

Broader considerations in the management of CLL

The importance of education and Holistic Needs Assessment in CLL patient care

What information should HCPs provide to people living with CLL at each stage of their treatment journey?

Diagnosis



The focus at initial diagnosis/prognosis should be on understanding the diagnosis/prognosis, management strategy and how the diagnosis impacts **on everyday life**.¹

- For indolent diseases such as CLL, this may be a rationale for watch and wait
- Often the doctor, along with a CNS, will spend some time exploring some of the important issues with the individual and their family or carer
- An information booklet is given and a HNA may be carried out to identify needs and concerns

Time of treatment



At this stage, details about the different treatment choices are given, with the pros and cons for each choice along with the practicalities of treatment.² This information is often discussed with the treating doctor in clinic and written information is given afterwards to **consolidate learning**.



The CNS may provide a face-to-face session to discuss proposed treatment, side effects of treatments, give a tour of treatment facilities and signpost to other support services. The CNS may also follow up with the person living with CLL to answer any further questions once they've had the chance to review the information.

If a clinical trial is being considered, then personnel concerned with this may become involved at this stage.

Response assessment and living with CLL



Response assessment can be discussed by the doctor or CNS while treatment is ongoing or following treatment for fixed-duration therapies. Expectations for length of remission may also be discussed.²

- If there are complications, eg, psychological effects or weight loss, different members of the team may be involved such as psychological support or a dietitian
- If appropriate, palliative care may be asked to be involved for symptom management, or transition to end-of-life care
- Patient scans and blood results can be discussed throughout the treatment journey

Should HCPs personalise information?

Where possible, HCPs **should personalise information given to the patient**. This may include being guided by how much the person living with CLL wants to know, hear and understand about their diagnosis.



You do not want to overwhelm the patient with everything given all in one go, so it may be best to give the information in bite-sized chunks. Think about how the individual may want to retain information



Some people like to take notes as a way of understanding, while others request to record conversations



Some would rather not think about it and will leave the worrying about their disease to the HCPs

Information also needs to be tailored to patients according to their capabilities

What is a HNA?

A HNA is a **simple questionnaire used by HCPs**. The use of HNAs contribute to better identification of individuals' needs and concerns. The assessment can be carried out at any stage of the cancer pathway to:³



Identify a patient's concerns



Share the right information, at the right time



Start a conversation about needs



Signpost to relevant services



Develop a personalised care and support plan

HNAs are a key intervention of personalised care for people living with cancer.³

How are HNA tools used by nurses and other HCPs in CLL patient care?

The effective use of HNAs by HCPs can enable early intervention and diagnosis of side effects or consequences of treatment, as well as identifying other needs that may not be directly related to the cancer diagnosis.³⁻⁵

1

Individual takes questionnaire

The person living with CLL rates their overall distress and identifies their specific concerns. These can be answered on paper or electronically.

2

Discuss the needs together

Needs and concerns may be physical, emotional, practical, financial or spiritual. The individual may like to bring a carer, family member or friend to be part of the discussion.

3

Create care plan together

A care plan includes information to help people self-manage, along with contact details of any helpful services. Individuals may take a copy of their care plan with them and use this to help monitor how they are doing. The HNA can be revisited throughout the treatment journey.