



THE COLLABORATION GUIDE

Building a strong partnership is like riding a tandem bicycle. Each rider plays a role in making the journey better for the other person. They work together to navigate the road ahead. Like sharing a tandem bike, a strong partnership relies on effective communication.¹

It can be tough to talk about how chronic lymphocytic leukemia (CLL) makes you feel and to ask for support. The communication tips in this guide are for you and your care partner to help get you both geared up for better conversations about CLL.²

I'M LIVING WITH CLL



I'M A CARE PARTNER



CONSIDER THE OTHER RIDER

Think about your care partner—their personality, strengths, likes, and dislikes. Decide how they can best help you and then ask them for that help.

KEEP PEDALING

Communication is most effective when everyone is actively participating. Pick a time of day when your caregiver is least likely to be distracted with other tasks or thoughts.³

You know the person you're supporting. Based on your relationship, decide if you need to be the one to ask them how you can help.¹

KEEP PEDALING

Everyone acts a little differently in times of stress. Reflect on past experiences with the person you're supporting. See if you notice any familiar signs that suggest they are struggling.^{4,5}

MAKE SURE THE DIRECTION IS CLEAR

Whether it's an errand you need to run or a challenge you're facing—being clear about what you need helps. Explain how you feel and the specific tasks you need help with.²

KEEP PEDALING

Before the conversation, write down what you need and how your care partner can help. If your care partner can't do everything, you can discuss who can.⁶

Listen and respond with your understanding of what's been shared so you can make sure you're clear on what's being asked of you.²

KEEP PEDALING

After you explain your understanding of what's been shared, ask for clarification. You might say, "Does that sound right?"



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CHOOSE SOMEONE TO STEER

As you live with CLL, you will have a lot of decisions to make. It's OK to let your care partner take the lead, but only if you choose to let them. Talk about what works best for your relationship.^{4,7}

KEEP PEDALING

If you decide to put your care partner in charge of your medical needs, trust that they have your best interest in mind. Remember that you can step in at any time.^{1,7}

Ask the person you're supporting about the role they want you to play in making decisions. They might want full control. Maybe they want you to take the lead. Discuss what's best for your relationship.⁴

KEEP PEDALING

If the person you're supporting has made you the key decision maker, check in often. That way, they still have the option to participate in decisions that matter to them.¹

STAY IN SYNC

Be honest with yourself and your care partner about whether you're getting what you need. Check in with each other to discuss what is and isn't going well so you can make changes if you need to.⁸

KEEP PEDALING

Showing a little appreciation can go a long way. Thank your care partner for the big and small things they do so they know what their help means to you.^{4,9}

Be honest and realistic about what you can do for the person you're supporting. That way, you can discuss the best resource, whether it's a friend, family member, or organization.¹

KEEP PEDALING

Actively seek out feedback from the person you're supporting. If there are things that need improvement, ask them what might help and talk about how you're going to tackle it.^{5,8}

REFERENCES

1. American Cancer Society. *Caregiver Resource Guide: Caring for a Loved One With Cancer*. American Cancer Society website. <https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/american-cancer-society-caregiver-resource-guide.pdf>. Published September 2018. Accessed August 27, 2019. 2. Lorig K, Holman H, Sobel D, Laurent D, Gonzalez V, Minor M. *Living a Healthy Life with Chronic Conditions*. 3rd ed. Boulder, CO: Bull Publishing Company. 3. Baider L. Communicating about illness: a family narrative. *Support Care Cancer*. 2008;16(6):607-611. 4. National Cancer Institute. *Facing Cancer with Your Spouse or Partner*. National Cancer Institute website. <https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/spouse-or-partner>. Updated September 26, 2018. Accessed August 27, 2019. 5. National Cancer Institute. *When Someone You Love Is Being Treated for Cancer*. National Cancer Institute website. <https://www.cancer.gov/publications/patient-education/when-someone-you-love-is-treated.pdf>. Published May 2014. Accessed September 5, 2018. 6. American Cancer Society. *Telling Others About Your Cancer*. American Cancer Society website. <https://www.cancer.org/treatment/understanding-your-diagnosis/talking-about-cancer/telling-others-about-your-cancer.html>. Updated April 28, 2016. Accessed August 27, 2019. 7. Institute of Medicine (IOM). *Cancer care for the whole patient: meeting psychosocial health needs*. Adler NE, and Page AEK, eds. Washington, DC: The National Academies Press; 2008. 8. American Society of Clinical Oncology: ASCO ANSWERS. *Effective caregiving at home*. American Society of Clinical Oncology website. https://www.cancer.net/sites/cancer.net/files/asco_answers_effective_caregiving.pdf. Accessed August 27, 2019. 9. Monin J, Poulin M, Brown S, et al. Spouses' daily feelings of appreciation and self-reported well-being. *Health Psychol*. 2017;36(12):1135-1139.