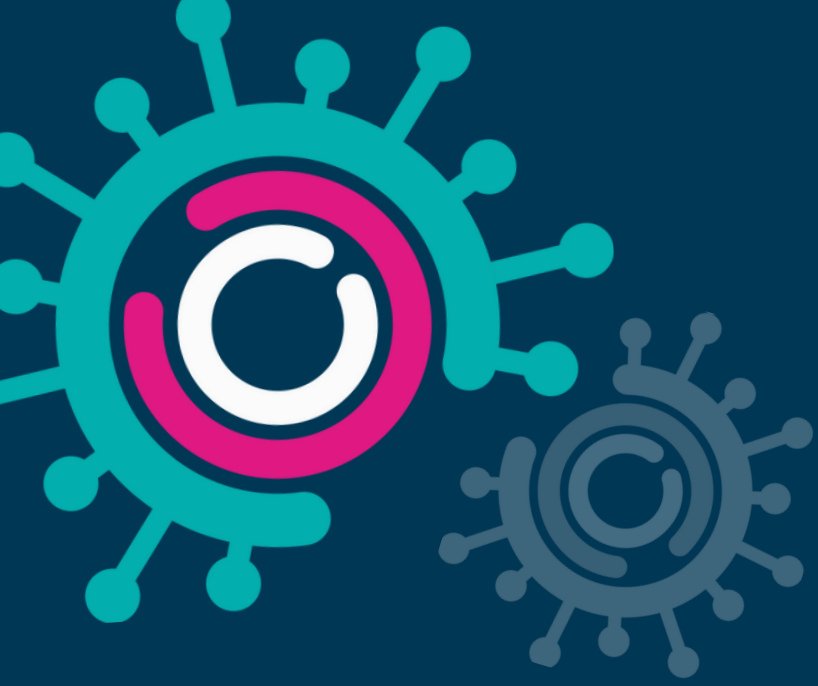

Navigating a post-pandemic world:

A guide for immunocompromised blood cancer patients

ICBCC
International COVID-19 Blood Cancer Coalition

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Preface

While COVID-19 has become a less significant issue for most people, some groups like certain blood cancer patients remain at elevated risk with profound effects on their lives. If you belong to this cohort of patients, you may live with a weakened immune system due to your illness or the treatment you receive and can suffer from frequent or severe infections that do not go away easily. Even a simple cold or flu could last longer and hit you harder than others. You may also be more susceptible to infections that others can fight off without much difficulty. If you find that you have frequent colds or flu and catch infections more easily than before your blood cancer diagnosis, it is likely that your immune system is not working well due to your blood cancer or your treatment. For this reason, a possible COVID-19 infection could remain a risk for you. What is more, your immune status may continue to have a negative impact on your psychological health and wellbeing due to the need to continue to balance risk when carrying out activities of daily life.

The following are some practical tips and recommendations to help you to live a better quality of life and empower you when making decisions. The aim of this guide is to help you navigate and manage the risks arising from the combination of a compromised immune system and possible COVID-19 infection. The recommendations herein may also be applicable to other types of infection.

I. Managing risk

There are many different steps and measures how blood cancer patients with a weakened immune system can manage their risks of getting COVID-19. Many of these, in particular **vaccines and masks, have been proven effective in past years**. However, even up-to-date vaccines cannot guarantee that an immune-compromised patient will mount an adequate response to the vaccine.

A "layered approach" to reduce risks is therefore important. Depending on your personal situation and the environment you are in, you can apply different layers of protection to your risk management.

Your healthcare provider (general practitioner, family doctor, primary care nurse or haematologist/oncologist) can discuss your individual risks with you, strategies to reduce them and if any COVID-19 treatment options (including vaccination, booster shots and other treatments) are available and accessible to you.

1. Recommended safety measures

The following is a list of recommended safety measures:

Vaccination

There is clear evidence that **vaccines work and can prevent the development of serious illness** with COVID-19 or hospitalisation in immunocompromised patients.[1, 2, 3] Do get vaccinated against COVID-19 and other infections. Ideally, your household contacts are also vaccinated, as vaccinated people are less likely to transmit the virus than those who are not vaccinated if they are infected.[4, 5, 6, 7, 8, 9]

Your doctor will provide you with the necessary information. The timing of your vaccination should be decided based on your ongoing or planned immunosuppressive treatments, your overall health, and how you are expected to react to the vaccine.

Booster vaccine shots

Immunocompromised people should take up the offer of **additional or "booster" vaccine doses**. There is strong evidence that immunocompromised blood cancer patients respond better with repeated doses.[10] Talk to your doctor about a vaccination plan that aligns with your primary medication. This may include regular administration of booster vaccine shots as needed.[11]

Access to post-exposure prophylaxis and antivirals

When vaccination has not provided sufficient protection, you should get access to treatments to treat infection. There are drugs available today that have been shown to reduce the severity of the infection, such as nirmatelvir/ritonavir (Paxlovid).

You can find more information on post-exposure prophylaxis ((these are medicines to limit infection after contracting COVID-19) **and antivirals** (these are medications that help your body fight off certain viruses that can cause disease) **in this guide under IV. What to do if you have tested positive for COVID-19.**

Please talk to your doctor about what options are available to you and how you can access them.

Continued masking and personal protection

Good quality masks have been shown to provide strong protection against infection with COVID-19 and can help in reducing the risk of infection when in crowded spaces or anywhere that is enclosed or poorly ventilated. **It is helpful to always have a mask at hand for when you feel you need it.**

Wearing a good **quality mask (FFP2, FFP3, KN95, or N95 masks or higher)** that fits well offers best self-protection and is therefore key. For example, a study shows that if there are two people in an environment and both wear a well-fitting FFP2 or KN95 mask, there's only a 0.1 percent risk of infection.

If both people wear ill-fitting FFP2 or KN95 masks, the risk goes up to 4 percent. It may not always be possible to ask the people to wear a mask when with you, but if you are able to, this will give you additional protection.[12]

When out and about, **maintain your personal space as much as the situation permits if that feels right for you.**

It's important to wear your mask when you're in places like hospitals or clinics and to let doctors and nurses know that your immune system is weaker, so they can take extra precautions. Don't forget to use hand sanitizer and wash your hands regularly as this is one of the most effective ways to prevent infection in general. Always carry hand sanitizer with you in case it is not available in public areas.

Unfortunately, it can be difficult to continue wearing a mask when others aren't. You may be harassed or feel you are being socially excluded, which can have a negative impact on your psychological well-being.

However, don't let this distract you! It's in your best interest. Your health is your responsibility, and you know what is best to keep you safe. Remember you are not alone.

2. A layered approach to managing risk

Living with blood cancer can be complicated and exhausting. Always worrying about the risks in your daily life can be stressful and psychologically draining. However, not all activities and engagements with the world are equally risky. Assessing and understanding the risks you may be facing, and applying a "layered approach" will help reduce your risk of infection, and relieve stress.

It may be helpful to identify activities that carry a higher risk and take some common sense approaches to reduce this risk:

Activities with higher risk:

Regularly mixing with people:

Meeting lots of different people often can increase your chances of getting COVID-19. The more people you are in contact with, the higher the risk of getting infected.

You can reduce this risk by mixing with people less often. Stay connected with friends and family by phone or online.

Being in large groups or crowded places:

Big gatherings or crowded places make it difficult to keep a safe distance from others. When many people are close together, there is a greater chance of the virus spreading.

You can reduce this risk by meeting up with people individually or in smaller groups to minimise your exposure.

Engaging in close physical contact with people:

Getting too close to others, like hugging or shaking hands, makes it easier for the virus to pass from one person to another. Keeping your distance helps lower the risk of getting the virus.

You can reduce this risk by keeping your distance from others and choosing who to be close with.

Indoor socialising:

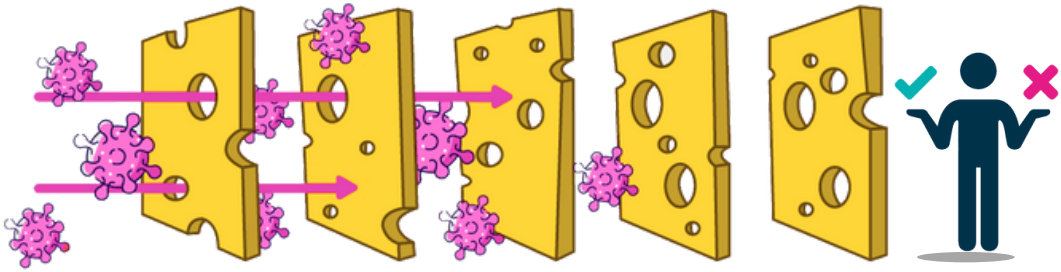
Being indoors, especially in places with poor ventilation, increases the chances of the virus lingering in the air. This makes it more likely that you could get infected.

Reduce this risk by opting for an outdoor setting where possible. For example, meet at an outdoor cafe rather than indoors or take a walk with a friend. If meeting indoors is unavoidable, choose well ventilated indoor spaces and incorporate additional measures as mentioned below.

Being around people who don't wear masks:

If others around you are not wearing masks, there is a higher chance of being exposed to COVID-19.

Asking others to wear masks can be difficult but there are some situations where others can or will do so upon request. For example in healthcare settings or at hairdressing appointments.



The following is a list of measures and precautions that have proven to be effective. They are all part of a layered approach to risk and a combination of these may help you manage risk around your daily activities:

- Get regular booster shots.
- Wear a mask where needed.
- Encourage people that you spend more time with or live under the same roof as you to get vaccinated if possible. It can reduce the risk of them transmitting the virus when infected with COVID-19, though not eliminate the risk.[13]
- Ask friends and family members to please let you know on time if they are sick and potentially contagious. Be clear that you would prefer to reschedule your meeting.

- **When meeting others**
  - Before meeting:
    - Encourage people to test themselves before meeting up with you (e.g. rapid antigen test).
    - Avoid meeting others if they show symptoms despite a negative test.
  - Venue considerations:
    - Opt for an outdoor coffee.
    - Take a walk outside if possible.
    - Meet in well-ventilated areas.
  - Consider wearing your mask when appropriate
  - Ask the people you are with to wear a mask if possible.
- Practise good hygiene and avoid sharing items with a high risk of transfer, such as towels, napkins, or cutlery.
- Do your shopping or visit to the hairdresser at times when it is less busy, or use online delivery services whenever possible.

- Avoid hugging or shaking hands as a form of greeting others. Both make it easier for the virus to pass from one person to another.
- When scheduling appointments, consider your options, e.g. check if virtual or phone appointments are possible, or choose out-of-hours appointments when less busy. Be sure to wear your mask.
- Minimise travel and prioritise essential trips. If you have to travel, opt for private transportation whenever possible.

Remember: it may not be possible to completely avoid certain risks, such as going to work. In these cases, it is important to follow workplace guidelines, possibly also in coordination with your employer, and take necessary precautions to minimise the risk of exposure. For example, you may be able to request a remote working option. Your local blood cancer patient organisation may be able to provide you with information that can be useful when talking to your employer about this.

Ultimately, in society today it is important that as an immunocompromised patient who is vulnerable to COVID-19 and other infections it makes sense to protect yourself and your health.

II. Improving outcomes: Act proactively

Even before a potential COVID-19 infection, a few simple measures in coordination with your doctor can help reduce the impact should you become infected.

Primary healthcare providers such as general practitioners or family doctors, nurses and care workers should be aware of the special needs of immunocompromised (IC) patients. If you haven't already, be sure to **discuss your immune status and a treatment plan in case of infection** with your healthcare team at your next visit. This may prevent future complications.

Such a treatment plan can include:

- The necessary tools for home use (e.g. rapid antigen tests).
- A list of places nearby where and how you can get the critical treatments against COVID-19 such as antivirals and further testing (e.g. PCR tests).
- All necessary documents and information (e.g. on your primary disease, medication you are taking and your health history).
- A household isolation plan should you or someone in your household test positive (e.g. having plenty of high-quality face masks available).
- A plan for further hospitalisation and treatment if necessary.

You can find examples of a treatment plan here: cllsociety.org/covid-19-home/action-plan/.

Your healthcare team may offer immunocompromised blood cancer patients specific time slots for appointments to minimise your exposure to potential COVID-19 carriers. If you test positive for COVID-19, work closely with your doctor to explore available treatment choices and ensure that you get treated quickly to lower the risk of severe illness.

Whenever possible and reasonable with regards to your health situation, make a virtual appointment instead of going to the doctor's office or hospital to avoid infection with COVID-19, but also other diseases and germs - especially in the colder seasons when hospitals are often overcrowded and longer waiting times are to be expected. Here are some further general principles - https://rb.gy/3kbffe to protect against COVID-19, but also against other infections.

It may be helpful to **contact a patient organisation for support and information**. These directories provide examples of what is available in many countries: Patient Organisation Search tool on Orphanet (https://rb.gy/t56lhk) or CLL Resource Hub (www.clladvocates.net/cllresources). Please note that this is not an exhaustive list. Your healthcare team may be able to help you find a suitable organisation.

III. Stay vigilant and recognise the symptoms

Although they might change a little with new variants, there are some symptoms that remain the same and appear about 5-6 days after exposure and last up to 14 days. The symptoms you get and the order in which you get them can vary.

If you experience one or more of these symptoms and are unsure whether it is COVID-19 or a different disease, **immediately do a rapid antigen test**, and then test again if your first result is negative. Tests may be falsely negative early in the infection, so **repeated testing while symptomatic is recommended**.

Rapid antigen tests can usually detect the virus as early as 4 days after infection.

The most common symptoms are: [15,16]

Less common symptoms are:

- Muscle aches and heavy arms or legs
- Severe tiredness or fatigue
- Runny or blocked nose or sneezing
- Headache
- Sore eyes
- Dizziness
- New and persistent cough
- Chest tightness or chest pain
- Shortness of breath
- Hoarse voice
- Numbness or tingling
- Loss of appetite, nausea, vomiting, abdominal pain or diarrhoea
- Loss or change in the sense of taste or smell
- Difficulty sleeping

If you experience the following symptoms, you should contact your doctor or go to hospital immediately:

- Difficulty breathing, especially at rest, or inability to speak in sentences
- Confusion
- Drowsiness or loss of consciousness
- Persistent pain or pressure in the chest
- Cold or clammy skin, pale or bluish colour
- Loss of speech or movement

If you were exposed to someone who has COVID-19 and you **do not have symptoms, wait at least 5 full days after your exposure before testing**. If you test too early, you may have an inaccurate result.[14]

IV. What to do if you test positive for COVID-19?

Should you test positive for COVID-19, don't panic. Most cases of COVID-19 infection will pass with mild to moderate symptoms, especially if your vaccination is up-to-date.

However, if you still have a more severe COVID-19 disease course, there are certain treatments that can significantly reduce the risk of death and help manage the progression of symptomatic disease.

For example, starting treatment with nirmatelvir/ritonavir (Paxlovid) as soon as possible and definitely within 5 days of the first symptoms can ease symptoms, help you get better faster, and lower the chance of having to stay in the hospital. However, it's important to be aware of potential interactions with other treatments, such as ibrutinib, acalabrutinib, zanubrutinib, and venetoclax, which may require temporary pauses or dose adjustments.

Please talk to your haematologist about recommended dose adjustments for your treatment in advance. Depending on the circulating COVID-19 variants and treatments available, other options like oral molnupiravir or remdesivir may be considered. E.g., Paxlovid has shown good results both in clinical studies and in practical use.

In summary, the timing and amount of these treatments depends on the severity of COVID-19 and other factors such as

- your underlying condition and its treatment
- the immunosuppressants being used
- possible issues when different drugs interact or have similar harmful effects
- secondary infections

Keep in mind that 2 to 5 days after stopping antiviral treatment, you could show symptoms again, that may still show up on tests and may be contagious. If these symptoms continue and your test is still positive, a second round of antiviral treatment may be considered.

In all cases, it is important that you speak to your physician, including your general practitioner or family doctor and your oncologist or hematologist. They will have additional advice on possible treatment options, and they can also monitor the progression of your infection.

If you test positive, you almost certainly have COVID-19 and do not need to retest to confirm the diagnosis. Discuss with your healthcare team if and when to retest.

Do not, under any circumstances, use unlicensed and unproven medicine to treat your COVID-19 infection. This can seriously damage your health! Don't trust rumours, anecdotal evidence, or information obtained from questionable websites – **you are responsible for your health and know best how to stay safe**.

V. Psychological support and mental wellbeing

Your mental health and wellbeing are just as important as your physical, bodily health. Taking care of your mental health will also make you feel better in your body and in the world around you. The COVID-19 pandemic has had a profound impact on the mental and psychological health and wellbeing of many people around the globe, especially those who, due to their illness or condition, often have to isolate themselves socially and be more careful than others.

Psychological support services can play an important role in reducing this burden – particularly for the immunocompromised who need to continue shielding and physical distancing despite the relaxation and removal of public safety measures. Patients and their organisations have developed the following recommendations to improve your psychological wellbeing:

Emotional support

Reach out to support networks, such as family, friends, or support groups, who can provide emotional support and understanding during challenging times. Connecting with others who share similar experiences can be comforting.

Maintain a healthy lifestyle

Focus on maintaining a balanced diet, regular exercise, and enough sleep to support your overall wellbeing. This can positively impact mental health and strengthen your immune system.

Engage in stress-reducing activities

Try stress-management techniques like meditation, deep breathing exercises, mindfulness, or engaging in hobbies. These activities can help reduce stress and help you relax.

Seek professional mental health support

If the psychological strain becomes too much, consider seeking support from mental health professionals. They can provide counselling, therapy, or other support that fits the needs of blood cancer patients.

Doctors treating immunosuppressed blood cancer patients should therefore be able to recognise potential psychological symptoms of anxiety and depression and to perform simple screenings. If you are at risk of developing mental health problems, you should be screened regularly, and psychological support should be offered.

VI. Stay informed: reliable sources of information

Staying up to date is not only crucial for researchers and doctors; it is especially important for those with a compromised immune system for the sake of their health. Patient organisations often provide educational resources, so reaching out to them or checking their websites and social media can be helpful. Also, physicians, especially general practitioners or family doctors can play an important role in sharing reliable, scientifically sound and meaningful information.

You can find examples of reliable sources of information below:

- The National Institutes of Health - covid19treatmentguidelines.nih.gov (US)
- The National Cancer Institute - cancer.gov (US)
- Blood Cancer UK - bloodcancer.org.uk (UK)
- Leukaemia Care - leukaemiacare.org.uk (UK)
- The Leukaemia Foundation - leukaemia.org.au (AUS)
- The Leukemia & Lymphoma Society - lls.org (international)
- CLL Society's COVID-19 Action Plan - cllsociety.org (US)
- CLL Advocates Network - clladvocates.net (international)
- CLL Empowerment - cllempowerment.com (international)
- CLL Support Association - cllsupport.org.uk (UK)

COVID-19 management has gone through major changes in the past few years, and we'll keep learning new things as we go along.

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