories) and locally acting steroids, such as budesonide, are less likely to cause bone weakness than steroids taken by mouth or intravenously.

Making changes to your lifestyle can help you maintain healthy bones. See our information sheet **Bones.** 



#### SIDE EFFECTS

Although steroids are produced naturally by the body, steroid medicines can cause unwanted side effects. Around 1 in every 2 people taking steroids experiences side effects. Your doctor will help manage any side effects by only prescribing the lowest effective dose of steroids for the shortest time. Some side effects may be mild and go away on their own. Others may be more serious and could require treatment or mean that steroids aren't suitable for you.

Speak to your IBD team if you experience any side effects. The most common side effects while taking steroids include:

- **Cosmetic changes,** including acne, rounded "moon" face, growth of unwanted body hair or stretch marks.
- Changes in mental health or mood changes, such as depression or experiencing extreme highs and lows in your mood.
- Salt and fluid retention, which can lead to raised blood pressure and ankle swelling.
- Changes to your hormones, which can cause weight gain, diabetes or raised blood sugar levels.
- **Higher risk of infections,** including colds and flu and more serious infections like pneumonia and sepsis.
- **Eye problems,** such as glaucoma, cataract or other problems with vision.
- Joint, bone and muscle problems, such as osteoporosis (weak bones), muscle and joint pain or muscle weakness.
- Gut problems, such as stomach pain, stomach ulcers or nausea.
- **Problems with growth** in children and young people.

#### Tell your doctor or IBD team immediately if you develop any of the following:

**Allergic reaction,** including a rash, itching, difficulty breathing or swelling of your face, lips, throat or tongue.

**Changes in your mental health or mood,** such as feeling depressed, high, or your moods go up and down. Also contact your doctor if you feel confused, irritable, anxious, have suicidal thoughts or difficulty sleeping.

**If you think you have an infection,** feeling feverish or generally unwell, or if you come into contact with someone with chicken pox, shingles or measles.

#### Do not suddenly stop taking steroids

If you've been taking steroids for more than a few days you'll need to reduce the dose gradually before stopping completely. Your IBD team will carefully guide you on this.

It's very important not to miss a dose or suddenly stop taking steroids. While you're taking steroid medicines, you stop making enough of your own steroids – which are important in keeping your body functioning. A sudden withdrawal from steroid medication may cause secondary adrenal insufficiency, a sharp fall in blood pressure and affect blood sugar levels. You'll need to undergo a gradual reduction (taper) of your steroid dose to give your body time to start making its own steroids again.

#### 66

The side effects I've experienced include heart palpitations, being ratty and the dreaded moon face. The sleepless nights were annoying, but nothing that I couldn't handle.

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Rachel, age 25 living with Crohn's Disease

#### **STEROIDS**

#### 66

Always speak to your IBD nurse if you have any concerns or side effects. They see lots of people with IBD and have lots of valuable experience.

Barry, age 41 living with Crohn's Colitis Some symptoms of secondary adrenal insufficiency are similar to those of Crohn's and Colitis, and include:

- fatigue
- Ioss of appetite and weight loss
- abdominal pain
- nausea and vomiting
- headache
- joint pains
- dizziness
- fever

99

Sometimes reducing the dose of steroids can make your Crohn's and Colitis symptoms come back (known as steroid dependence). If this happens, you'll be offered other drugs, such as azathioprine, to help you come off steroids completely.

#### PREGNANCY AND FERTILITY

It's generally agreed that steroids are safe for men and women wanting to conceive.

Taking steroids during pregnancy is a low risk to your baby, but you should still tell your doctor if you're planning to get pregnant or find out you're pregnant. Steroids are an effective treatment and there's usually a greater risk to your baby if you're unwell with Crohn's or Colitis. Having active Crohn's or Colitis at conception or during pregnancy increases the risk of pre-term birth and babies may have a lower birthweight or be smaller for their gestational age.

Although small amounts of steroids may cross the placenta, up to 40mg prednisolone daily is considered safe for the baby. If you're taking a high dose of steroids, or you're taking steroids long-term or repeatedly during pregnancy, your baby may be at an increased risk of intrauterine growth retardation – this is when a baby grows more slowly in the womb. Your doctors will check your baby's growth as part of your routine antenatal appointments.

Women with Crohn's or Colitis taking steroids may have an increased risk of developing gestational diabetes – your doctor will monitor you closely for gestational diabetes and will advise you on how to manage this condition.

There may also be a very small risk of cleft lip and palate in babies born to women taking steroids during the first three months of pregnancy, but this has not been found in all studies and not all experts agree on this.

There hasn't been much research into taking budesonide during pregnancy, but a small study of eight pregnant women with Crohn's did not find any adverse effects in the mother or the baby.

Tell the healthcare team involved in your birth that you're taking steroids or have taken steroids during your pregnancy.

#### BREASTFEEDING

Steroids may pass to the baby in the milk – but it's a very small amount, so it's usually safe to breastfeed while taking steroids. However, if you're taking a high dose of steroids (over 40mg prednisolone daily), check with your IBD team first – as you may need to leave some time between taking your steroids and breastfeeding.

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#### TAKING OTHER MEDICINES OR VACCINATIONS

Steroids are often taken alongside other medicines used to treat Crohn's or Colitis, and your IBD team will consider all of your medicines when prescribing steroids. However, there are some medicines that can interact with steroids – so you should talk to your doctor or pharmacist if you're taking, or plan to take any other medicines. This includes over the counter medicines (medicines that you can buy yourself without a prescription) or any herbal, complementary or alternative medicines or treatments.

Common medicines that interact with steroids include:

- Anticoagulants (such as warfarin)
- Antifungal drugs
- Bronchodilators (such as salbutamol)
- Diabetes drugs
- Diuretics
- Epilepsy drugs
- HIV drugs
- Live vaccines (see the section below Vaccinations while taking steroids)
- Some antibiotics

There's an increased risk of stomach ulcers and internal bleeding if you take nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen or aspirin, while you're also taking steroids. If you need to take both, your doctor may give you an additional drug called a proton pump inhibitor to help reduce this risk.

#### Vaccinations while taking steroids

It's not safe to have 'live' vaccines while taking high doses of steroids (over 40mg prednisolone daily for more than 7 days) or for a longer period of time (over 20mg prednisolone daily for more than 14 days) because steroids weaken your immune system. If this is the case, you'll have to wait 3 months after you stop taking steroids before having a live vaccine. Speak to your IBD team to make sure your vaccinations are up to date before you start taking steroids, or if you're planning to travel. If you've recently had a live vaccine, you should wait least 3 weeks before starting steroids.

In the UK, live vaccines include:

- BCG (tuberculosis)
- Chicken pox (varicella)
- Measles, mumps and rubella (either as individual vaccines or as the triple MMR vaccine)
- Yellow fever
- Rotavirus (babies only)
- Flu nasal spray (children only)

Everyone with Crohn's or Colitis should have the annual flu jab (injection) – this is not a live vaccine and is safe to have while taking steroids.

#### 9

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#### **STEROIDS**

If someone in your household is due to have a live vaccine, ask your IBD team if you need to take any special precautions.

#### Tell other health professionals you're taking steroids

You must tell any doctor, dentist or other health professional treating you that you're taking steroids. If you have a steroid alert card, always carry this with you.

#### **DRINKING ALCOHOL**

You can drink alcohol in moderation while taking steroids, but you may be more likely to have stomach problems. The Department of Health recommends drinking no more than 14 units of alcohol per week – that's around six pints of beer or six glasses of wine.

#### **ALTERNATIVES TO STEROIDS**

#### If you have Crohn's Disease

Enteral nutrition (a special liquid diet that provides all necessary nutrients instead of eating food) is an effective alternative to steroids for children with Crohn's. Enteral nutrition is preferred if there are concerns about steroids affecting a child's growth. There's not enough evidence to say whether enteral nutrition is as effective as steroids for adults with Crohn's, but liquid diets may be used to support nutrition. Speak to your IBD team if you want to find out more about enteral nutrition.

If your symptoms return when you try to reduce or stop taking steroids (steroid dependency) you may be offered an immunosuppressant, such as azathioprine or mercaptopurine, to take in combination with steroids. If your disease is severe and you're not getting better with steroids and/or immunosuppressants, you may be offered a biological treatment, such as infliximab or adalimumab. See our information sheet **Biologic medicines**.

#### If you have Ulcerative Colitis

You'll likely be offered topical or oral 5-ASAs before steroids. If your symptoms return when you try to reduce or stop taking steroids (steroid dependency) you may be offered an immunosuppressant, like azathioprine or mercaptopurine, to take in combination with steroids. If your Colitis is severe and you're not getting better with steroids and/or immunosuppressants, you may be offered a biological treatment, such as infliximab or adalimumab. See our information sheet **Biologic medicines**.

#### If you have Microscopic Colitis

As well as prescribing steroids, your doctor will help you identify lifestyle changes, such as stopping smoking and some medicines, identifying trigger foods in your diet and taking anti-diarrhoeal medicines (such as loperamide) to help control symptoms. If this doesn't help, there may be other drug treatments you can try, although there's much less research into the effectiveness of these. See our information sheet **Microscopic Colitis** for details.

#### WHO TO TALK TO IF YOU'RE WORRIED

Taking different medicines and managing side effects can be difficult – we understand and we're here to help. Our Helpline can answer general questions about different treatment options and can help you find support from others with the conditions.

Your IBD team are also there to help you. You can talk to them about your steroid dosage, how they'll be monitoring you and what alternatives may be available. You should also get in touch with your IBD team if you have any new symptoms or side effects.

It can take time to find the medicine that's right for you, so keep pushing through. Don't be afraid to ask questions and seek out extra support when you need it.

This information on steroids is general and doesn't replace specific advice from your doctor or any other health professional. Talk to your doctor or IBD team for more information. You can also check the Patient Information Leaflet that comes with your medicine or go to **medicines.org.uk/emc.** 

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

We're here for you whenever you need us. Our award-winning publications on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment. We'll help you find answers, access support and take control.

All publications are available to download from our website: **crohnsandcolitis.org.uk/publications** 

Health professionals can order some publications in bulk by using our online ordering system, available from the webpage above.

If you would like a printed copy of a booklet or information sheet, please contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- help you understand more about Crohn's and Colitis, diagnosis and treatment options
- provide information to help you live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk

See our website for LiveChat: crohnsandcolitis.org.uk/livechat Crohn's & Colitis UK Forum

11

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This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum

#### Help with toilet access when out and about

If you become a member of Crohn's & Colitis UK, you will get benefits including a Can't Wait Card and a RADAR key to unlock disabled toilets. This card shows that you have a medical condition, and combined with the RADAR key, will help when you need urgent access to the toilet when you are out and about. See our website for further information: crohnsandcolitis.org.uk/membership or call the membership team on 01727 734465.

#### **OTHER ORGANISATIONS**

Medic Alert medicalert.org.uk 01908 951045 info@medicalert.org.uk

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We hope that you've found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at **publications@crohnsandcolitis.org.uk.** You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE or contact us through the **Helpline: 0300 222 5700.** 

#### ABOUT CROHN'S & COLITIS UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This publication is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit **crohnsandcolitis.org.uk.** 

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