Directions for Completing the COVID-19 Planning Checklist

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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 In science and medicine, information is constantly changing and may become out-of-date as new data emerge.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.

CLL Society highly encourages everyone to prepare ahead of time and have a comprehensive COVID-19 Plan already in place in case of known exposure, becoming symptomatic, or having a positive test result. The following items are guidelines to assist you in completing the steps within the COVID-19 Planning Checklist. CLL Society suggests keeping all printed information 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 have often coincided with a COVID-19 case surge. So, it is important to purchase 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.).
- Attain good quality N95 masks. It is important to always keep these in stock since it has proven to be more difficult to obtain them throughout the pandemic during times when case numbers are surging. The government will begin giving out three free N95 masks to every person that visits a community health center, as well as participating pharmacies and retailers like CVS, Costco and Walmart in February 2022. You can find a pharmacy participating in the federal 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 rapid antigen COVID-19 home tests on hand. These tests can be ordered through online stores (Target, Walmart, Amazon, etc.), and up to eight tests per month will be reimbursable through your health insurance plan. They can also be ordered for free (up to four tests per household per month) through the US Government’s Department of Health and Human Services website. Many state governments also provide them free of charge to their residents. Some treatments can be initiated based on a positive home test.
- Acquire a supply of Over-the-Counter (OTC) medications. Keep the same things on hand that would normally be taken 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 (those with electrolytes) to remain hydrated.
- Stock up on miscellaneous household items. No matter the time of year, it's 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 and air purifiers to help with symptom management.

2) Remain Up-To-Date on the COVID-19 Vaccination Series
- Please make sure you are up-to-date on your primary COVID-19 vaccination series, and have received all of your additional primary shot(s) and booster dose(s) per the CDC guidance for immunocompromised individuals. This guidance may change from time to time based on the most up-to-date knowledge as well as the circulating variants of concern. Talk with your treating CLL physician about when it is time for you to receive additional vaccination doses.
3) **Obtain Pre-Exposure Prophylaxis (Evusheld):**
   - Talk with your healthcare provider about how to obtain Evusheld, the only long-acting monoclonal antibody that can help prevent COVID-19 before exposure. It is only authorized for those who are immunocompromised and immunosuppressed, so a prescription is necessary. Please utilize this [therapeutic locator tool](https://www.cllsociety.org/therapy-locators/) to help locate doses that may be available near you.
   - As time passes, it will be essential for you to know when you need to obtain subsequent doses of this preventative COVID-19 therapy. It is important to talk to know (and anticipate) what date you will need your next dose and discuss this with your healthcare provider before the time comes. Additional dosages may be recommended as new variants of concern arise. Please check [here](https://www.cllsociety.org/) for the most up-to-date guidance.

4) **Know Where to Go you will go to get tested for COVID-19, and confirm they will perform the necessary testing:**
   - The location you choose should be willing to offer you BOTH the rapid (lateral flow) test and the PCR test at the same time. Remember, the Rapid test can indicate evidence of COVID-19 infection, but the PCR is typically more accurate. (Please also note, some rapid tests will not detect variants with high accuracy).
   - Always err on the side of caution and get tested right away should you experience any unusual headaches, respiratory symptoms, gastrointestinal symptoms, or if you have had known exposure to COVID-19. *Do not dismiss any respiratory symptoms during the pandemic as allergy or cold symptoms!*
   - The earlier you know, the earlier you can receive therapeutics which can lessen the severity of the disease, which is of utmost importance for those with CLL.

5) **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 three options include either the oral antiviral pills, intravenous (IV) antiviral injections, or COVID-19 monoclonal antibody infusions.

   If you are having difficulty obtaining a prescription for either of the oral COVID-19 antivirals, you can go to one of the government’s [Test to Treat](https://www.carrige.com/) locations and obtain a prescription right away. The only requirement is a report of a positive test result. Retesting is NOT required per the [FAQ sheet](https://www.cllsociety.org/) which you may want to print out and take with you. *It is important to note that whatever treatment is chosen, all three of these options should be started as soon as possible to be most effective!* Test early, notify your healthcare provider of your known exposure and/or positive test result asap, and immediately advocate for the arrangement of one (or more) of these treatments!

**COVID-19 Oral Antiviral Medications**

Currently, the two oral options authorized for emergency use are Paxlovid (made by Pfizer), and Molnupiravir (made by Merck). Both oral antiviral options must be started **within five days of symptoms**, and you must have a positive test result to obtain a prescription (a home test qualifies). That is why early testing is so important! A positive *home test* is all you need. If you have difficulty filling your prescription, you can look [here](https://www.cllsociety.org/) to find where these important life-saving medications have been distributed near you. Please share all medications, vitamins, and supplements you are on with your prescribing healthcare provider, as there are MANY known drug interactions with these oral antivirals that can occur.

- **Paxlovid** is nearly 90% effective at preventing severe disease due to COVID-19 in high-risk individuals. This is the preferred COVID-19 antiviral due to its better efficacy.
- **Molnupiravir** is 30% effective at preventing severe disease. However, there has been a more recent large study out of India indicating that it may have higher effectiveness and prevent severe disease up to 80% of the time. 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 Paxlovid is not available.
COVID-19 Intravenous (IV) Antiviral Medication
Remdesivir was the first drug approved to treat COVID-19 and has been used since October 2020. However, in late 2021 it was shown that early administration of IV Remdesivir within 7 days of a positive test or symptom onset in non-hospitalized individuals 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 given in the outpatient setting as a short IV infusion daily for three consecutive days in non-hospitalized, high-risk individuals who test positive for COVID-19.

COVID-19 Monoclonal Antibodies
COVID-19 monoclonal antibody (CmAb) infusions have proven to help prevent high-risk patients from progressing to severe disease. This therapy should be given within 7 days of either a positive test result or symptom onset, and is administered in the outpatient setting, usually an infusion center. The earlier someone with COVID-19 receives the CmAb the better! It is important to understand that not all the COVID-19 monoclonal antibody therapies that have been authorized for use against previous variants will continue to work against new variants. Therefore, it is important that you receive ones that have been proven to be effective against the variant of concern which is most prevalent in your community.

You must investigate ahead of time which hospitals or infusion centers in your area provide rapid access to critical CmAb treatments! These infusions are not available everywhere and are less likely to be found at smaller community hospitals. Please spend time to find out exactly where you can access them quickly should you need them. It is also important to understand the criteria that make you eligible to receiving these critical treatments should there be any pushback when you advocate for receiving them:

- Under the emergency use authorization for these CmAb therapies healthcare providers are authorized to administer monoclonal antibodies to patients if they have experienced the onset of mild to moderate symptoms of COVID-19 in the last 7 days, have tested positive for COVID-19, and have high-risk factors (CLL included).
- Search this map to find the locations in your area that have CmAb therapy available. Information may not always be kept up to date, so it's wise to call the facility after you have located the available therapeutic and ask about availability.
- If you cannot find a location ahead of time, you can call the “Combat COVID Monoclonal Antibodies Call Center” at 1-877-332-6585 for further assistance.
- Talk to your physician about when and if to go to the emergency room for treatment. It is not recommended that anyone go to the emergency room for COVID-19 testing alone. However, if you test positive and are experiencing symptoms, as an immunocompromised individual your CLL physician might possibly want you to be assessed in the emergency room setting.

6) Healthcare Team Contact Information:
It is important to make a list of all healthcare provider names, their location (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.

7) 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).

8) CLL Society Documents to Place in COVID-19 Planning Folder:
- Print a copy of CLL Society’s Official Statement for Prioritizing CLL Patients Emergency Room Care Related to COVID-19 to hand to the emergency room staff when you arrive.

9) **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) and/or *quarantine* (when you have known exposure, but you do not have a confirmed infection yet).
   • After you have read the plan, it is 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.