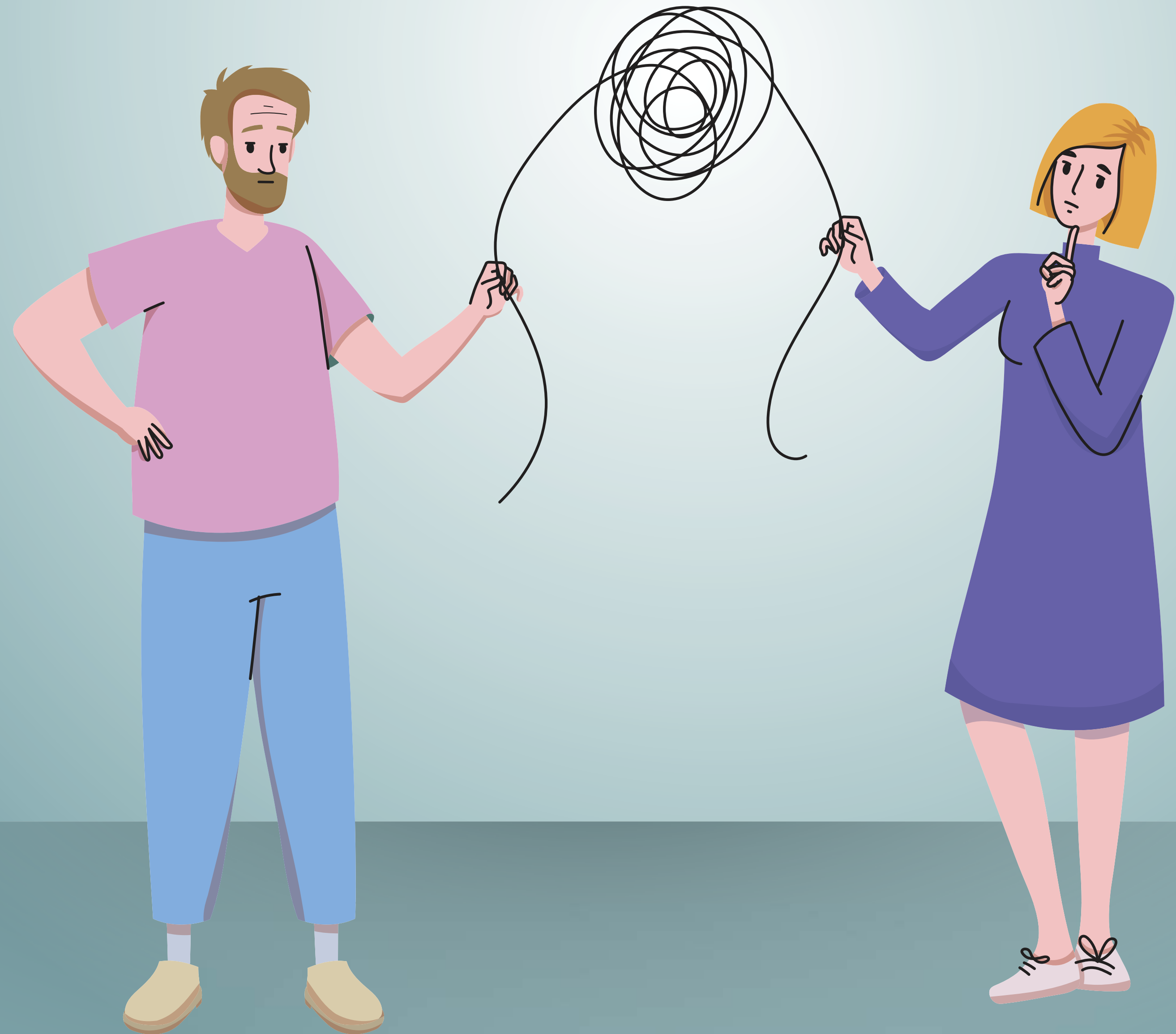
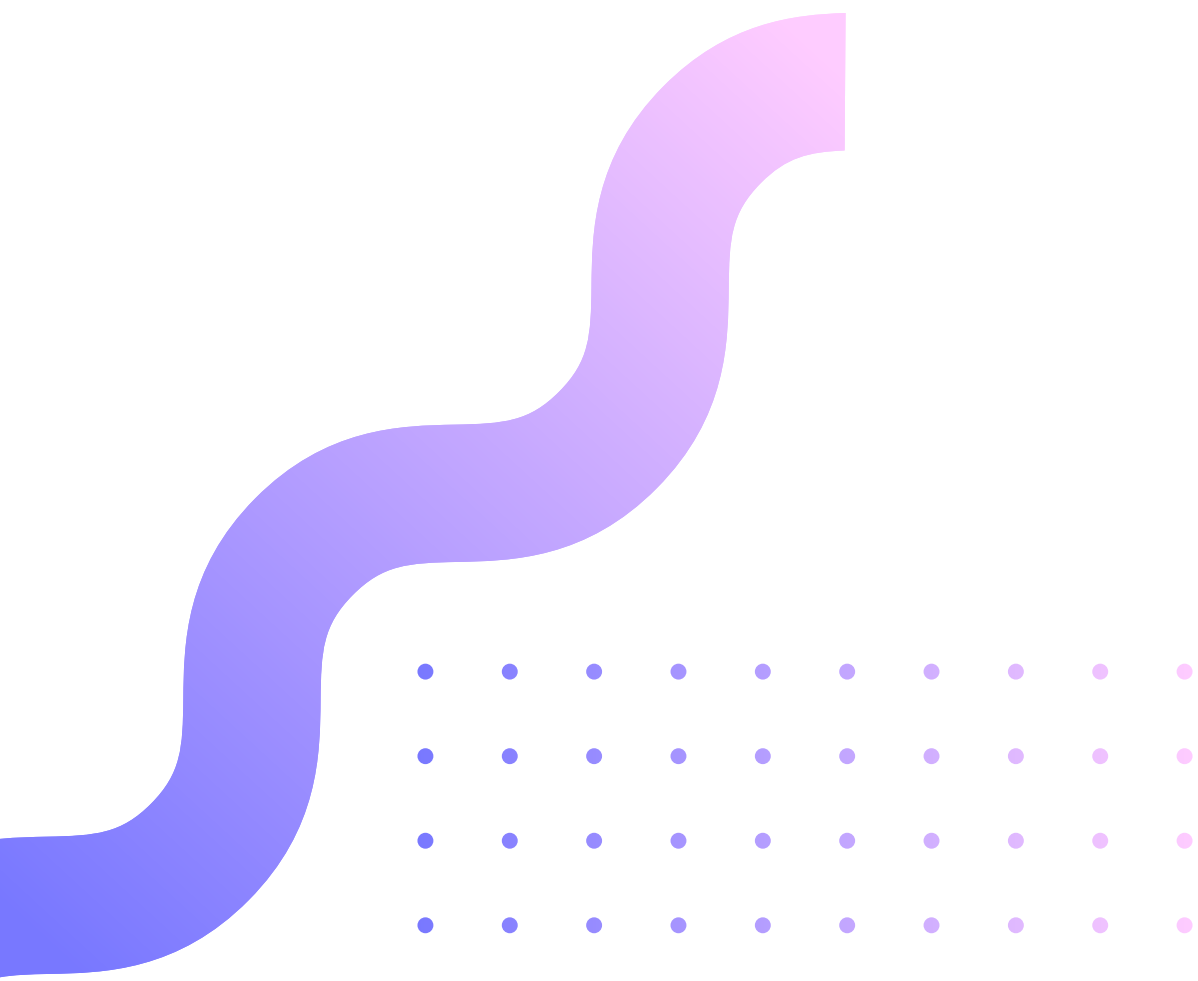

A CLL EMPOWERMENT GUIDE

Psychological effects of illness





People receiving a diagnosis like CLL often say that it feels like they have to put their entire life on hold. This can be due to the many changes that can follow a diagnosis (see leaflets on "Newly diagnosed with CLL", "Effects of illness on aspects of Life"). CLL may affect various aspects of your life, for example, your emotions and thoughts, your relationships, your work, and your identity.

EMOTIONS AND THOUGHTS

Emotions come and go as living with CLL can sometimes be like a roller coaster, this is not at all unusual. **In your journey, it is normal to experience a variety of emotions that may shift again and again.** For instance, at different stages of the journey, you may experience anger, anxiety, or uncertainty about the future. Every now and then, you may think back to your life before CLL or feel sad about possible changes.



Nevertheless, there may be times that you are feeling hopeful and grateful, as CLL may be a reminder of what truly matters to you.



Similarly, a lot of thoughts might probably be running through your mind. Thoughts about CLL or your life in general. Some people may wonder "why me?" or believe that this is unfair and they don't deserve it. Moreover, some people may wrongfully feel guilty or that they have become a burden to the people around them. However, remember it is only natural people would want to support you, and you would do the same for them. So, look around you, identify those who care about you and will be there for you.

Others, might feel that they themselves have somehow caused CLL. However, this is untrue as there is no scientific evidence to support this. **So, try not to blame yourself for what has happened to you.**



All these thoughts and feelings are normal, as we all try to make sense of what is happening around us. Living with CLL can bring about all kinds of experiences which can sometimes seem too much. Remember that you are allowed to feel them, take as much time as you need to do and remember it will get better.

*The more CLL becomes a part of your life,
the more these thoughts will fade away.*

*...take as much time as you need,
and remember it will get better*

RELATIONSHIPS

CLL can possibly have an effect on your relationships too. Talking about CLL is **completely your choice and you shouldn't feel any pressure to do otherwise**. At times, you may want to share your experience or how you feel with others, while there can also be times when you would like to talk about anything but CLL.

People around you may often don't know what to say and while they might have good intentions, they can put you in a difficult position. You can always **set your boundaries and express your needs and preferences**, for example choosing to talk about something else rather than the illness.

Other people may avoid asking you questions or talking about CLL, because it might be difficult for them. This doesn't mean that they don't care about you. They too might need some time to understand the situation. Remember, their reaction has little to do with you. Give them time to process and be clear as to how they can best support you.

Family, friends or colleagues may try their best to help you through your journey, but sometimes you may find that you would need various forms of support, such as practical, emotional, or informational. **When you are ready, it is important to communicate your needs and be open about your feelings.** Being honest with people you feel close to could lead to more meaningful and supportive relationships.





Ultimately, CLL can be a difficult experience, and you may want someone who can support you and be by your side. You may distance yourself from some people, but you may also get closer to others. Getting through difficult times together can strengthen your bond with them.



WORK

People with CLL can continue to work with only some adjustments, even if they are minimal. These may depend on whether or not you are on treatment and your overall symptoms (see "Treatments" and "Watch & wait" leaflets). For example, if you are not on treatment you may only need to take some time off for your scheduled appointments and generally continue working as usual.

On the other hand, if you are on treatment you may need to consider any side effects you could be experiencing. Similarly, if you experience some symptoms **you may need to adjust your activities accordingly**. Nevertheless, for the most part, all of these should be managed successfully in collaboration with your physician.

There are several resources you could use to facilitate your work. For example, asking for an occupational health assessment or flexible working, taking sick and if necessary annual leave may all be recourses you could use in order to recover should you need to. **Your employer should be able to provide the above or similar reasonable adjustments in order for you to successfully continue working.** Should you meet any challenges with the above, your local patient society should be able to provide you with advice, advocacy and support.

ADHERENCE

CLL involves routine check-ups (see "Watch & wait" leaflet) and sometimes taking medication (see "Treatments" leaflet). These have been put in place according to your preferences and the latest evidence and guides. Their goal is to increase your physical quality of life and thus your wellbeing.

With time, it may get a little more difficult to stay on top of your appointments or your medication. For example, if there is little change over time and you are doing well, you may start neglecting your medication. You should remember though that taking your medication is what is keeping you well. Should you find yourself troubled with the above, you could have a conversation with your hematologist. They can help explain the reasoning for taking medication and if possible, make alternative arrangements that work for you. You can always rely on your hematologists as they are there to support and help you through this.

IDENTITY

The changes brought by CLL in several aspects of your life may redefine your identity, meaning the sense of who you are. Some people continue to live as previously, without making any major changes. On the contrary, others move to a new life, and make their CLL diagnosis part of who they are. These two paths may take different forms, but at the end of the day, they are both equally good.

As you come to terms with your diagnosis, it is useful not to lose sight of who you are as a person and what is important to you. Keeping up with your responsibilities and the things you enjoy can help you adapt better and remind you that life goes on.



However, it is essential to understand any new needs that you have and adjust your life accordingly. For instance, you may need more help in the house or go out less often. Listen to your body and understand what is good for you, both physically and mentally. This will help you find the balance between your old and your new self and continue with a renewed sense of purpose.

GROWTH

People often report life is getting better after their diagnosis. For some, it comes naturally, while for others it may take some effort. This might seem strange and unexpected at first glance. Nevertheless, people might take CLL as an opportunity to reflect and make positive changes in their lives; to see what they have gained, not only what they have lost. If you would like, take a moment to think about what you may have gained.

Think back on how things were before this diagnosis and how they are now.

- | Are there any improvements in your relationship with others?
- | Have you noticed any new opportunities?
- | Do you feel like you have found more strength in yourself?
- | Could you say you are more connected to your spiritual beliefs?
- | Has your appreciation of life changed at all?

All of the above are questions that could help you make peace with what has happened and guide you to find new meaning in your life. Take a moment to write your thoughts about the above questions down and share them with a loved one.

Gradually, things will get better (see "Adaptive coping"). CLL will not be the center of your life, but only a part. It is important to do things that you like. For example, reaching out to people you have lost contact with, taking up hobbies like volunteering or joining group activities (see "Peer support groups" leaflet), reading a book, going to the movies, going for a long walk in nature. At the same time, try to also remember the little things, like getting regular exercise, eating and sleeping well (see "Complementary care and lifestyle modifications in CLL" leaflet).

*CLL will not be the center of your life,
but only a part.*



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