Psychological Support for People Living with CLL

What are the psychological impacts of watch and wait, and active treatment?

Watch and wait

People living with CLL who are on watch and wait report experiencing higher levels of cancer-related distress. Reasons for this include:

It can be distressing for people to understand why 'nothing' is being done when cancer has been detected.[1]

Those on watch and wait report clinically significant levels of anxiety and depression as a result of feelings of perceived loss of control, loss of self-efficacy and that their life is on hold.[2]

Patients can experience a consistent fear of the cancer progressing and hyperawareness of perceived physical symptoms, and therefore a perpetual state of unsafety.

Patients on watch and wait also report higher levels of unmet needs in comparison with their active treatment counterparts.

It is hypothesised that these unmet needs are a result of less frequent appointments and/or contact with HCPs who are best placed to screen for unmet needs or distress.[2]

- **Delayed or latent processing of their disease**
- **Lack of immediate treatment**
- **Lack of visible disease**
- **Lack of information about their diagnosis**
- **Living with symptoms**
- **Fear of disease progression**
- **Feeling forgotten about**

As those with CLL can be in the watch and wait period for years, living with this prolonged uncertainty can potentially take a toll on their QoL.

Active treatment

Common psychological and emotional experiences faced by those on active treatment include:

- **Delayed or latent processing of their disease**
- **Adjustment-related worry and/or anxiety**
- **Increased anxiety related to treatment regimen**
- **Perceived/real psychological burden of disease**
- **(New) struggles with physical symptom burden** resulting in 'negative' psychological **responses**
- **Fears for or perceived loss of future**
- **Relief and sense of control**

Active treatment for CLL can be daunting and confusing for patients, especially as there is no standard 'fit for all' approach.

People living with CLL can face several remissions and relapses which can make it hard to manage distress and the range of emotions that can occur before, during and following treatment.[1]

As CLL is chronic and very cyclical in its nature of treatment vs watch and wait, the psychological impact of active treatment with periods of watch and wait is also an important consideration.

People living with CLL may experience a sense of furthering loss of control over their lives as it becomes, at least for a time, centred around treatment and managing side effects.[2]

Many of those living with CLL may feel relieved that finally something is being done. Feeling seen and cared for is an emotionally containing and relieving experience.

For those initially on watch and wait, going on treatment can bring about feelings of failure, shame and guilt for 'not being able to fight the cancer for longer'.

How can you support your patients?

- **Patient participation and shared decision making –** including the person living with CLL in conversations around treatment and decision making enhances personalisation of care, whilst empowering them to play an active role in composing their cancer care[4–6]
- **Consider the language you use –** how do you describe CLL to your patients? Studies have shown that the language used by HCPs is strongly related to subjective distress and QoL outcomes[7,8]
- **Make sure to ask questions –** many people living with CLL may only report physical issues because that is what they think you will want to hear. A simple question such as, "What worries you most about your CLL?" could help to highlight underlying emotional distress
- **Be aware –** find out about the specialist support available in your trust and support groups that you can signpost to if/when needed

CLL, chronic lymphocytic leukaemia; HCP, healthcare professional; QoL, quality of life

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