

My gut feeling

Patient guide for ulcerative colitis (UC)

Name: _____ Date of completion: / / Patient weight: _____

Date of UC diagnosis and age: / / Date of last hospital admission for UC: / /

Previous procedures/treatment history: (e.g. date of last colonoscopy, surgery, endoscopy, failed medications) _____

Have you ever had? IV steroids **Y** **N** Cyclosporin **Y** **N** Biologics **Y** **N**

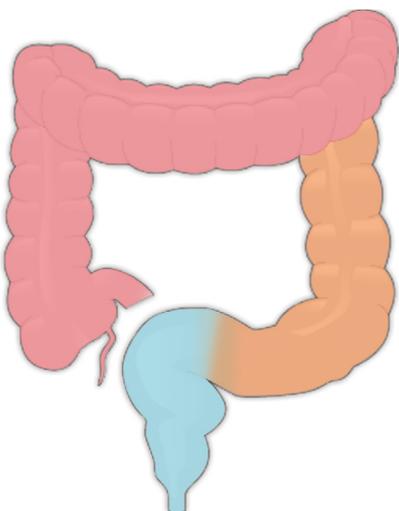
Previous corticosteroid therapy: _____

Considerations: (e.g. family history of colorectal cancer or osteoporosis, smoking status) _____

Medication allergies: _____

My UC

Ask your doctor to illustrate on this diagram the extent of your UC



Annual health checks:

Pap smear (if applicable) **Y** **N** Year of last: _____

Skin check **Y** **N** Year of last: _____

Influenza vaccine **Y** **N** Year of last: _____

Vaccination history:

HBV vaccine **Y** **N** Year: _____

HPV vaccine **Y** **N** Year: _____

Varicella zoster vaccine **Y** **N** Year: _____

Pneumococcal vaccine **Y** **N** Year: _____

Other relevant vaccinations: _____

My GP:

Ph: _____ Alternative contact: _____

My IBD nurse:

Ph: _____ Alternative contact: _____

My gastroenterologist:

Ph: _____ Alternative contact: _____

My dietitian: _____ Ph: _____

My pharmacist: _____ Ph: _____

? About this patient guide for UC

The outlook for most patients is good, with mild to moderate symptoms of UC being well controlled with medication. When you receive a diagnosis of UC, ask your doctor to help you complete all the relevant information on this sheet. You may want to consider creating a file for this information – you can update it over time, take it with you to your first gastroenterologist visit and then update it for future visits.

My UC management

UC is a chronic relapsing disease of the large intestine (the colon and rectum) whose cause is currently unknown. There is currently no cure for UC, so the aim of treatment is to relieve symptoms during a flare (when you are sick) and prevent symptoms from returning during remission – this is known as maintenance therapy. Your doctor may prescribe you different medications for when you're in remission (when you are well) and when you have a flare.

! Considerations

- **Diet:** It is important to discuss interventions that are right for you with a registered dietitian and with your doctor.
- **Emotional well-being:** Having UC can be stressful. Stress can make your UC symptoms worse. You could try some simple stress reduction techniques or discuss referral to a psychologist with your doctor.
- **Pregnancy:** People with UC have normal fertility and good pregnancy outcomes. However, if you are planning a pregnancy, it is best to be in remission and to consult your gastroenterologist before trying to get pregnant.
- **Osteoporosis:** People with UC, especially those on long-term corticosteroids, are at increased risk of osteoporosis (a disease causing fragile bones). Speak to your doctor about the need for a bone density scan to assess and monitor your risk.
- **Colorectal cancer:** People with UC generally have an increased risk of colon cancer. The risks are greater if more of your bowel (colon) is affected or if your disease is not well controlled. Some people with UC are advised to have their large intestine checked by colonoscopy from time to time. Check with your doctor about when you should start these checks and how often you should have them.



When I am feeling my best... complete with your doctor (circle as appropriate).

My stool frequency is _____ per day



I usually do/don't have **night-time stools**

I usually do/don't see **blood in my stools**

I usually do/don't need **to rush to the toilet**



When my symptoms are changing... keep a diary for 3-4 days (tick as appropriate).

Date	Stool frequency			Night-time frequency			Blood in stools		
	0-3	4-6	Over 6	0	1	2 or more	No	Trace	Large amount
/ /	<input type="radio"/>								
/ /	<input type="radio"/>								
/ /	<input type="radio"/>								
/ /	<input type="radio"/>								

? What should I do?

Mostly **GREEN**: continue taking maintenance medication (as recorded in the treatment plan below).

Mostly **ORANGE**: increase to flare medication dose (as recorded in the treatment plan below) and make an appointment to see your local doctor or gastroenterologist within 1-2 weeks.

If you ticked ANY RED: contact your local doctor, gastroenterologist or IBD nurse straight away. Go to hospital if you feel very unwell or develop fever, lots of bleeding and/or severe abdominal pain.

Note: 'stools' includes incomplete bowel movements when you only pass mucus and/or blood.



My UC medication... complete this list with your doctor (update it at each visit).

Maintenance medication	Dose	How often
Flare medication	Dose	How often

Take your medication as prescribed.

If you feel your medication is not working or is causing you problems, or if you have any questions, talk to your healthcare professional.

Do you take any complementary or alternative medication? Y N **Details:** _____

If you find yourself not taking your medication for the reasons below, please discuss further with your gastroenterologist.

- Do you ever forget to take your medication?
- Are you careless at times about taking your medication?
- When you feel better, do you sometimes stop taking your medication?
- Sometimes, if you feel worse when you take the medication, do you stop taking it?



Additional information

Gastroenterological Society of Australia (GESA): For more information on diets <http://www.gesa.org.au/resources/patients/low-fodmap-diet/>; and for more information on IBD <http://www.gesa.org.au/resources/patients/inflammatory-bowel-disease/>

Crohn's & Colitis Australia: <https://www.crohnsandcolitis.com.au/>

IBD Support Australia: <http://www.ibdsupport.org.au>

IBDclinic.org.au: <http://www.ibdclinic.org.au>



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