

How do I explain my cutaneous T-cell lymphoma (CTCL) diagnosis to family and friends?



This leaflet is intended for patients diagnosed with CTCL

There is no 'right' way to communicate your CTCL diagnosis with loved ones.

As your life and each relationship is unique, every conversation will be different. Planning difficult conversations can help reduce some of the anxiety you might feel. Think about:

- **WHEN** you want to share
- **WHO** you want to tell
- **WHAT** you want to say



When should I share?

Before a confirmed diagnosis

Some people may have waited years to receive a diagnosis of CTCL. The process of seeing different doctors in lots of different clinics can be frustrating and confusing. This can also be a worrying time for your family and friends. It is important for you and your loved ones to know:

- **It is not unusual for a diagnosis of CTCL to take time**
- **They can come with you to appointments (when possible) to support in your journey**

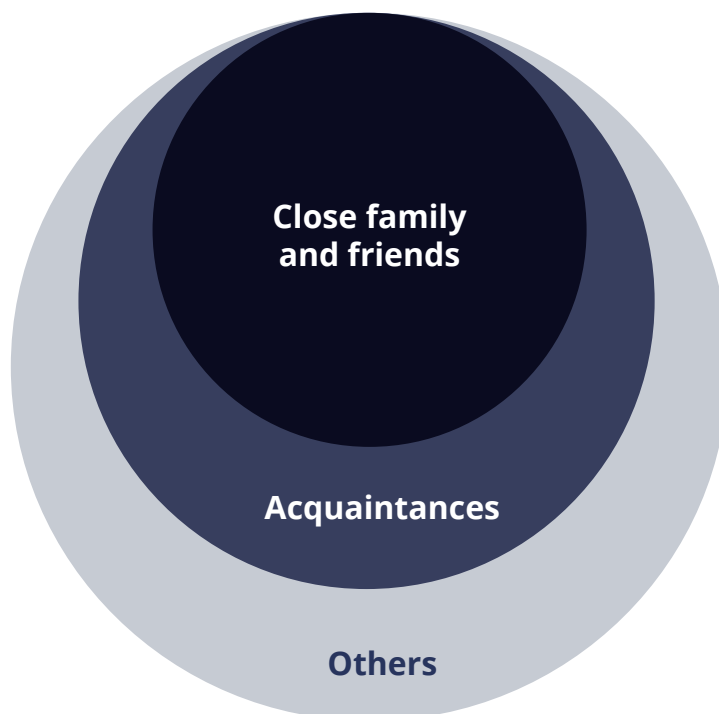
Once you have received a diagnosis

If possible, it is really helpful to have someone with you when you have an appointment to discuss what your diagnosis means for the first time. It can be hard to remember everything you are told at appointments. There can also be practical instructions about help you might need to administer treatments.

- **Take someone with you to your first appointment for a 'second set of ears' to pick up on information you might miss**
- **Take someone to learn how to help you administer treatments such as lotions in hard-to-reach areas**

Who should I tell?

Deciding who to tell can be a challenge. Thinking about your connections with others can help you feel prepared for difficult conversations.



Close family and friends

Close family and friends, like your partner, parents or best friend, will probably be some of the first people you tell. Remember, this is a new situation for you and them. Scheduling some time to talk one-on-one can help you to discuss your feelings and for them to share theirs. You can also let them know how they can support you and what you might not find helpful.

Acquaintances

Another group of people to think about are people who you are not close with but see regularly (acquaintances). This could be extended family, friends or people you work with. Take some time to think about what you are comfortable sharing and what information is important to tell the other person. For example, you might need to discuss workplace adjustments with your employer.

Others

There might also be people you don't want to tell at all. This is perfectly fine! However, because CTCL affects the skin, it can be helpful to have a 'script' prepared so you can handle questions.

Find more tips on who to tell at **Cutaneous Lymphoma Foundation**



Find tools to help you cope with other people's reactions at **Changing Faces**



What could I say?

CTCL is a rare condition, so your family and friends will naturally have a lot of questions about it. Likely, they will want to know how they can help you. To help your family or close friends to understand CTCL, if possible, you can bring them to your hospital appointment if you would like the help of a doctor or someone else on your care team to discuss your diagnosis.

Speaking to children can be especially challenging. What you say depends on the child's age; give them as much information as you think they will be able to understand.

Depending on which type of CTCL you have, it might be helpful to explain CTCL as a long-term disease. It can be reassuring to know that people often live in good health for a long time with CTCL.

CTCL is not

Infectious/contagious

This means it won't spread to other people

Genetic (usually)

This means it is not inherited from parent and that you are unlikely to pass it on to your children

Related to specific food

Certain foods have not been linked to the development of CTCL

CTCL can be

Visible

Skin symptoms such as rash might affect confidence, but it is still safe to do usual activities

Tiring

Some people might experience low energy, known as fatigue, due to CTCL. Sometimes the treatments used in CTCL may also affect levels of tiredness



Things to remember



- **Many people take time to adjust to their diagnosis**
 - A CTCL diagnosis understandably brings anxiety for you and your loved ones



- **It is okay to carry on with usual work, social and family commitments**
 - People usually cope better with their diagnosis if they keep living their life as normally as possible



- **For some people with CTCL, skin symptoms might be the only sign of CTCL for a long time**
 - The rash might be controlled by skin treatments (this could mean skin symptoms improve or that the rash does not worsen or spread), which can be reassuring
 - However, if there are changes in your symptoms, your treatment and daily routines might need to change (any changes in your signs or symptoms of CTCL should be discussed with your doctor)
 - You may need to revisit conversations with your loved ones to discuss changes on how they can best support you

If you have more questions on how to communicate with loved ones about CTCL, always ask your dedicated healthcare team