CROHN'S & COLITIS UK

COVID-19 for people with Crohn's or Colitis

This information is about COVID-19 for people with <u>Crohn's</u> or <u>Colitis</u>. Our information can help you understand:

- Your risk of getting COVID-19
- How COVID-19 may affect you and what to do if you catch it
- COVID-19 treatments you may be able to access
- COVID-19 vaccines and whether you need booster vaccines
- What rights you have in the workplace in relation to COVID-19

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Key facts

- Most people with Crohn's or Colitis are not at increased risk of getting COVID-19.
 They are also at no more risk of having more severe COVID-19 if they do get it.
- Taking medicines to keep your Crohn's or Colitis under control can help prevent flare-ups and needing steroids. These are risk factors for COVID-19.
- If you catch COVID-19, you should talk to your IBD team about whether to temporarily stop your Crohn's or Colitis medicines.
- COVID-19 vaccines are safe for people with Crohn's or Colitis. If you are taking
 medicines that weaken your immune system (immunosuppressants), you may have
 a reduced response to the vaccine. Or you may or lose protection faster.
- Some people with Crohn's or Colitis may be eligible for booster vaccines and free COVID-19 tests and treatments. This includes if you take immunosuppressants or have other factors that increase your risk.

Risk of COVID-19 with Crohn's and Colitis

COVID-19 is now considered to be a mild illness for most people. As such, it's generally treated like any other common, respiratory virus. There are no longer any COVID-19 restrictions in the UK. But COVID-19 is still with us, and you may well have questions about getting it if you have Crohn's or Colitis.

Are people with Crohn's and Colitis at higher risk?

Early in the pandemic, the British Society of Gastroenterology developed a 'risk grid' for people with Crohn's or Colitis. This was based on factors like current medication, disease activity, age, and other health conditions. The risk grid helped identify people with Crohn's or Colitis who were thought to be at higher risk from COVID-19.



Now we know more about COVID-19, and we have vaccines and medicines to treat it, the risk grid is no longer relevant. From the knowledge we have of COVID-19, there is reassuring evidence that most people with Crohn's or Colitis:

- Are **not** at higher risk of getting COVID-19 because of their condition or treatment
- Do not have more severe illness with COVID-19 because of their condition or treatment

What affects your risk of COVID-19?

Everyone's risk is different and can be affected by many things. These can include the following.

- Whether you have been vaccinated. Getting vaccinated is the best thing you can do to reduce your risk of becoming severely ill with COVID-19.
- Whether your Crohn's or Colitis is under control. Being in a flare-up may increase your risk of getting COVID-19 and becoming seriously ill with it.
- The treatment you are on. Oral or injectable <u>steroids</u> may increase your risk of severe COVID-19. This is not the case for topical steroids, like budesonide or beclomethasone. Other medicines that weaken your immune system (known as immunosuppressants) may reduce how well the vaccine works. We explain this further in the section <u>Will Crohn's or Colitis affect how well the vaccine works?</u>
- Other conditions that you may have such as lung disease, heart disease and diabetes. These may also increase your risk of becoming seriously ill if you get COVID-19.
- How old you are. Older age increases your risk.
- Your ethnic background. One study has looked at ethnic background in people
 with Crohn's or Colitis. It found Black or Hispanic people had a greater risk of
 severe COVID-19 than non-Hispanic white people.

These factors may put you at higher risk of getting COVID-19 or having a more serious illness if you get it. But the rules for who can get vaccine boosters or COVID-19 treatments because of their risk are slightly different.



How Crohn's and Colitis medicines affect risk

Research to date has shown that most Crohn's and Colitis medicines do not increase the risk of getting COVID-19. They also do not increase risk of getting seriously ill if you do get it. This includes <u>5-ASAs</u>, <u>azathioprine</u>, <u>mercaptopurine</u>, <u>biologics</u> and JAK inhibitors.

Oral and injectable steroids can increase your risk of serious illness with COVID-19. You may need steroids if you have a flare-up of your Crohn's or Colitis. This is why it's best to keep taking your usual Crohn's or Colitis medicines.

Taking your usual Crohn's or Colitis medicines will help prevent flare-ups and needing steroids. These are both risk factors for COVID-19.

Some of the medicines that weaken your immune system (immunosuppressants) may affect your risk in a different way. This is because they can reduce your response to the COVID-19 vaccine. Because of this, you may be classed as being at higher risk if you take an immunosuppressant.

If you're worried about how your medicines may affect your risk, please discuss this with your IBD team.

Protecting yourself if you are at higher risk

There is guidance available for people who are classed as higher risk because they have a weakened immune system. This is different depending on whether you are living in England, Scotland, Wales and Northern Ireland.

There's no longer any need to 'shield' as was advised for some very vulnerable people early in the pandemic. But if you are at higher risk for any reason, you may benefit from more protection.



Depending on the reasons why you're at higher risk, some of the following may apply.

- You may be eligible for additional COVID-19 vaccine boosters. If you are at higher risk, it is important to keep up to date with vaccinations.
- You may be eligible for COVID-19 treatments and free lateral flow tests.
- You may wish to try to avoid contact with people with COVID-19 symptoms. You
 may also choose to take further precautions, such as avoiding crowded places and
 wearing face masks. This can reduce your risk.

You can read more about this in the sections, <u>COVID-19 treatments</u> and <u>COVID-19</u> vaccines.

What to do if you have COVID-19

It's natural to feel concerned if you get COVID-19 symptoms or have a positive test result. But remember that for most people, including those with Crohn's or Colitis, COVID-19 is a mild illness.

Common symptoms of COVID-19 include:

- A high temperature
- A new, continuous cough
- A loss of or change in your sense of taste or smell
- Muscle aches and pains
- A headache
- A sore throat, or a blocked or runny nose
- Diarrhoea and feeling or being sick

Some of the symptoms of COVID-19, like diarrhoea, may be like those of a Crohn's or Colitis flare. But COVID-19 does not seem to cause any flare-up or worsening of Crohn's or Colitis.



Do I need to test?

Most people no longer need to do a COVID-19 test if they have symptoms. This includes people with Crohn's and Colitis. But you can buy lateral flow tests yourself if you wish.

If you are at highest risk of severe disease and eligible for COVID-19 treatments, you should also have access to free lateral flow tests. See the separate section on COVID-19 treatments.

Do I need to isolate?

There are no longer any rules about isolating if you have COVID-19. But if you have symptoms including a high temperature and you feel unwell, it is best to avoid contact with other people. This advice is the same for any respiratory virus. If possible, stay at home until you feel better.

If you have had a positive COVID-19 test, try to avoid other people for 5 days after you took the test. The advice is 3 days for children and young people under 18.

If you are due to attend a medical appointment, contact your healthcare provider and let them know about your symptoms or positive test.

How can I look after myself at home?

Most people with Crohn's or Colitis will be able to follow standard advice about managing their COVID-19 symptoms at home. This includes:

- Get plenty of rest
- Drink fluids to stay hydrated
- Use medicines like paracetamol to help with symptoms such as fever
- If you have a cough, avoid lying on your back, and try simple remedies, like honey or cough medicines
- Use relaxation and breathing techniques to help with breathlessness



If you are getting severe symptoms or are worried, contact your IBD team, GP, or NHS 111. In an emergency if you are feeling seriously unwell, go to your nearest A&E department or call 999.

Should I stop taking my Crohn's or Colitis medicines?

If you have tested positive for COVID-19, contact your IBD team to ask them whether to stop taking your Crohn's or Colitis medicines. This will be individual to your own situation. It's especially important to talk to your IBD team if:

- Your COVID-19 symptoms are severe
- You are at a higher risk of complications due to your age or other health conditions
- You are having a flare-up of Crohn's or Colitis symptoms

If you are taking 5-ASAs, it's safe to carry on taking them while you have COVID-19.

Your IBD team may ask you to stop or delay taking medicines that weaken your immune system until you feel better. These include the following.

- Adalimumab
- Azathioprine
- Ciclosporin
- Filgotinib
- Golimumab
- Infliximab
- Mercaptopurine
- Methotrexate
- Ozanimod
- Risankizumab
- Tacrolimus
- Tofacitinib
- Upadacitinib



- Ustekinumab
- Vedolizumab

Do not stop taking steroids suddenly as this can be dangerous. Instead, your IBD team may advise you to gradually reduce your dose.

This is general information and does not replace the advice of your doctor or IBD Nurse. Do not stop taking any of your Crohn's or Colitis medicines until you've spoken to someone in your IBD team. If you can't get hold of your IBD doctor or nurse, contact your GP.

For some people, it might be better to stop taking medicines that weaken their immune system while they recover from COVID-19. But stopping your Crohn's or Colitis medicine may increase your risk of a flare-up, which is itself a risk factor for severe COVID-19. This is why it's important that you talk to your IBD team. They can help to weigh up the risks and benefits of stopping your medicine, and assess what's best for you.

We know it can be very concerning if you are advised to stop taking your medicine. The immunosuppressants listed above are slow-acting medicines. This means they stay in the body and continue to work for some time, even when you stop taking them. So, if you've had to delay or miss a dose, it's unlikely to have a significant impact on your Crohn's or Colitis.

Children and young people under 18 years old are at less risk of serious illness with COVID-19, so may not need to stop their medication. Contact your IBD team for advice.

Am I at greater risk of getting long COVID?

Some people who get COVID-19 continue to experience symptoms for several weeks or months after the infection has cleared. This has been termed 'long COVID'. Studies to date have shown that people with Crohn's or Colitis are not at increased risk of getting long COVID. Reassuringly, medicines for Crohn's and Colitis also do not seem to affect your risk of getting long COVID.

That means there's no added risk if you are continuing your usual medication during COVID-19 infection or straight afterwards.



COVID-19 treatments

Only people classed as being at the highest risk of getting seriously ill with COVID-19 may be eligible for treatment. This includes some people with Crohn's or Colitis, and applies to people in all parts of the UK. You have these treatments at home or in community hospital units. You do not need to be admitted to hospital. They are not a cure for COVID-19. But they can help reduce the risk of complications or needing to be admitted to hospital.

Who can get COVID-19 treatments?

You should be offered COVID-19 treatment as soon as possible if all the following apply:

- You have tested positive for COVID-19 and
- You are at highest risk of getting seriously ill from COVID-19 (see below) and
- You have symptoms of COVID-19 that are not getting better

There are lots of things that can increase your risk of getting COVID-19. We discuss this in the section on Risk of COVID-19 with Crohn's and Colitis. But only those people classed as being at the highest risk will be eligible for COVID-19 treatment. This includes those with Crohn's or Colitis aged 18 years and over who:

- Also have other conditions that increase their risk, such as:
 - o Body Mass Index (BMI) greater than 30
 - Diabetes
 - Hypertension
 - Severe kidney, liver, or lung problems
- Have been taking steroids equivalent to 10mg or more of prednisolone every day for at least 28 days before a positive COVID-19 test.
- Are currently taking azathioprine, mercaptopurine, ciclosporin, mycophenolate or tacrolimus.



- Currently have, or have had in the 3 months before a positive COVID-19 test, active or unstable disease which required:
 - o A new immunosuppressive treatment or increase in dose of an existing one
 - A steroid injection
 - Oral steroids

It's important to note that being on this list does not mean that you will definitely receive the treatment. A clinician will assess you first and make the final decision.

In children and young people aged under 18 years, the risk of complications or hospitalisation from COVID-19 is very low. Some children may be offered treatment. But your child's doctor will discuss this with a group of specialists first.

How do I get treatment?

If you are in the <u>highest risk group</u>, you should have received a letter or email from the NHS with further information. This should tell you how you may be able to get treatment if you develop COVID-19.

If you are eligible to receive COVID-19 treatments, you are also eligible for free lateral flow tests. You should keep some lateral flow tests at home so you can test as soon as you have symptoms of COVID-19, even if they're mild.

If you're in Scotland:

You can order these free online or by calling 0800 008 6587.

If you're in England, Northern Ireland or Wales:

You may be able to get these from your local pharmacy.

You can find out if a pharmacy near you in England is offering free tests using the <u>Find a</u> pharmacy service.

You can find out if a pharmacy near you in Wales is offering free tests from NHS 111 Wales.



Someone else can pick these up for you. They'll need to know:

- Your medical condition(s) if you have an email or letter confirming you are eligible for treatment they should take this.
- Your NHS number (if available).
- Your full name.
- Your date of birth.
- Your address.

If your test is positive, call your GP surgery, NHS 111, or hospital specialist. They'll decide if you need treatment. The NHS website has more information about accessing treatments for COVID-19.

If you have recently started medicines that would make you eligible for treatment, you may not be automatically contacted. If you think you are eligible but you have not had a letter or email, contact your GP or specialist to discuss whether you are in one of the highest risk groups.

What treatments are available?

There are different treatments available for people at highest risk of complications of COVID-19. These include the following:

- Antiviral treatments, including nirmatrelvir plus ritonavir, remdesivir and molnupiravir. These work by stopping the virus from growing and spreading in your body. This reduces your risk of severe illness. You may have them as tablets or an injection into a vein (infusion).
- Monoclonal antibody treatments, including sotrovimab. Monoclonal antibodies are
 like the antibodies that your body makes to fight infection, but they are made by
 scientists in a lab. Monoclonal antibodies work by attaching themselves to the
 virus, stopping or reducing infection. You have them as an injection or infusion.



Does it matter if I've had the vaccine?

Your vaccination status will not affect your eligibility for COVID-19 treatments. However, it is advised to get your vaccine (and boosters), especially if you are at higher risk.

COVID-19 vaccines

The COVID-19 vaccine is the best way to protect yourself and others against severe illness with COVID-19. If you are at increased risk of complications from COVID-19, getting vaccinated and having any boosters you are entitled to is even more important.

There are some important points to bear in mind about having the vaccine if you have Crohn's or Colitis:

- COVID-19 vaccines are safe for people with Crohn's and Colitis, no matter what medicines you are taking.
- COVID-19 vaccines are not live vaccines they do not cause infection with COVID-19.
- There is no evidence that vaccines will cause a flare-up in your Crohn's or Colitis.
- Having Crohn's or Colitis does not make the vaccine any less effective for you.
- People taking certain immunosuppressant medicines may have a reduced response to COVID-19 vaccines. Or they may lose protection faster. This means they may need extra booster doses.
- Even if you have a reduced response to the vaccine, it is still better than not having the vaccine at all.



Is the COVID-19 vaccine safe for people with Crohn's or Colitis?

As with many vaccines, it is possible you may get some side effects after the COVID-19 vaccine. The most common ones include:

- A sore arm where you had the vaccine
- Feeling tired
- Headaches
- Muscle aches

These effects are usually mild and go away within a few days. People with Crohn's and Colitis have similar side effects to the rest of the population, and these are usually mild. This is the case no matter what treatments you may be taking.

COVID-19 vaccines are not live vaccines (they do not contain any live virus). This means there's no risk of it causing infection with COVID-19.

There is no evidence that having the COVID-19 vaccine will cause a flare-up in your Crohn's or Colitis. A few people have reported having a flare-up soon after having the vaccine. But these numbers are similar to people who have not been vaccinated.

If you feel you have had a side effect from the COVID-19 vaccine, you can report it via the MHRA Yellow Card reporting site. Speak to your IBD team too if you're concerned.

Does having Crohn's or Colitis affect how well the vaccine works?

Having Crohn's or Colitis does not make the vaccine any less effective. If you're on a <u>5-</u>
<u>ASA medicine</u> or no medicine at all, the vaccine should work as well as for someone without Crohn's or Colitis. However, being on certain immunosuppressant medicines may make the vaccine work less well.

Vaccines work by 'tricking' your immune system into launching an attack against a virus before you have been exposed to it. If you are then exposed to the virus later on, your body is already prepared and protects you from getting ill. If you are taking immunosuppressant medicines, your immune system might not respond as well to the vaccine as other people's.



Evidence from major studies such as <u>CLARITY</u> and <u>VIP</u> shows that people taking anti-TNF medicines, such as <u>infliximab</u>, or the JAK inhibitor <u>tofacitinib</u> have a reduced response to the COVID vaccine. This can mean:

- They produce fewer antibodies (proteins produced by your immune system in response to an infection)
- There is a reduced T-cell response (these are types of cells that fight infection in your immune system)
- They have a greater number of 'breakthrough infections' (infection with COVID-19 after vaccination)
- Their protection after vaccination reduces faster over time

We can't be sure yet whether other immunosuppressants have a similar effect. But there are promising results that azathioprine, ustekinumab and vedolizumab do not reduce vaccine response.

If you were taking immunosuppressant medicines when you had your first (primary) COVID-19 vaccines, you should have been offered an extra (third) dose. This extra dose should help to improve your protection.

Having a reduced response to the vaccines does not mean you should stop your treatment before getting vaccinated. Stopping treatment can lead to a flare of your Crohn's or Colitis, which puts you at greater risk from serious complications of COVID-19.

Even if the COVID-19 vaccine works slightly less well for you, it will still offer greater protection than not having the vaccine. You may also be eligible for vaccine boosters. These help to improve your immune response against current strains ('variants') of COVID-19.

Seasonal Covid-19 booster vaccines

COVID-19 vaccines are normally given seasonally. If your NHS record suggests you may be eligible for a seasonal COVID-19 vaccine, the NHS will contact you with information on when and where you can get your booster.



Depending on where you live in the UK, you can get information about current COVID-19 booster programmes, including who is eligible, from the following places.

- England NHS England
- Scotland NHS Inform
- Wales Public Health Wales
- Northern Ireland NI Direct

The COVID-19 variants in circulation are under constant review. If a new, more infectious, or serious variant were to emerge, people at higher risk may be offered additional boosters.

If you are also eligible for the flu vaccine, you can usually have them at the same appointment. You will have one vaccine in each arm. It is safe and effective to have the COVID-19 and flu vaccines at the same appointment.

What should I do if I have not been vaccinated at all?

From 30 June 2023, the NHS stopped providing initial COVID-19 vaccines for people who are not at higher risk of severe illness. If you are at higher risk from COVID-19, you can still get vaccinated. This will usually be when booster programmes are running. Follow the links in the section, <u>How can I get a booster vaccine?</u> to find out how to book an appointment.

If you develop a new health condition or start treatment that severely weakens your immune system, you may be able to get vaccinated sooner if your clinician or GP surgery advises it.

When is the best time to have the COVID-19 vaccine?

Experts recommend that you have any vaccines and boosters that you're eligible for as soon as you are able.



- Having active Crohn's or Colitis or taking treatments should not stop you from getting the vaccine.
- There is no need to leave a gap between a biologic injection or infusion and having the vaccine.
- You can have the vaccine at any point in your treatment cycle. The timing of your treatment is not likely to affect how well the vaccine works.

But there may be times when it's better to delay having a vaccine or a new medication for a short time.

Examples include:

- If you feel very unwell on the day of your appointment, for example if you have a high fever or symptoms of COVID-19. You should delay having the vaccine until you have fully recovered, or for 4 weeks if you have had a positive COVID-19 test.
- If you are having a flare-up of Crohn's or Colitis symptoms. It is safe to have a vaccine during a flare-up. But it can make it hard to tell whether any symptoms are due to your illness or side effects of the vaccine. Some medicines you may need to take during a flare-up can also affect how well the vaccine works.
- If you are taking steroids. Your IBD team may recommend that you taper down or
 finish your course of steroids before you have the COVID-19 vaccine. This is
 because high doses of steroids can affect how well the vaccine works. It is still
 safe to have the vaccine while taking steroids.
- If you are about to start a new or higher dose of biologic or other
 immunosuppressant medicine. Speak to your IBD team about the best time to
 have your vaccine doses. Once you start these medicines, the vaccines might not
 work so well for you. However, it is still safe to have the vaccine when on these
 medicines.

Whether or not it is better to delay having a vaccine is something you should discuss with your IBD team. It is likely to depend on many factors that will be individual to you.



COVID-19 in the workplace

The impact on work was a major concern for people with Crohn's and Colitis early in the pandemic, especially those who needed to shield.

Most people are now able to follow general **guidance** on staying safe and preventing the spread of respiratory diseases like COVID-19. There are no longer any regulations for employers to allow working from home for people at higher risk from COVID-19. But if working from home is something you would prefer to do, you should discuss it with your employer.

If you are not able to work from home, speak to your employer about what arrangements they can make to reduce your risk. It may be that you are entitled to a reasonable adjustment under the **Equality Act** (in England, Scotland and Wales) or the **Disability Discrimination Act** in Northern Ireland.

How can my employer help protect me?

Employers are no longer required by law to carry out a risk assessment specifically for COVID-19. But they still have legal obligations under health and safety, employment, and equality law.

There is also guidance on staying safe at work in relation to COVID-19 for each nation, which employers are encouraged to follow. These are listed below. They include measures like improving ventilation, maintaining a clean workplace, and enabling flexible or hybrid working when possible.

- England: Reducing the spread of respiratory infections, including COVID-19, in the workplace
- Scotland: Coronavirus (COVID-19): safer workplaces and public settings
- Wales: <u>Public health advice for employers</u>, <u>businesses and organisations</u>:
 <u>coronavirus</u>
- Northern Ireland: <u>Coronavirus (COVID-19): staying safe at work</u>

What can I do if I feel my employer is not considering my safety?



Employers may not understand the unpredictable course of Crohn's and Colitis. If you experience a flare-up or change medications you may be more at risk. Our **guide for employers** has information on how employers can support an employee with Crohn's or Colitis.

If you feel your employer is not taking reasonable steps to help protect you, you can raise a concern in the following ways:

- Report this to the local authority for your workplace
- Contact your employee representative
- Contact your trade union if you have one. If you're not a member of a trade union, you can find advice on joining one on the <u>GOV.UK website</u>
- Use the Health and Safety Executive (HSE) contact form
- Contact HSE by phone on 0300 003 1647

Other organisations

NHS

For latest COVID-19 advice, including treatment and vaccination programmes.

Health and Safety Executive

Advice for workplaces on COVID-19

ACAS

Advice for employers and employees on COVID-19

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information 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 and employment. We'll help you find answers, access support, and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

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

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

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers, and other professionals. They are prepared as general information and are not



intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

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 information 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 <u>crohnsandcolitis.org.uk</u>.

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Crohn's & Colitis UK information is research-based and produced with patients, medical advisers, and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

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.

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