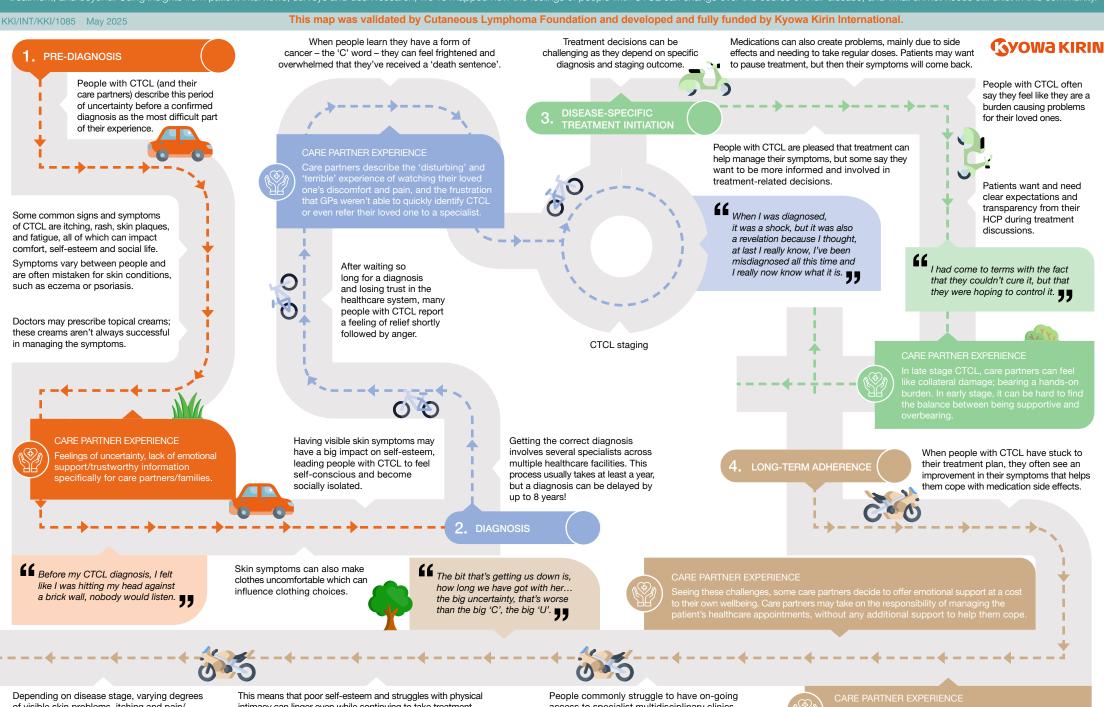
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KKI/INT/KKI/1085 May 2025

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Before my CTCL diagnosis, I felt like I was hitting my head against a brick wall, nobody would listen. Skin symptoms can also make clothes uncomfortable which can influence clothing choices.

The bit that's getting us down is, how long we have got with her... the big uncertainty, that's worse than the big 'C', the big 'U'.



CARE PARTNER EXPERIENCE

Seeing these challenges, some care partners decide to oner emotional support at a co to their own wellbeing. Care partners may take on the responsibility of managing the patient's healthcare appointments, without any additional support to help them co



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People with CTCL report a willingness to 'try anything' to get better.

People commonly struggle to have on-going access to specialist multidisciplinary clinics.



CARE PARTNER EXPERIENCE

Care partners can also find they have to juggle the logistics of care alongside family and financial pressures.

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1. PRE-DIAGNOSIS People with CTCL (and their care partners) describe this period of uncertainty before a confirmed diagnosis as the most difficult part of their experience.

Some common signs and symptoms of CTCL are itching, rash, skin plagues, and fatigue, all of which can impact comfort, self-esteem and social life.

Symptoms vary between people and are often mistaken for skin conditions, such as eczema or psoriasis.

Doctors may prescribe topical creams; these creams aren't always successful in managing the symptoms.

CARE PARTNER EXPERIENCE

Feelings of uncertainty, lack of emotional support/trustworthy information specifically for care partners/families.

Before my CTCL diagnosis, I felt like I was hitting my head against a brick wall, nobody would listen. Skin symptoms can also make clothes uncomfortable which can influence clothing choices.

Having visible skin symptoms may have a big impact on self-esteem, leading people with CTCL to feel self-conscious and become socially isolated.

UNMET NEEDS:

- There is a lack of awareness of the resources available to patients. They are often not sought out due to the disease not being taken seriously enough, especially in early stages
- There is a lack of access to emotional support to help for people with poor mental health caused by CTCL symptoms

When I was diagnosed, I really now know what it is.



they were hoping to control it.





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When people learn they have a form of cancer - the 'C' word - they can feel frightened and overwhelmed that they've received a 'death sentence'.

After waiting so

long for a diagnosis and losing trust in the

healthcare system, many people with CTCL report a feeling of relief shortly followed by anger.

CTCL staging

Getting the correct diagnosis involves several specialists across multiple healthcare facilities. This process usually takes at least a year, but a diagnosis can be delayed by

up to 8 years!

When I was diagnosed, it was a shock. but it was also a revelation because I thought. at last I really know, I've been misdiagnosed all this time and I really now know what it is.

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EMOTIONAL EXPERIENCE

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EMOTIONAL EXPERIENCE

hope, stress, burden, uncertainty and

Treatment decisions can be challenging as they depend on specific diagnosis and staging outcome.

DISEASE-SPECIFIC

TREATMENT INITIATION

Medications can also create problems, mainly due to side effects and needing to take regular doses. Patients may want to pause treatment, but then their symptoms will come back.

People with CTCL often say they feel like they are a burden causing problems for their loved ones.

People with CTCL are pleased that treatment can help manage their symptoms, but some say they want to be more informed and involved in treatment-related decisions.

When I was diagnosed, I really now know what it is.

Patients want and need clear expectations and transparency from their HCP during treatment discussions.

I had come to terms with the fact that they couldn't cure it, but that they were hoping to control it.

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TREATMENT DECISION-MAKING:

- Patients can typically try many different treatments. This can vary depending on individual journeys, including factors such as the duration and severity of symptoms, stage of disease and time since diagnosis
- · With multiple therapies often having to be trialled before experiencing relief from symptoms, patients report that treatment sometimes feels like a 'trial and error' process, but they must be reassured that it is actually a thoughtful and well-researched methodology

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UNMET NEEDS:

· Lack of awareness around treatment options, including efficacy, side effects, when to expect to see improvements in symptoms, and how long the course of medication will last

· Lack of guidance for healthcare professionals on how to support shared decision making

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CARE PARTNER EXPERIENCE

Care partners describe the 'disturbing' and 'terrible' experience of watching their loved one's discomfort and pain, and the frustration that GPs weren't able to quickly identify CTCL or even refer their loved one to a specialist.

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In late stage CTCL, care partners can feel like collateral damage; bearing a hands-on burden early stage, it can be hard to find the balance between being supportive and overbearing.

4. LONG-TERM ADHERENCE

When people with CTCL have stuck to their treatment plan, they often see an improvement in their symptoms that helps them cope with medication side effects.

EMOTIONAL EXPERIENCE

Shame, loss of self-confidence, embarrassment, low self-esteem stigma, uncertainty and hope.

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of visible skin problems, itching and pain/

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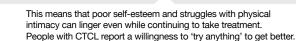
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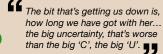


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UNMET NEEDS:

- · Lack of awareness of information about how the symptoms of CTCL and side effects of treatment can impact daily life
- · Peer support networks for people with CTCL and their care partners are not signposted enough by the healthcare system
- Lack of access to specialist multidisciplinary clinics and on-going specialist care





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