A CLL EMPOWERMENT GUIDE

Sexual life & relationships





Among the most basic human needs are the sexual ones; even if they change as we grow older, they rarely fade completely. Sexual needs are complex and relate to other needs, such as physical (e.g., a caress, a hug), emotional (e.g., love), and psychological (e.g., acceptance, intimacy).

At times, a leukemia diagnosis and its consequences (e.g., fear, anxiety) including any treatment side effects (e.g., fatigue, nausea) may interfere with your sexual life. This can happen; people sometimes may lose their connection with their body and sexual needs due to a major diagnosis.

However...

...these experiences are temporary and with time you may want to go back to your previous sexual activities.

When that time comes, you should keep in mind that how the body deals with germs and minor injuries can sometimes be affected in CLL. To this end, as a general guide, having around 50.000/µL or more AND 1.000/µL or more neutrophils is a good starting point for considering sexual activities or intercourse. If your levels are somewhat lower than those, you should consider some alternative, low-intensity sexual activity, like gently enjoying your own touch; your physician will be able to advise you on an individual basis.



Following is some further medical information that is good to remember before you take up your sexual activities again:

Visually inspect your personal areas for any changes.

It is best not to engage in any sexual activities if you or your partner have any symptoms in the area (e.g. white fluid, small lump, open wounds, pain with urination, cold sores) or if either of you is unwell (e.g. having a cold, influenza).

Take all appropriate measures to protect yourself against sexually transmitted infections. Ask your physician or local sexual health clinic for further details.

Gently wash your intimate parts before and after any sexual activity.

In consultation with your physician and if applicable to you, it's best to use contraception (e.g., pills, condoms). This will minimize the chance of getting pregnant while on treatment.

Regardless of the contraception method of choice, you should take measures (e.g., condom, dental dams) that protect against bodily fluid exchange. This is especially important at least three days after you last had chemotherapy. The medication you are taking may mix with bodily fluids and cause mild toxicity to your partner. Your hematologists will be best placed to clarify this.



Also, remember:

Talk to your partner about issues around your sexual needs and share any possible worries you may have.

Having leukemia, does not mean you have lost all sexual desire.

Even after CLL, meeting your sexual needs can be an enjoyable process.

If you feel any pain or discomfort, you should stop and have a break; if it persists, talk with a specialist.

Don't force yourself to do something you don't want to do or feel ready for.

You can meet your sexual needs and experience pleasure in many ways.

If you are not as satisfied with the experience, take a break and then consider trying again later.

Should you have difficulties with your erection or lubrication respectively, consider consulting with your physician about using some aids.

Try not to focus on your performance, but on the enjoyment of the experience.



The experience may not be exactly as before, yet it can still be very pleasurable. Give yourself time to go back to how things were.

Your sexual activity will not affect the course of the disease.

If you are not in any long-term relationship, you can talk to your new partner about your diagnosis only when you feel it is the right time.

If you feel you need more time to engage again with your sexual activities, you can begin gradually, over the course of several weeks or months. For example, you could routinely apply some body lotion on your naked body to help you feel more connected to it. When you feel ready, you can start enjoying your own touch in a way that feels natural to you. After a while, you could move to giving or receiving a full body (non-sexual) massage so you can start feeling close to your partner again. Lastly, you could move to having sex with your partner gradually going back to how things were.

Here are some things that you can discuss with your doctor:

am I physically able to have sex?

can I enjoy my touch or the touch of my partner?

can CLL or its treatment affect my ability to have children?

in relation to CLL, when would it be the best time to have children?

If you feel like discussing any of the above, talk to your physician, a mental health or a sexual health specialist.

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