

BRIAN'S CLL COMMANDMENTS

1. Build your team.

This is our first and most vital step. We must find a true CLL expert to lead our team. Almost as important as who is on the team is who is off it. We must not be afraid to fire team members including doctors who are not helping us. Read about Team Building at <u>http://cllsociety.org/toolbox/build-a-team/</u>

2. Ask for help when you need it.

We can't do it all alone. Cancer is a team sport. We can often gain by not trying to tough it out and accepting the support we need. The team we have assembled can help.

3. We have time, but we don't have forever.

CLL almost always gives us time to learn about our cancer. We should use that precious gift to do our homework, become as expert as we can to build our team to make our broad plans. But we must also be prepared to move from planning to action when the time is right.

4. Underreact.

It is guaranteed that we will get both good and bad news at some stage of our CLL journey. Realizing that things are constantly changing is best handled by staying calm. Don't make any decisions based on one data point, especially one lab result.

5. Expect the unexpected.

Control is an illusion. CLL can be willful and wild. Accepting that we can't predict the future is critical to staying level-headed and nimble in our response to the unexpected.

6. Risk is impossible to eliminate.

All actions and even inactions have their risks. Doing nothing is sometimes more dangerous than doing something, when the circumstances demand a decision. There are no guarantees and nothing is 100% certain.

7. You may need to make difficult decisions with imperfect knowledge and contradictory advice.

Treatment for CLL is rapidly evolving and there is much that is still unknown. Well-intentioned doctors often disagree on management. We should also realize that some physicians are better informed than others. We must choose wisely but don't expect unanimity or second-guess ourselves.

8. Think laterally and question authority.

The constantly changing therapeutic landscape in CLL demands that we sometimes push for a new best option and not settle for standard therapy. This also means that we need to think strategically about not just the next move, but also the moves after that. This is much easier to do when we have followed Rules 1-7.

9. Money Matters.

CLL treatments can be prohibitively expensive, but there are resources available to provide help. Planning and researching financial aid and insurance coverage will often be part of a successful journey.

10. Remember to live now.

CLL can smother our horizons and define every aspect of us. We can't let it rule every corner of our lives. We are so much more than our CLL. We can live well, beyond our CLL.

11. Give forward.

Being thankful for all that we have and sharing what we can helps both us and those whom we support to live stronger and more purposeful lives.

12. Stay strong.

CLL can be a challenge, but each one of us is smarter and stronger than our cancerous clone.

REMEMBER, we are all in this together!