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Directions for Completing the COVID-19 Planning Checklist

Last Updated: May 2024

Please note: Content was current as of the date it was released. In science and medicine, information is constantly changing and may become out-of-date as new data emerge. This is especially the case with COVID-19 information. Please check back often for new updates.

The following are general guidelines to assist you in completing the steps within the COVID-19 Planning Checklist. CLL Society suggests printing these documents and keeping them in a designated COVID-19 Planning Folder that can be easily accessed if or when it is needed.

1) Obtain Necessary Supplies and Keep Them on Hand:

Since the beginning of the pandemic shortages of necessary supplies has often coincided with a COVID-19 case surge. So, it is important to purchase the necessary supplies when they are available. We recommend you purchase and/or stock up on the following items so you have them available should you need them:

- **Obtain an oxygen (O₂) monitoring device (O₂ pulse oximeter)** and have it readily available in your home. Inexpensive O₂ pulse oximeters can be purchased online (through Target, Walmart, Amazon, etc.).
- **Buy good quality N95 or KN95 masks.** It is important to always keep these in stock since it has proven to be more difficult to obtain them during times when case numbers are surging. Free N95 masks have historically been available from the federal government through pharmacies, local health clinics, community support agencies, and other organizations (although this program may be subject to discontinuation depending upon future funding). Read more about this program [here](#).
- **Purchase reliable digital thermometers.** If you only have oral thermometers in your home, consider purchasing an inexpensive one for each member of the household to help prevent spreading the virus to other family members with shared use.
- **Have multiple home rapid antigen COVID-19 home tests on hand, and preferably a couple of home PCR tests as well.** Rapid antigen home testing kits can be ordered through online stores (Target, Walmart, Amazon, etc.), and many health insurance plans will reimburse you for them. You can read more about the importance of accurate testing methods on the CLL Society website [here](#). *PCR tests are the most reliable at diagnosing COVID-19, while rapid antigen tests are best used for determining when you are no longer contagious.*
- **Acquire a supply of Over-the-Counter (OTC) medications.** Keep the same things on hand that you would normally take for other cold and flu illnesses. These include OTC medications to manage symptoms such as headaches, cough, diarrhea, and fever/pain reducers. Some have found it helpful to have bottled water and other fluids (such as electrolytes) to remain hydrated.
- **Stock up on miscellaneous household items.** No matter the time of year, it is smart to always have on hand at least a week's worth of prescription medications, toilet paper, tissues, soap, disinfectant/cleaning supplies, medical supplies (such as blood sugar monitoring equipment), pet food, and nonperishables if possible. Some have also found it helpful to have access to humidifiers to help with symptom management. High-quality HEPA air purifiers can also help decrease the chance of transmission to other members of the household.

2) Remain Up-To-Date on all Recommended COVID-19 Vaccinations

- Please make sure you remain caught up on all the recommended COVID-19 vaccination doses. Everyone diagnosed with CLL/SLL is considered moderately to severely immunocompromised and should follow the special additional guidance for the number of vaccinations that should be received. **While some with CLL/SLL do not have a robust antibody response to vaccines, it**



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is still of the utmost importance to stay up-to-date with the most recent CDC vaccine recommendations. Research now tells us that COVID-19 vaccines stimulate other important parts of the immune system (such as memory T cells) besides just stimulating the production of the antibodies that can be measured with simple lab testing. Please see the [CDC's guidance](#) for immunocompromised individuals to make sure you are up-to-date on the most recent recommendations. The most recent CDC guidelines for immunocompromised individuals states, "People aged 6 months and older who are moderately or severely immunocompromised *may get additional updated COVID-19 vaccine doses 2 or more months after the last recommended COVID-19 vaccine.* Talk to your healthcare provider for more information."

- If you are looking for the availability of a specific type of vaccine near you, search [here](#).

3) Know Where to Go to Get PCR Tested for COVID-19:

- PCR tests are the gold standard for diagnosing COVID-19 much earlier than rapid antigen tests. Due to immunocompromised individuals needing to know if they have COVID-19 as early as possible so that life-saving antiviral therapies can be started in time, CLL Society recommends that you obtain a PCR test as early as possible, as it can take locations like CVS or Walgreens up to 48 hours to produce test results.
- Remember, the Rapid test *can* indicate evidence of COVID-19 infection, but typically not until you are symptomatic and are at least a couple of days already into the course of your infection. (Please also note, rapid antigen tests are generally more reliable when they produce a positive test result. Negative test results are not as accurate and should be repeated multiple times in subsequent days, especially if you are symptomatic).
- Home PCR tests are now available and are very reliable. They produce a test result within 30 minutes. Know that you must follow the step-by-step instructions extremely carefully so the test result is reliable. These rapid home PCR tests (such as the brand called Lucira) can be purchased through Amazon. While they are more reliable in *diagnosing* COVID-19, they do come at a slightly higher expense compared to the home rapid antigen tests.

4) Determine Where Critical COVID-19 Treatments Are Available Nearby:

There are three primary types of therapies a person can get when they test positive for COVID-19 to help prevent them from progressing to severe disease. The options may include either oral antiviral pills, intravenous (IV) antiviral injections, or COVID-19 High-Titer Convalescent Plasma. It is important to note that whatever treatment is chosen, all three of these options should be started as soon as possible in order to be most effective! Test early, notify your healthcare provider of your positive test result asap, and immediately advocate for the arrangement of one of these treatments!

Per the [updated NIH treatment guidelines](#), for those with COVID-19 who are not yet hospitalized or requiring oxygen but are at high risk of developing severe disease, here are the treatment options (listed in order of preference):

- Paxlovid
- Remdesivir (Veklury)
- [High-Titer Convalescent Plasma](#)
- Molnupiravir (should ONLY be considered when none of the other treatments are available, feasible to use, or clinically appropriate)

COVID-19 Oral Antiviral Medications

Currently, the two oral options authorized for emergency use are Paxlovid and Molnupiravir. Both oral antiviral options must be started **within five days of symptom onset**, and you must either have a positive test result to obtain a prescription (or someone within your home must have tested positive and you are symptomatic but have not yet had a positive test result). As an immunocompromised individual who is at



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high risk of developing severe disease, you *are eligible* to receive a COVID-19 oral antiviral if you have had known exposure, are symptomatic, but have not yet had a positive test result.

Please share all medications, vitamins, and supplements you are taking with your prescribing healthcare provider, as there are MANY known drug interactions with these oral antivirals that can occur. However, oftentimes those drugs that interact with the antiviral medication can be temporarily held while you take the medication and then restarted after the five-day course is complete. But *only do this at the direction of your healthcare provider!*

- Paxlovid is nearly 90% effective at preventing severe disease due to COVID-19 in high-risk individuals. This is the preferred COVID-19 antiviral for those with CLL/SLL due to its better efficacy.
- Molnupiravir is 30% effective at preventing severe disease. This difference in effectiveness is the reason that it should only be taken by CLL patients if Paxlovid is not clinically indicated, or in the case that BOTH Paxlovid and Remdesivir (IV antiviral) are not available.

To obtain a prescription for an oral COVID-19 antiviral, you can:

- Call your primary care provider and tell them you have had a positive test result and would like a COVID-19 antiviral to be prescribed for you since you are immunocompromised. However, know that if you are on certain [CLL/SLL therapies that interact with Paxlovid](#), they may insist that you obtain the prescription through your treating CLL healthcare provider.
- Try asking your pharmacist for the antiviral. Some pharmacists located at [certain pharmacies across the nation](#) can also now prescribe Paxlovid if you report having had a positive COVID-19 test result. However, keep in mind to do so they are going to want to be able to review your medication list and most recent set of laboratory results as they will not have full access to your medical history. Typically, you are not going to need to retest onsite and only need to report that you have had a positive test result.

COVID-19 Intravenous (IV) Antiviral Medication

Remdesivir (Veklury) was the first drug fully approved by the FDA to treat COVID-19 and has been used since October 2020. However, in late 2021 it was shown that [early administration of IV Remdesivir](#) given in the outpatient setting **within 7 days** of a positive test result or symptom onset (in those with mild COVID-19 disease and at least one high-risk factor) was shown to dramatically reduce the risk of progressing to severe disease by nearly 90%. It can be administered in the outpatient setting as a short IV infusion given daily for three consecutive days in non-hospitalized, high-risk individuals who test positive for COVID-19.

IV Remdesivir (Veklury) is unfortunately, much more difficult to obtain compared to the oral COVID-19 antivirals because it must be given IV (one time per day for three days in a row) in an outpatient infusion center. CLL Society highly suggests you speak with your healthcare provider in advance of becoming infected with COVID-19 to determine where you would go to obtain this treatment if needed as part of your COVID-19 Action Planning. As of the time this document was being updated, outpatient treatment centers where Remdesivir is being administered was *beginning* to be added to the government's [Therapeutic Locator Tool](#). You will need to select "outpatient Veklury", click "Ok", then enter your zip and the number of miles you are willing to travel to obtain the medication. A map will come up with locations near you that have Veklury available.

Antiviral Medication Financial Assistance Programs

Now that all the available antivirals have gone commercial, meaning the cost to obtain them must be covered by insurance companies instead of the federal government, the cost of obtaining the necessary antiviral medications can be of concern. If you need financial assistance, it is worth looking at the drug manufacturer websites which often offer some assistance, especially for those that are underinsured. There is a good summary on these programs that can be found [here](#).



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- For Paxlovid, there is a [Patient Assistance Program](#) through Pfizer that offers the medication free of charge for eligible individuals who have a prescription. If you are eligible, you will need to enroll in the program through this website. Pfizer also has a [Co-Pay Savings Program](#) for eligible individuals.
- Merck has both a [Patient Assistance Program](#) and a [Co-Pay Savings Program](#) that offers Molnupiravir for eligible individuals.
- Gilead has both a [Patient Assistance Program](#) and a [Co-Pay Savings Program](#) that offers some financial assistance for those needing to obtain IV Remdesivir.

High-Titer COVID-19 Convalescent Plasma

Convalescent plasma was a common COVID-19 therapy that was adopted early in the pandemic, but it was used exclusively for those who were hospitalized who had become very ill and were seeking treatment in the emergency room. This earlier form of convalescent plasma was later deemed to not be an effective therapy for those who were already days into their disease and were sick enough to be seeking treatment at a hospital. However, there are recent data indicating that [High-Titer COVID-19 Convalescent Plasma \(CCP\)](#) *is effective* for those who cannot make enough of their antibodies to fight the infection, such as those who are immunocompromised.

Many healthcare providers are unaware that convalescent plasma is still an available option and can be an effective tool in fighting COVID-19 infection for the immune compromised with CLL/SLL. It is an important option to discuss with your healthcare provider, but you may need to be prepared to advocate for yourself to obtain it. You can read more on this subject [here](#).

5) Healthcare Team Contact Information:

It is important to make a list of all healthcare provider names, their contact information (address/phone numbers), and print it out in case a hospital or other treating facility needs to obtain quick access to your prior health records in the case of an emergency.

6) Personal Paperwork to Place in Your COVID-19 Planning Folder:

- Create a list of all medications, vitamins/supplements, names, and dates of all vaccinations, and have your health history readily available should you need to go to the emergency room for COVID-19 treatment. If you are not taken to the hospital that you normally receive care at, the hospital may or may not have immediate access to your medical records, especially if they are not connected to your treating cancer center.
- Include copies of your Living Will, Power of Attorney, Physicians Orders for Life-Sustaining Treatment (POLST), and Advanced Directive readily available.
- Copies of the front and back of your insurance card(s).

7) CLL Society Documents to Place in COVID-19 Planning Folder:

- Print a copy of CLL Society's most recent [Official Statement for Prioritizing CLL Patients Emergency Room Care Related to COVID-19](#) to hand to the emergency room staff when you arrive.
- Print a copy of each element in CLL Society's COVID-19 Action Plan (Pre-Exposure Planning Document, Household Isolation Plan, and the Action Plan).

8) Household Isolation Plan:

Please read through the Household Isolation document and have all the supplies necessary for you to either *isolate* yourself within your home (isolation is what you do when you have confirmed infection)



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and/or *quarantine* (when you have known exposure to someone else, but you do not have a confirmed infection yet).

- After you have read through the Household Isolation Plan, **it is extremely important to discuss it with everyone in your home**. This is because if one of them need to isolate or quarantine they too should follow the plan in order to try and prevent transmitting the virus to others within the household.
 - Everyone in the home should understand how to put this piece of the plan into action immediately after known exposure, with **any** COVID-19 symptoms, or after obtaining a positive test result.
- 9) Consider Obtaining the Pre-Exposure Prophylaxis (PrEP) monoclonal antibody [Pemgarda](#), which helps to prevent COVID-19 infections in those who are immunocompromised. Pemgarda should not be used in place of vaccination. However, it serves as an added layer of protection in addition to vaccination, masking, and handwashing.