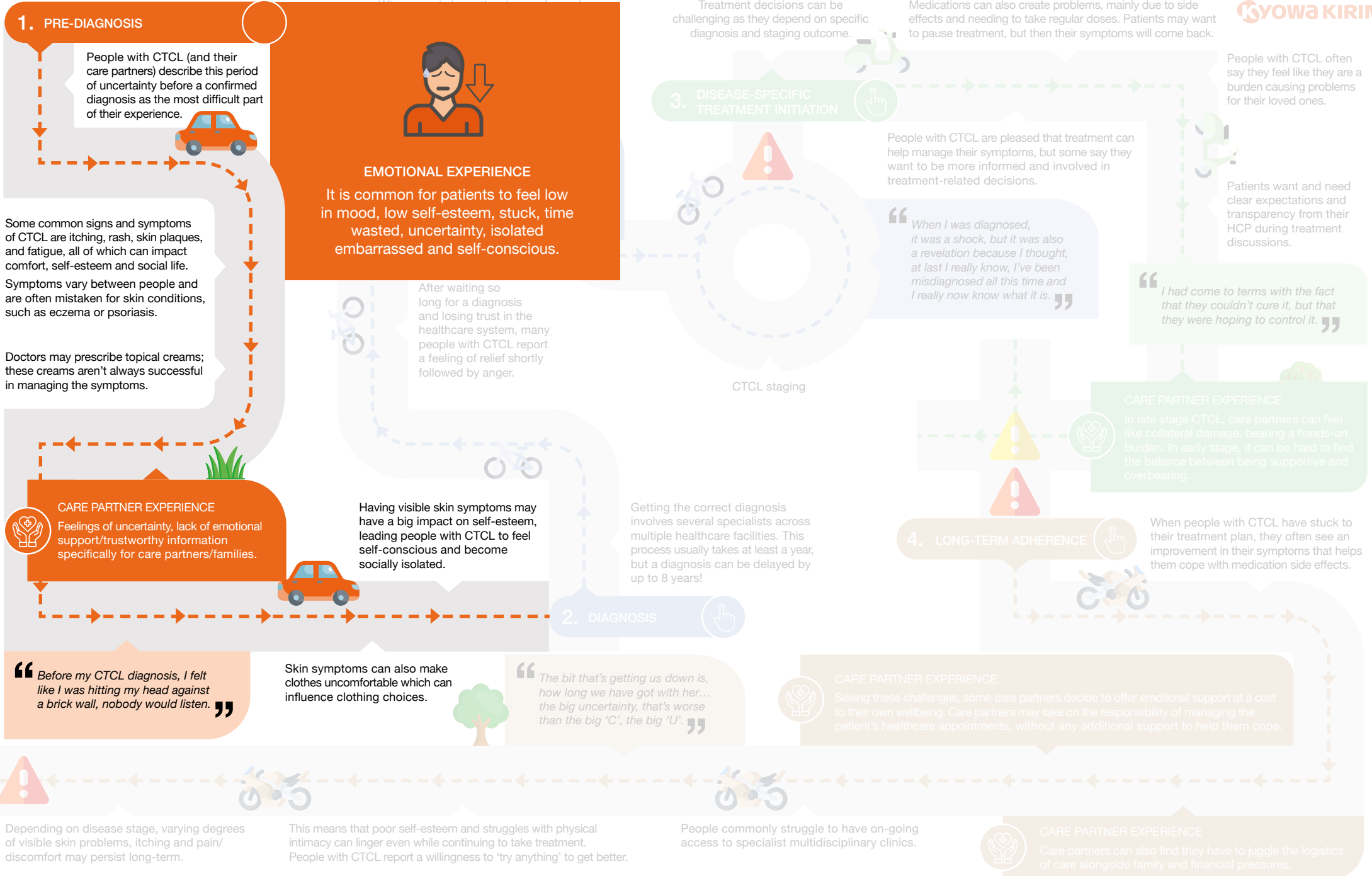


Grafički prikaz iskustva bolesnika s kožnim T-staničnim limfomom (CTCL; fungoidna mikoza i Sézaryjev sindrom)

Izazovi života s CTCL-om ne svode se samo na neugodne simptome. Oboljeli nose i emocionalni teret svoje bolesti, koji se mijenja ovisno o fazi CTCL-a, od dijagnoze do liječenja i nakon njega. Na temelju podataka dobivenih iz razgovora s bolesnicima, istraživanja i dodatnih analiza izradili smo grafički prikaz emocija bolesnika s CTCL-om u različitim fazama bolesti i nezadovoljenih potreba te populacije.

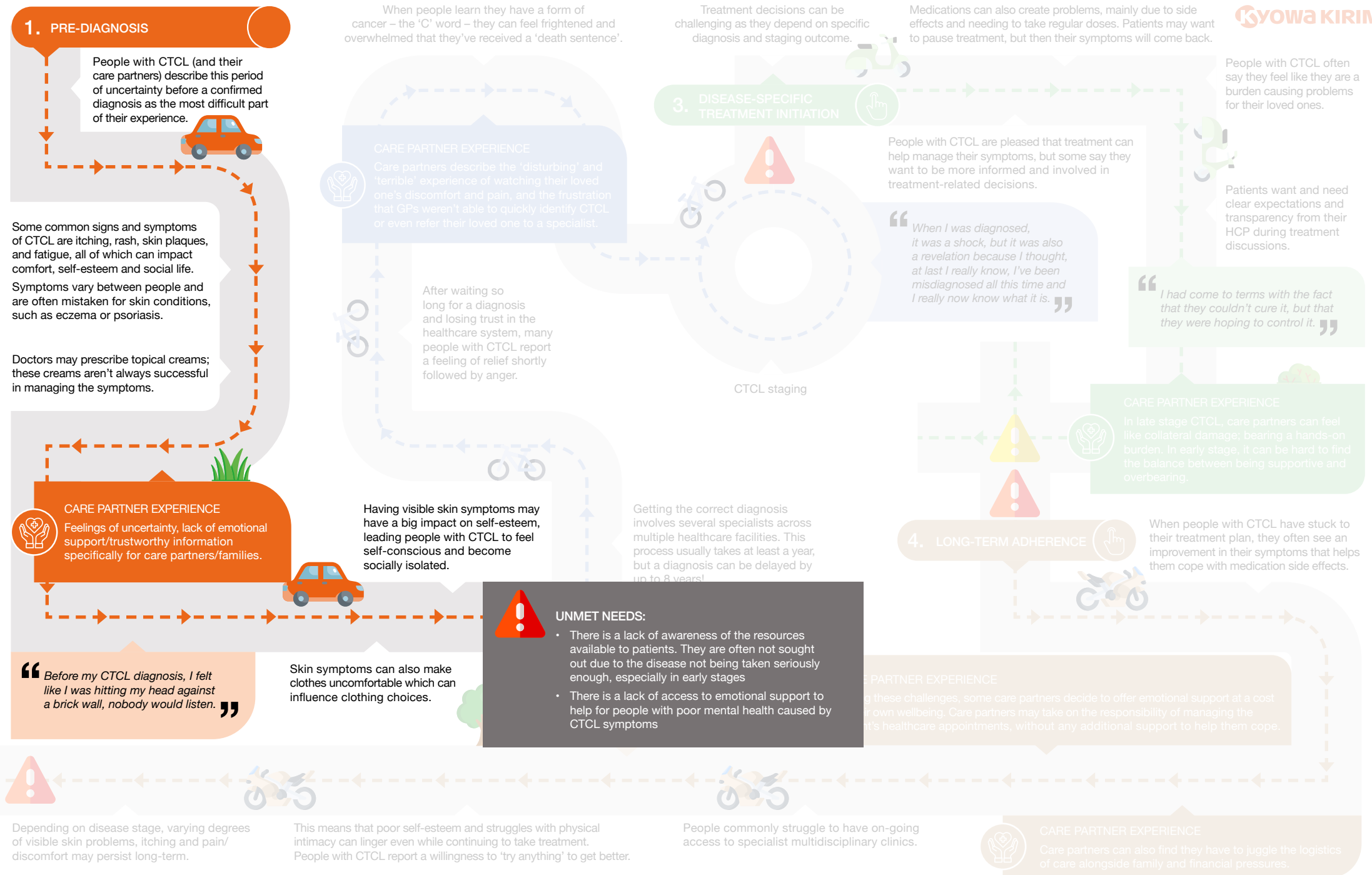


Mapping the lived healthcare experiences of people with cutaneous t-cell lymphoma (CTCL; mycosis fungoides and sézary syndrome)

The challenge of living with CTCL doesn't only come from uncomfortable symptoms; people with CTCL also struggle with the emotional burden of their condition. The emotional burden of CTCL can evolve over time, from getting a diagnosis to treatment, and beyond. Using insights from patient interviews, surveys and desk research, we've mapped how the feelings of people with CTCL can change over the course of their disease, and what unmet needs still exist in this community.

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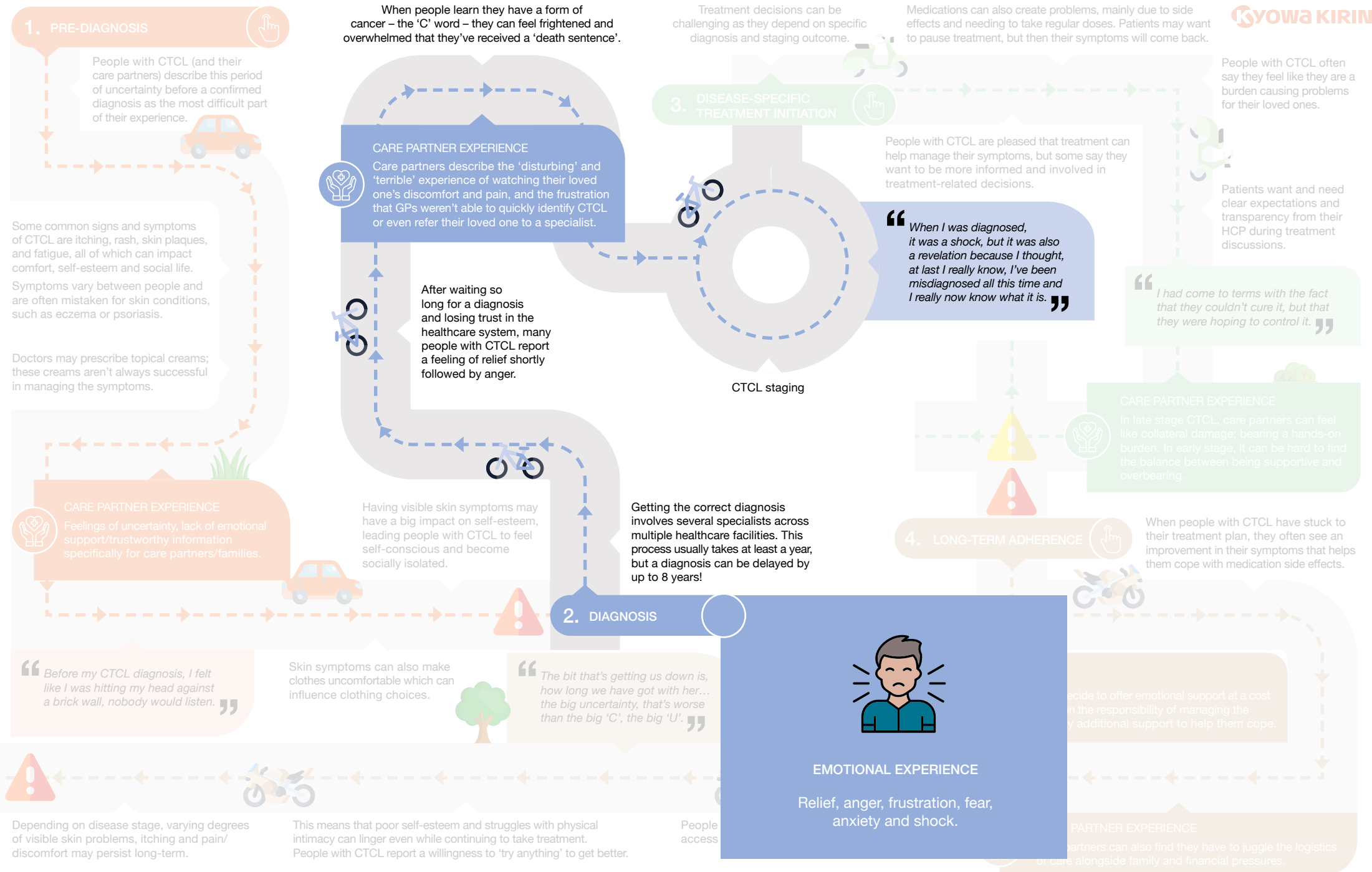
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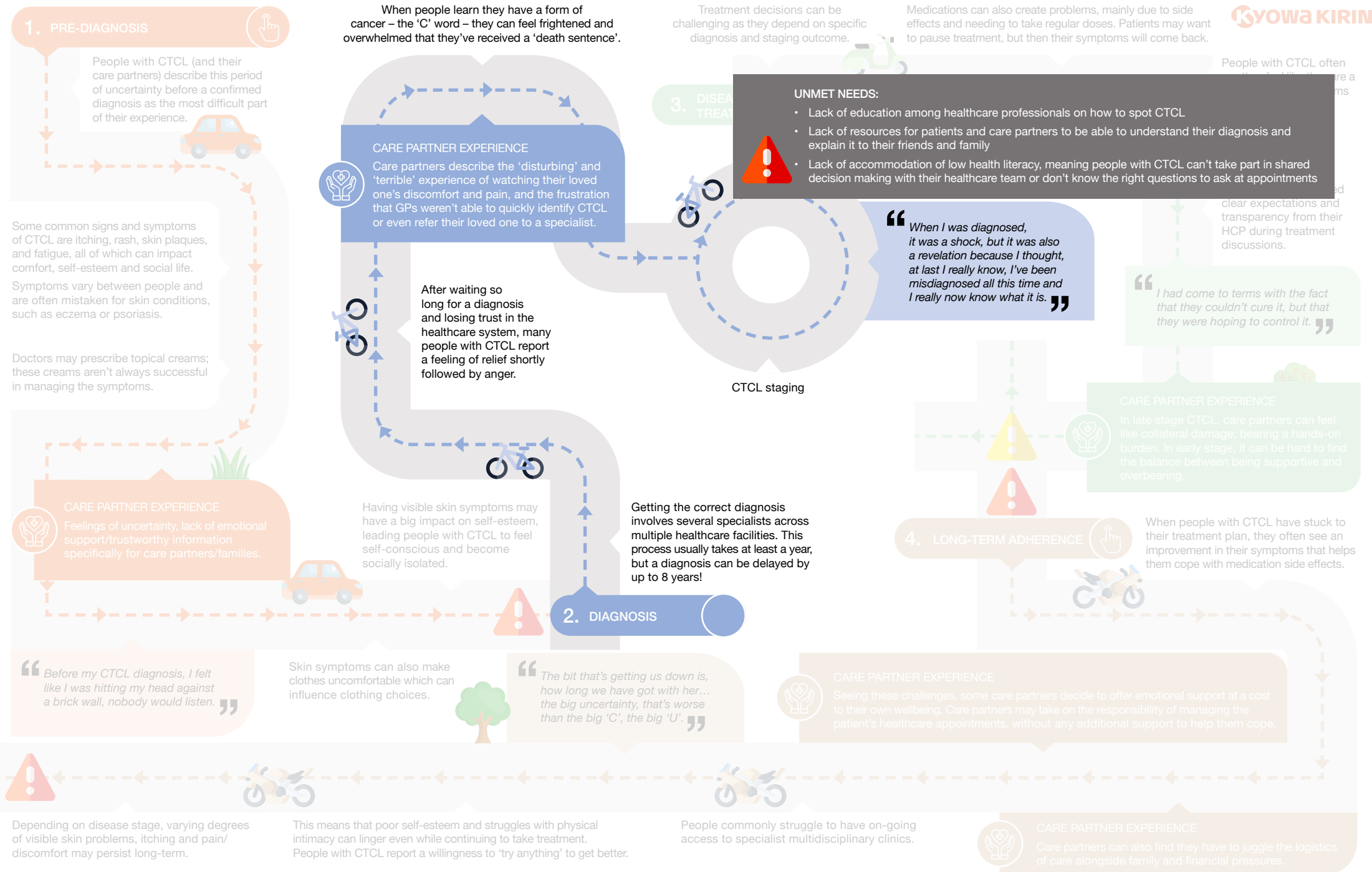


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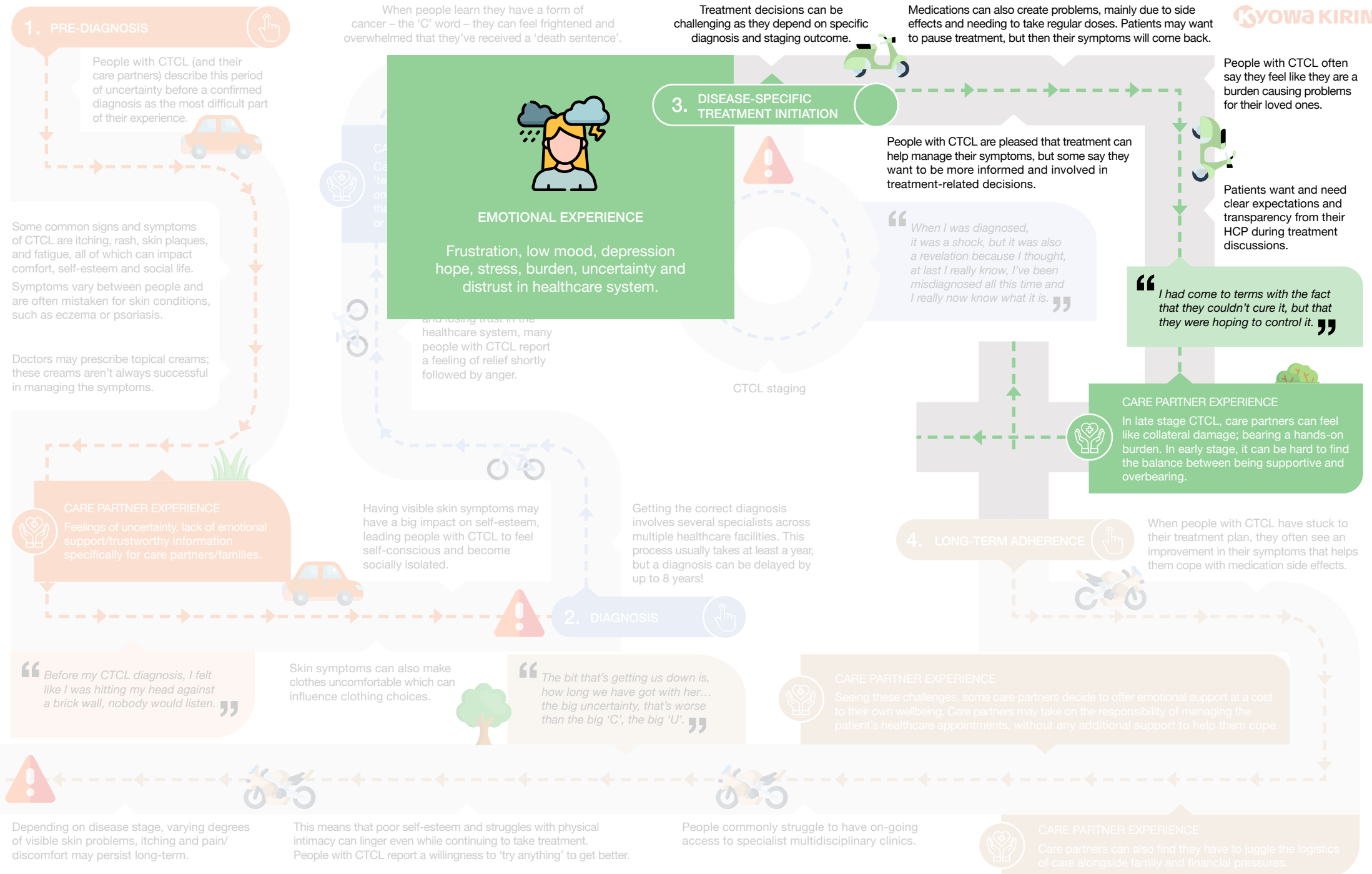


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1. PRE-DIAGNOSIS

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 plaques, 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."

Depending on disease stage, varying degrees of visible skin problems, itching and pain/discomfort may persist long-term.

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'.

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.

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.

Having visited multiple healthcare facilities. This process usually takes at least a year, but a diagnosis can be delayed by up to 8 years!

Skin symptoms can also make clothes uncomfortable which can influence clothing choices.

This means that poor self-esteem and struggles with physical intimacy can linger even while continuing to take treatment. People with CTCL report a willingness to 'try anything' to get better.

3. DISEASE-SPECIFIC TREATMENT INITIATION

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

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, 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."

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

Multiple healthcare facilities. This process usually takes at least a year, but a diagnosis can be delayed by up to 8 years!

"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'."

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

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.

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."

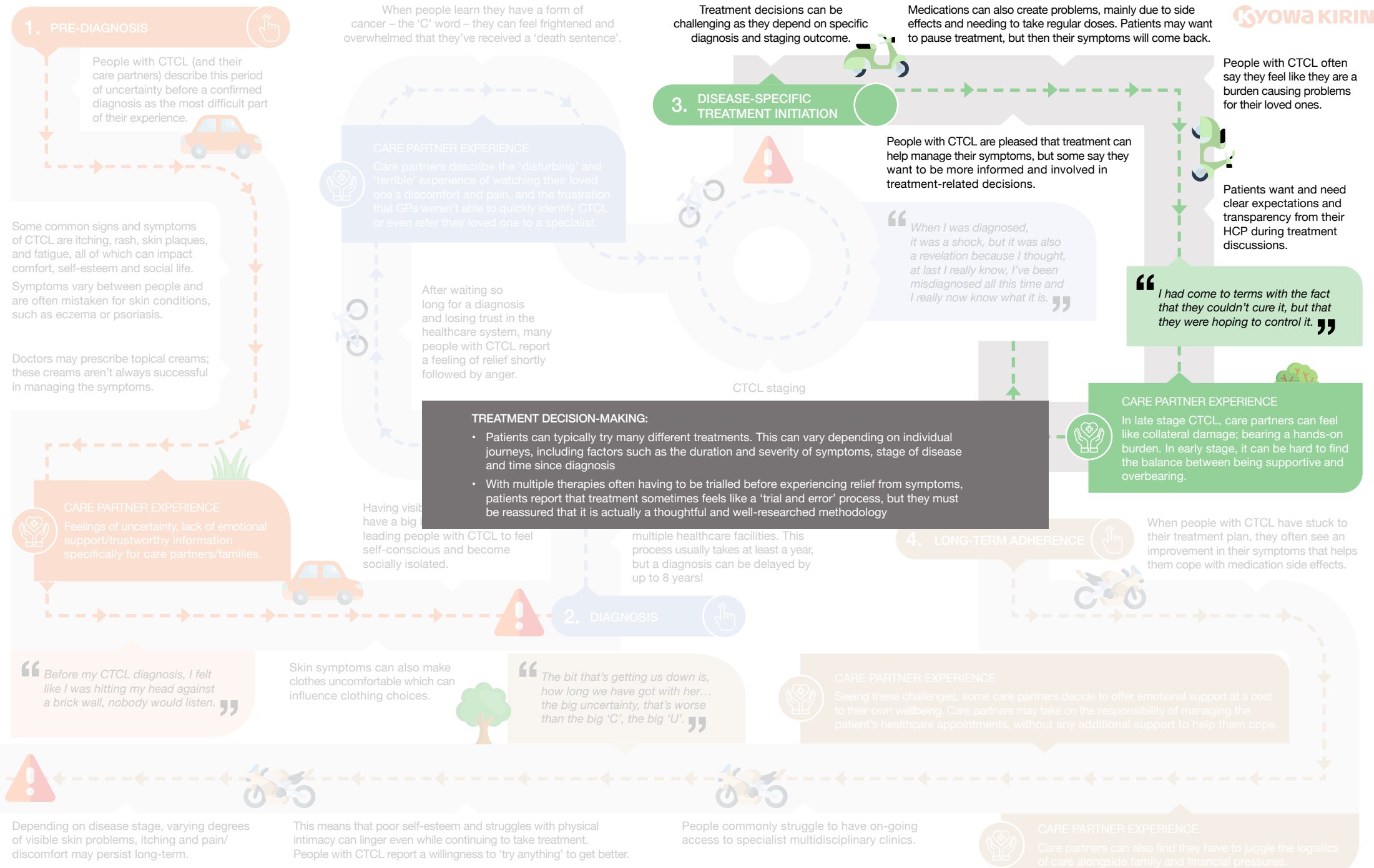
CARE PARTNER EXPERIENCE
In late stage CTCL, care partners can feel like collateral damage; bearing a hands-on burden. In early stage, it can be hard to find the balance between being supportive and overbearing.

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.

CARE PARTNER EXPERIENCE
Seeing these challenges, some care partners decide to offer emotional support at a cost 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 cope.

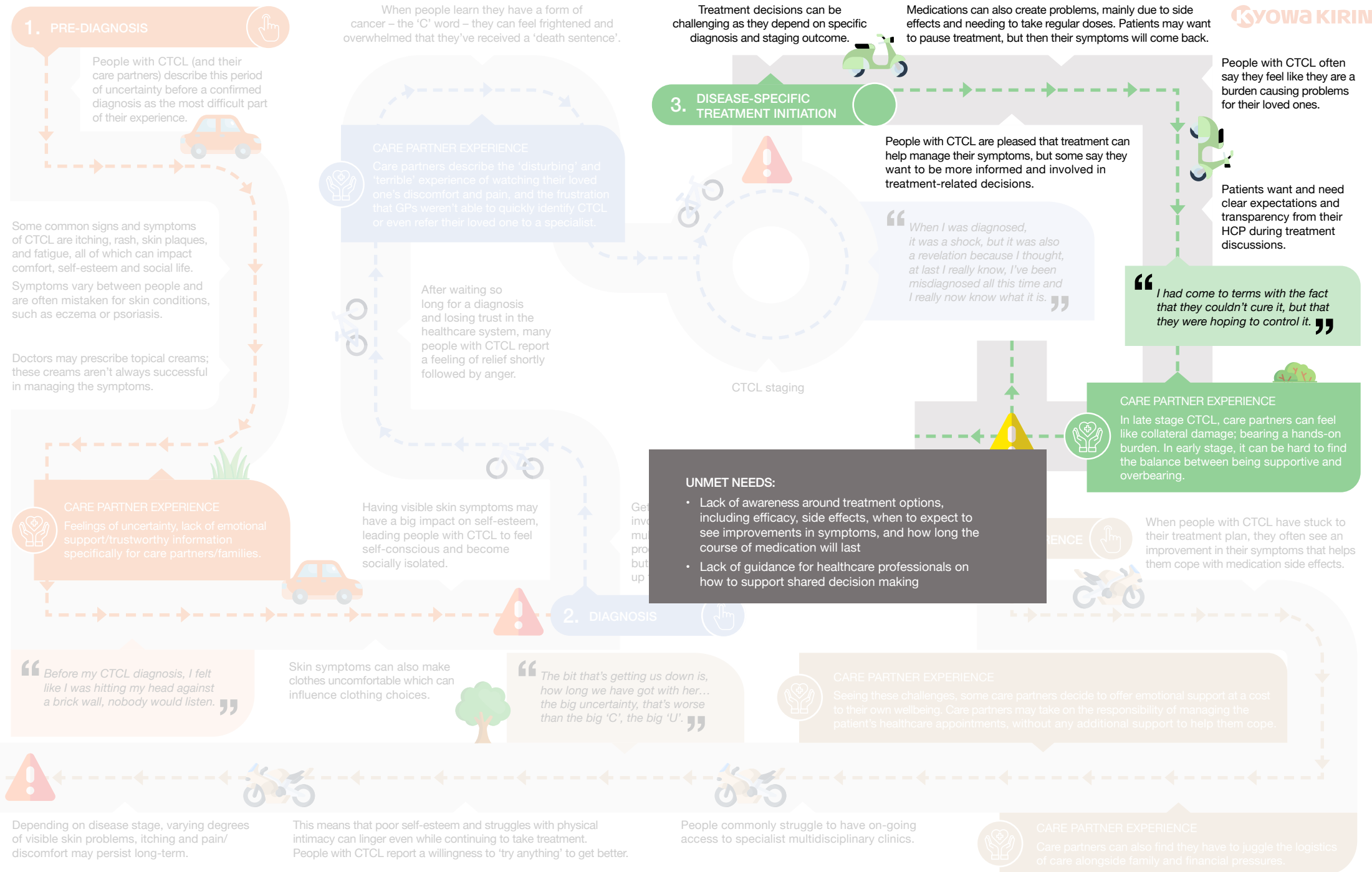
CARE PARTNER EXPERIENCE
Care partners can also find they have to juggle the logistics of care alongside family and financial pressures.



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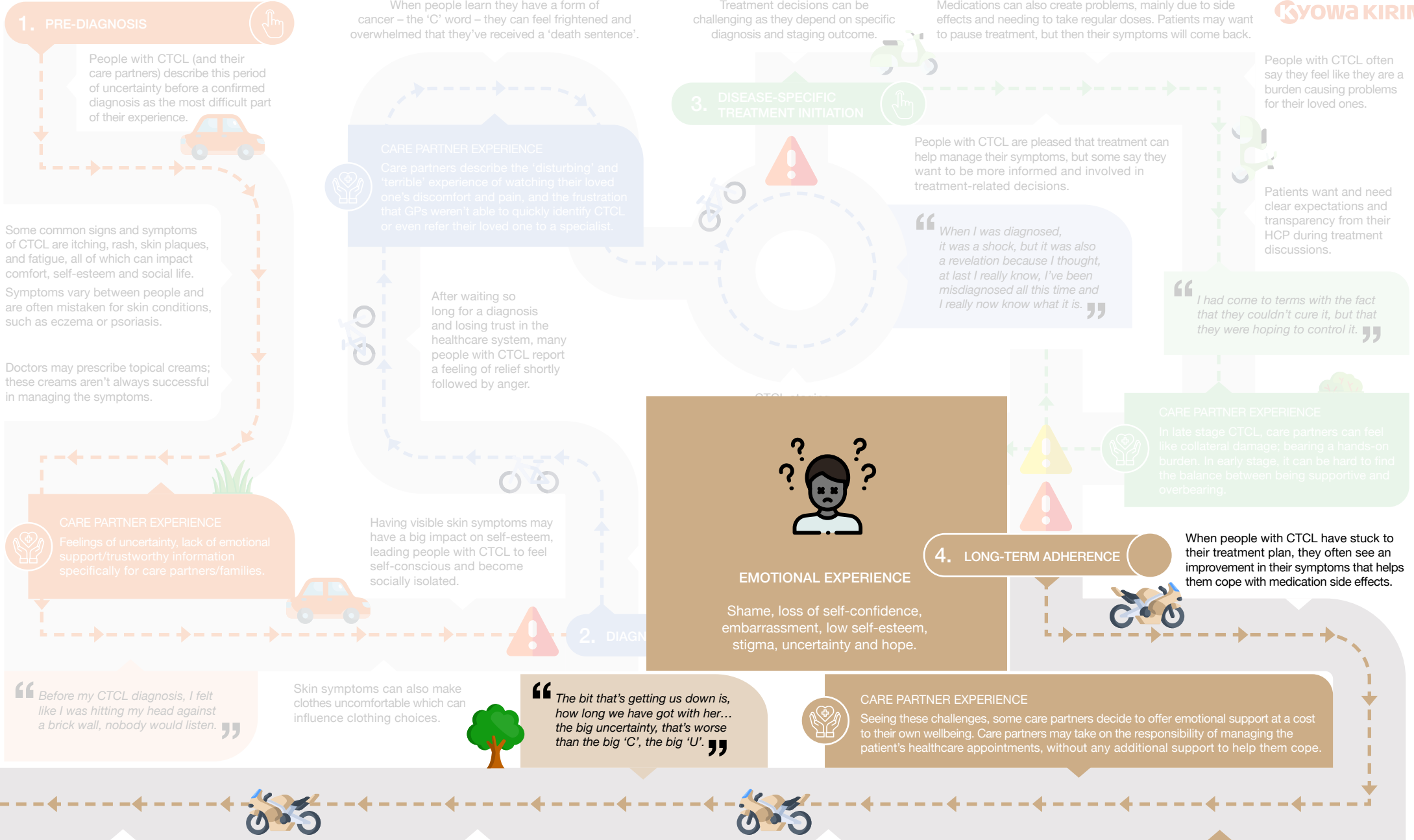


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People commonly struggle to have on-going access to specialist multidisciplinary clinics.

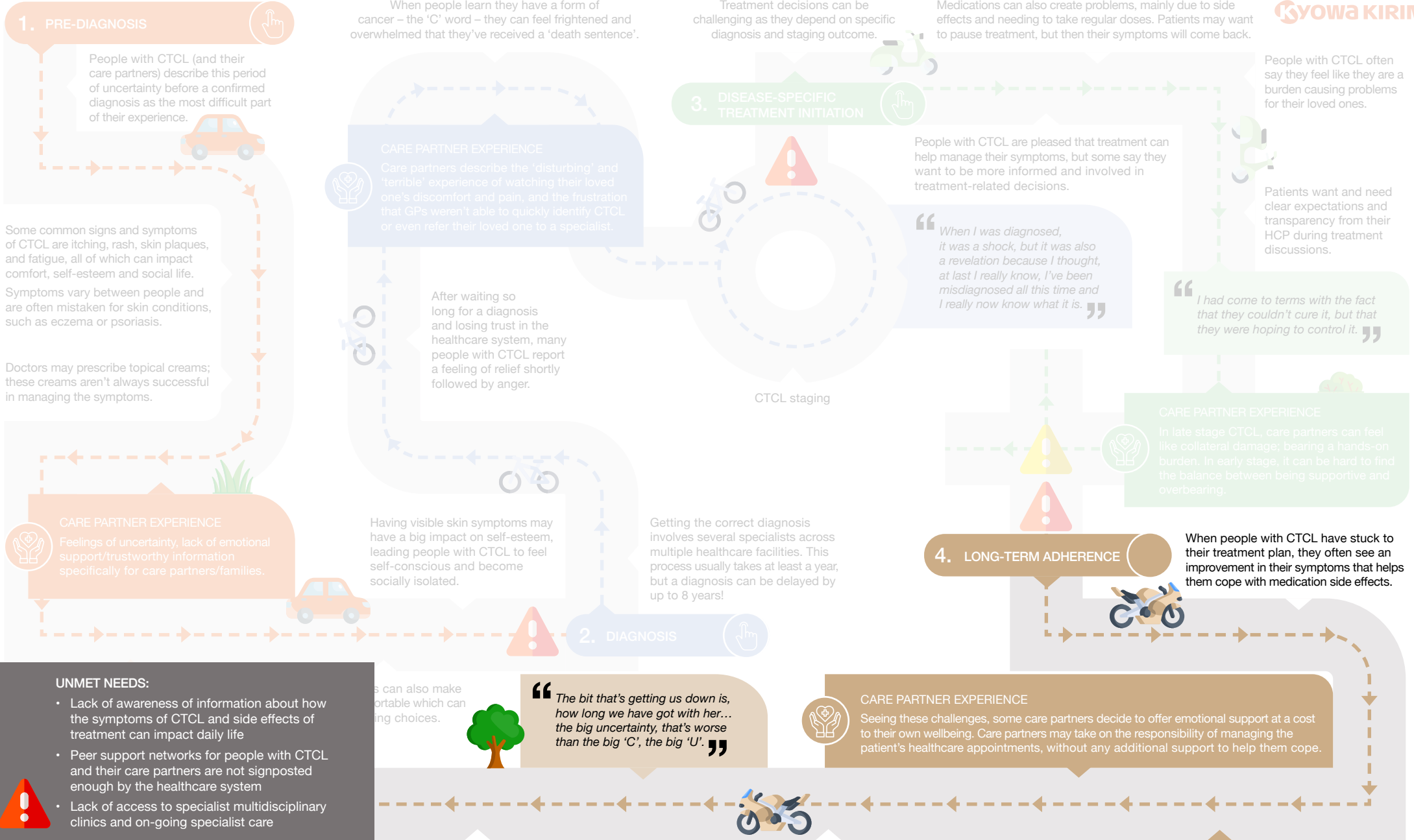
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- UNMET NEEDS:**
- Lack of awareness of information about how the symptoms of CTCL and side effects of treatment can impact daily life
 - Peer support networks for people with CTCL and their care partners are not signposted enough by the healthcare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

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