Supporting Your Loved One's Clinical Care

As a caregiver, you can offer practical support for your loved one's medical needs. Here are some ways you can help out:

Accompany your loved one to their medical appointments, with their consent

Bring a list of questions and updates to each doctor's appointment. Include your loved one's symptoms and treatment side effects.

Take thorough notes during the appointment. Ensure you understand new test results and the treatment plan. It's okay to ask the doctor to re-explain anything that is unclear using non-medical terms.

Be clear on the details of any and all new prescriptions. This may include dosage and side effects, when and how often prescriptions are administered, and whether they can interfere with other medications, supplements, or foods.

Help your loved one adhere to their treatment plan

- Ensure that your loved one is taking their medication and following their treatment regimen. Call, use sticky notes, or set alarms to effectively remind your loved one to take their medication.
- Acknowledge your loved one's right to make their own decisions and, if possible, offer them options in their care. It's helpful to remember that, as a caregiver, you can only do so much.

Learn what to expect from BTK inhibitor treatments

BTK inhibitor drugs are available as a targeted treatment option for some types of blood cancers, such as chronic lymphocytic leukemia (CLL) and previously treated mantle cell lymphoma (MCL). BTK inhibitors block signaling important to B cells, which are vital to some blood cancers' survival and growth.

Will my loved one experience any side effects from treatment with a BTK inhibitor drug?

- It is common to experience side effects that vary in degree of severity. These are not all the possible side effects of a BTKi, but some can be managed with the following strategies:

Headache	Diarrhea	Tiredness	Muscle aches	Bruising/Bleeding	Upper Respiratory Infections
Consider using caffeine, acetaminophen, or other over-the-counter pain relievers	Consume hydrating liquids and eat smaller meals	Take naps when needed and incorporate exercise into a daily routine	Stretch achy muscles to relieve tension and use over-the-counter pain relievers like acetaminophen	Ice the bruise to ease swelling and relieve discomfort. Notify the doctor if any significant bleeding occurs	Minimize the chance of catching or spreading an infection by washing hands regularly and contact the doctor if symptoms persist or get worse

BTK inhibitors may also cause serious side effects, including serious infections, bleeding problems, decrease in blood cell counts, new cancers, heart rhythm problems, high blood pressure, or tumor lysis syndrome (TLS). Ask your loved one's doctor about possible side effects and read the drug's Patient Information.

If any of these effects persist or worsen or if your loved one experiences any concerning side effects from their medication, please contact their doctor right away.

Are there any over-the-counter medications or foods that I should not mix with certain BTK inhibitor drugs?

- **It's important to give your loved one's doctor a list of all medications and supplements they take.** BTK inhibitor drugs interact with a number of other medications and supplements, including grapefruit juice, pomegranate juice, and St. John's Wort. The doctor can take this into account when creating your loved one's treatment plan.

Staying Well While Caregiving

Caregiving for a loved one with blood cancer takes a lot of energy and attention, and simultaneously keeping up with other responsibilities can be hard and become overwhelming.

Here are several tips on caring for yourself so you can be the best caregiver to your loved one:

Maintain your emotional and physical health

Make plans to look forward to:



- Sustain your social connections. Take a walk or a drive, or see a movie with a friend or family member. Make phone calls to those you can't see in person.
- Don't forget your personal projects and hobbies. Even 15 minutes a day can make a difference. Read a book, paint, exercise, bake — do whatever brings you joy.

Take things day-by-day:



- If overwhelmed, ask a family member to help with a small but meaningful task, like providing dinner once a week
- Devote time to spiritual practice, meditation, or journaling
- Although it's normal to feel burdened by caregiving responsibilities, it should not feel completely overwhelming. Please don't hesitate to seek professional help if you feel you need it. Some caregivers find it helpful to talk to a counselor, a social worker, another mental health professional, or a leader in their spiritual community

Common questions from caregivers



What if my loved one does not let me help them?

- Seeking advice from healthcare professionals is an important first step. Your loved one could be struggling with their diagnosis and need additional treatment
- Try to be diplomatic and sensitive; come from a place of understanding. This isn't easy and you want your care partner to know that you're on their side. You and your loved one are both in this together



How can I be a more emotionally supportive caregiver?

- Make yourself available to actively listen and share ideas with your loved one about treatment. Also, take time to talk about topics other than your loved one's disease
- Join a cancer caregiver support group, either online or in-person, that's local to your area. This will give you a support network of other caregivers who are able to understand your situation

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