
A CLL EMPOWERMENT GUIDE

Performing a psychosocial assessment

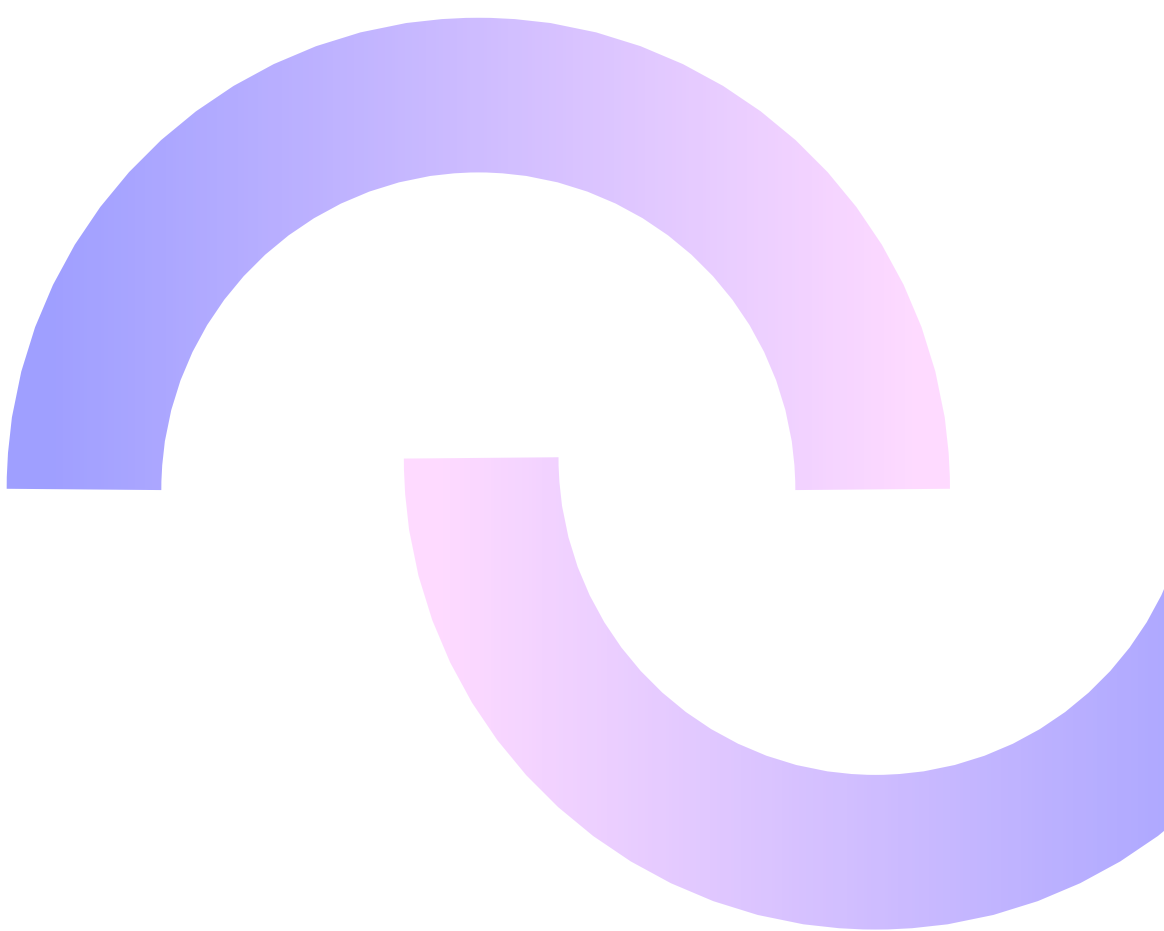


PERFORMING A PSYCHOSOCIAL ASSESSMENT



Like all people living with chronic conditions, individuals diagnosed with CLL might experience distress, anxiety and depression at some point or another along their disease path.

MANAGING CHALLENGES



These may differ in severity and ensue from:

- Physical symptoms or adverse events from the treatment, e.g., fatigue, night sweats, nausea
- Perceptions of CLL and coping style, e.g., feelings of hopelessness, fear of progression, loss of control
- Challenges related with the healthcare system, e.g., lack of time to express worries, difficulty to understand terminology leading to confusion
- Financial and occupational difficulties, e.g., unemployment
- Social functioning and family problems, e.g., inability to perform previously held roles
- Existential and spiritual challenges, e.g., confrontation with mortality

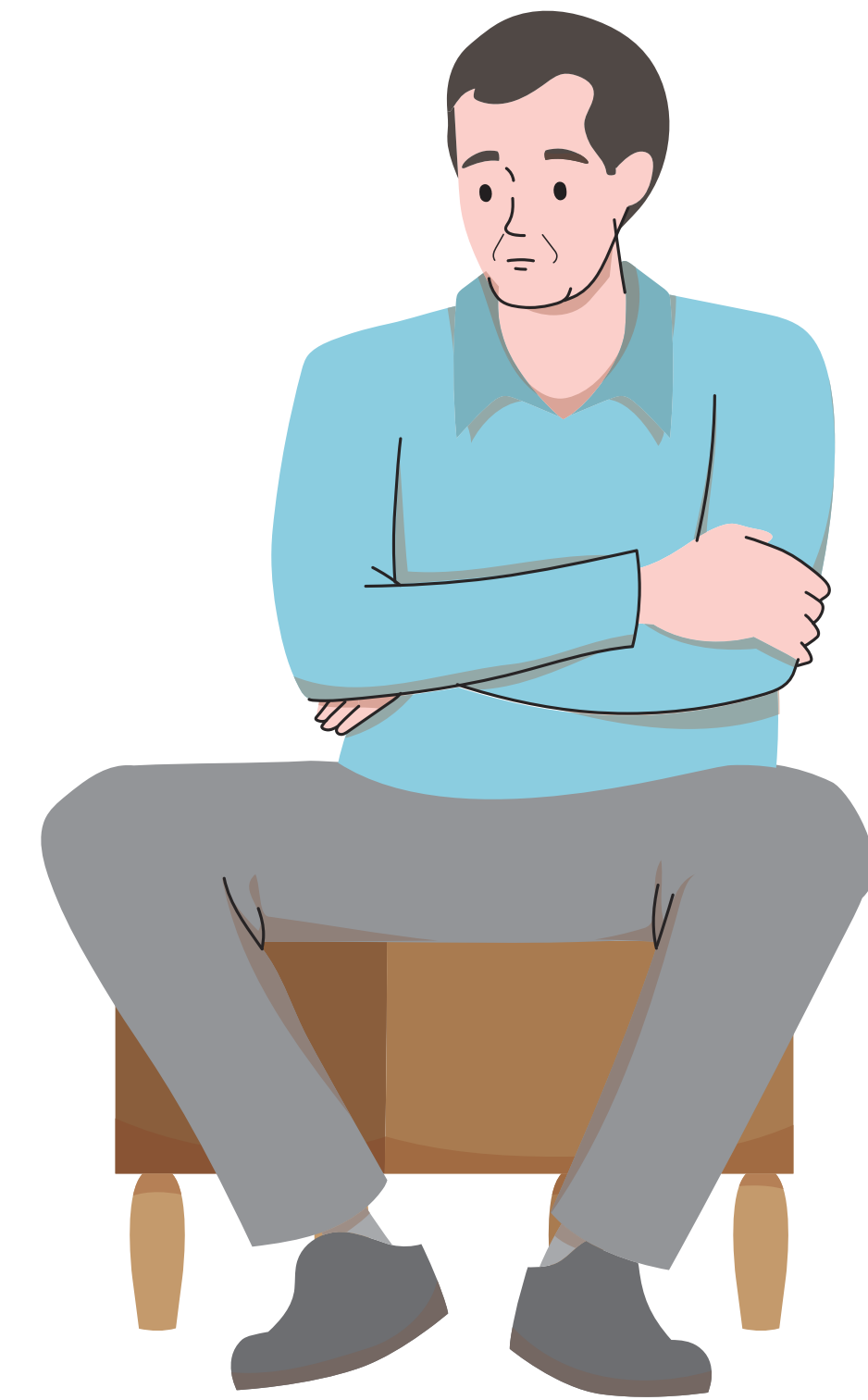
Screening for quality of life issues and mental health challenges is really important.

Nevertheless, it has been found that a large proportion of patients in need of psychosocial support are not informed about mental health care support services and do not receive proper psychosocial care. Thus, physicians' knowledge of psychosocial difficulties and how to assess them, as well as knowledge of available psychosocial services (see leaflet "Making informed referrals") for referring patients are key in granting patients access to such services.

This can in turn drastically improve patients' quality of life, treatment adherence, physical symptoms and reduce healthcare costs.

IN PRACTICE

A hematologist cannot be expected to be able to perform a comprehensive psychosocial assessment or give a psychiatric diagnosis. **Rather, their role in this domain involves being able to timely identify and screen for possible issues.**

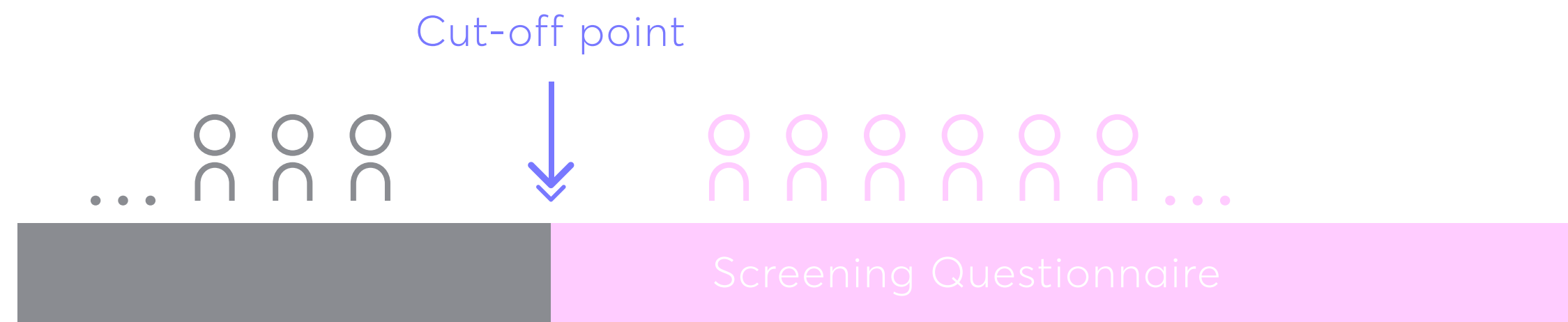


As patients are seen briefly in medical practice, screening instruments are the most applicable form of psychosocial assessment performed by hematologists.

These instruments indicate the presence of a specific mental health issue, such as anxiety or depression, or the impact of the disease on patients' quality of life, by employing easy scoring systems and validated cut-off values.

In case the patients' score indicate significant issues, referrals can be made to a mental health care worker for a more detailed assessment and treatment planning. Some hospitals have liaison psychiatry services, while in others there are mental health care professionals in the hematology department. In case there are no mental health care workers in the hospital, referrals can be made in other psychosocial services in the community.





Screening instruments are usually self-reported questionnaires which can be handed over and filled in by patients.

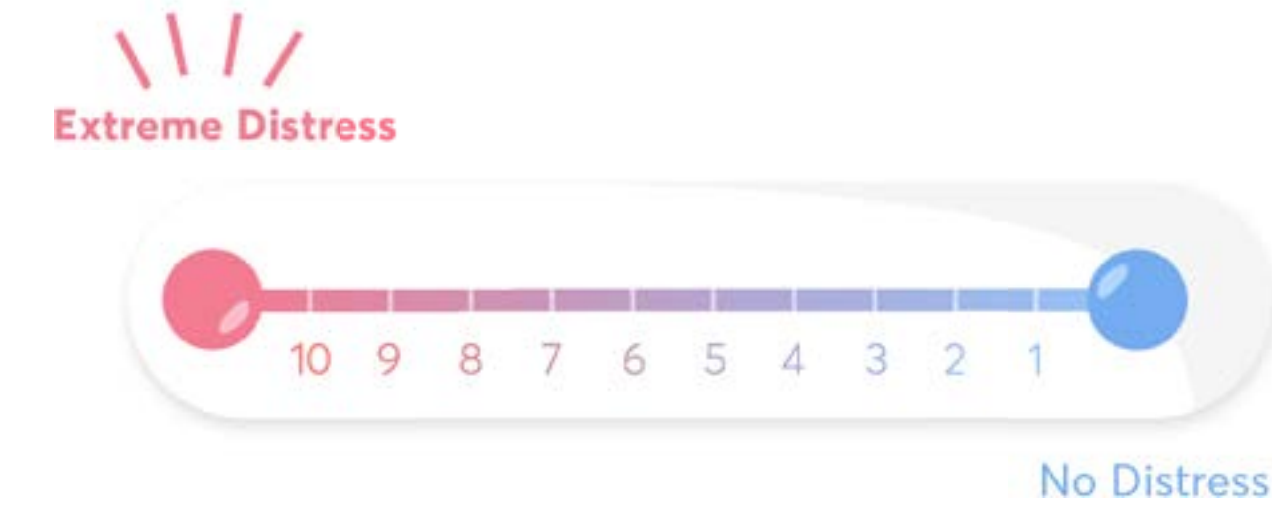
Below you can see some of the most fundamental psychosocial domains that are impacted in people living with CLL, along with frequently utilized screening instruments in cancer care.

PSYCHOSOCIAL DISTRESS

Psychosocial distress is a broad term, which refers to an unpleasant experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with CLL; its physical symptoms and its treatment. In clinical practice, patients' distress may be expressed as feelings of vulnerability, fear, worry or sadness. However, it can also encompass more severe issues or psychological reactions which should be identified and appropriately treated.

DISTRESS THERMOMETER

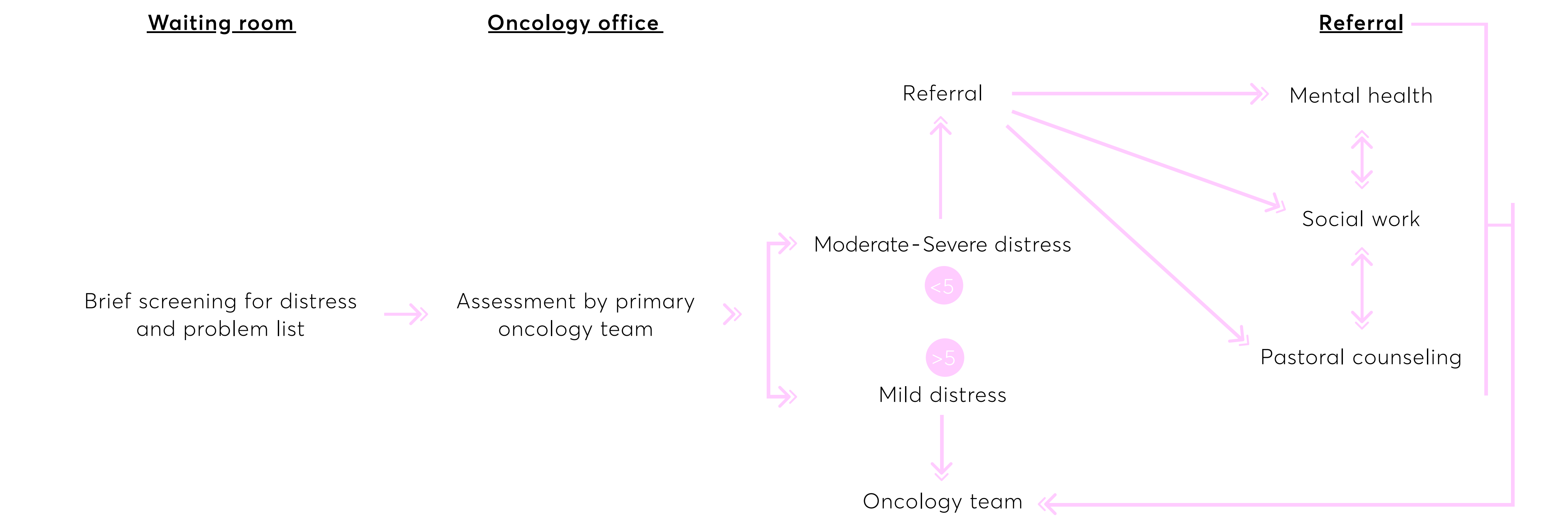
The [Distress Thermometer](#) can be used for a quick screening of distress in people living with CLL. It can easily be handed over to patients in the waiting room. It measures the levels of distress, along with possible reasons for distress, i.e., practical, family, emotional, physical problems and spiritual/religious concerns.



– QUESTIONNAIRE –

- ☐ Anger
- ☐ Nervousness
- ☐ Sadness
- ☐ Worry

NCCN DISTRESS THERMOMETER AND PROBLEM LIST
Treatment Guideline



<5 A value lower than 5, indicates that in the context of cancer, such as CLL, the patient’s distress is at expected levels.

>5 However, a score of 5 or higher, indicates moderate to severe distress, and the patient should be referred to the mental health team for further assessment and support.

ANXIETY

Anxiety encompasses a wide range of psychological, cognitive and physical symptoms and is expressed in a different way in each individual. Its common manifestations may include:

Psychological symptoms: fear of loss of control, fear of going crazy, nervousness, irritableness, inner tension

Cognitive symptoms: catastrophic thoughts, difficulties concentrating

Physical symptoms: increased heart rate, chest pain, shortness of breath, sweating, dizziness, lightheadedness, nausea, feelings of asphyxiation

DEPRESSION

Depression also includes a wide variety of symptoms, and being able to identify some of them can promote timely screening and referring patients. Namely, they include:

Psychological Symptoms: Feelings of guilt, hopelessness, low mood, loss of interest and enjoyment, feelings of worthlessness

Cognitive Symptoms: Reduction in the ability to think or concentrate, recurring thoughts of death

Physical Symptoms: loss of energy, weight loss or weight gain, sleep disorders

HOSPITAL ANXIETY AND DEPRESSION SCALES (HADS)

The [Hospital Anxiety and Depression Scales \(HADS\)](#) is a brief self-report questionnaire widely used for assessing anxiety and depression in the context of cancer.

As its name implies, it consists of two subscales. The sum of "A" questions gives a total score for the patient's anxiety, while the sum of "D" questions yields the score for the depression subscale.

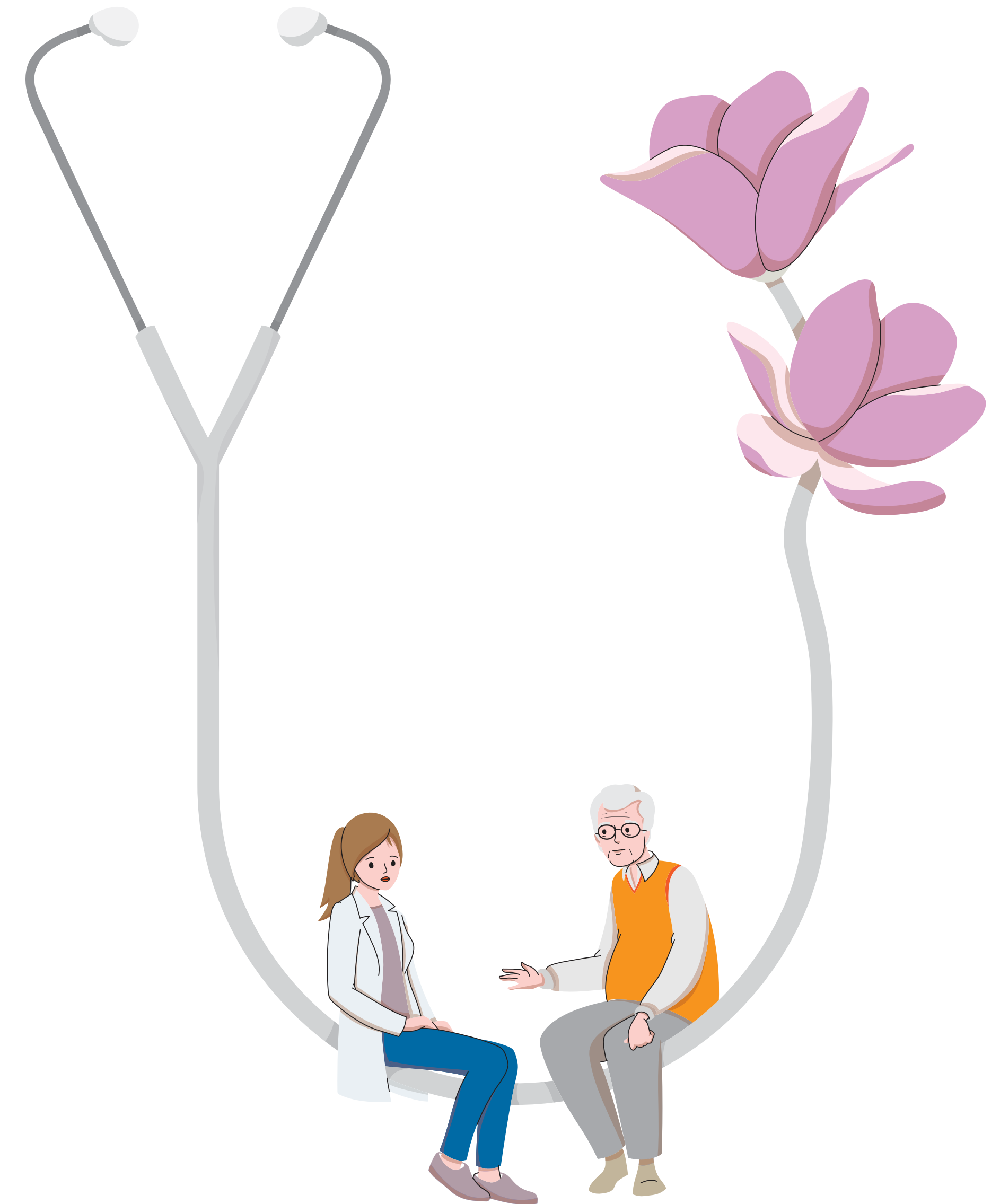
A score of 0-7 for each subscale represents normal anxiety/depression levels, while scores above 8 correspond to potentially significant levels of anxiety/depression which would require further assessment.

QUALITY OF LIFE

Quality of life is a multidimensional construct which encompasses the individual's physical, mental, emotional and social well-being, as well as their functioning abilities in everyday life.

Assessing the quality of life in people living with CLL can help measure the severity of their disease and its impact on their daily life. In turn, this can result in identifying goals for psychosocial and medical interventions, such as the alleviation of certain symptoms or directing the patient for help (e.g., financial aids, social issues) to specific services.

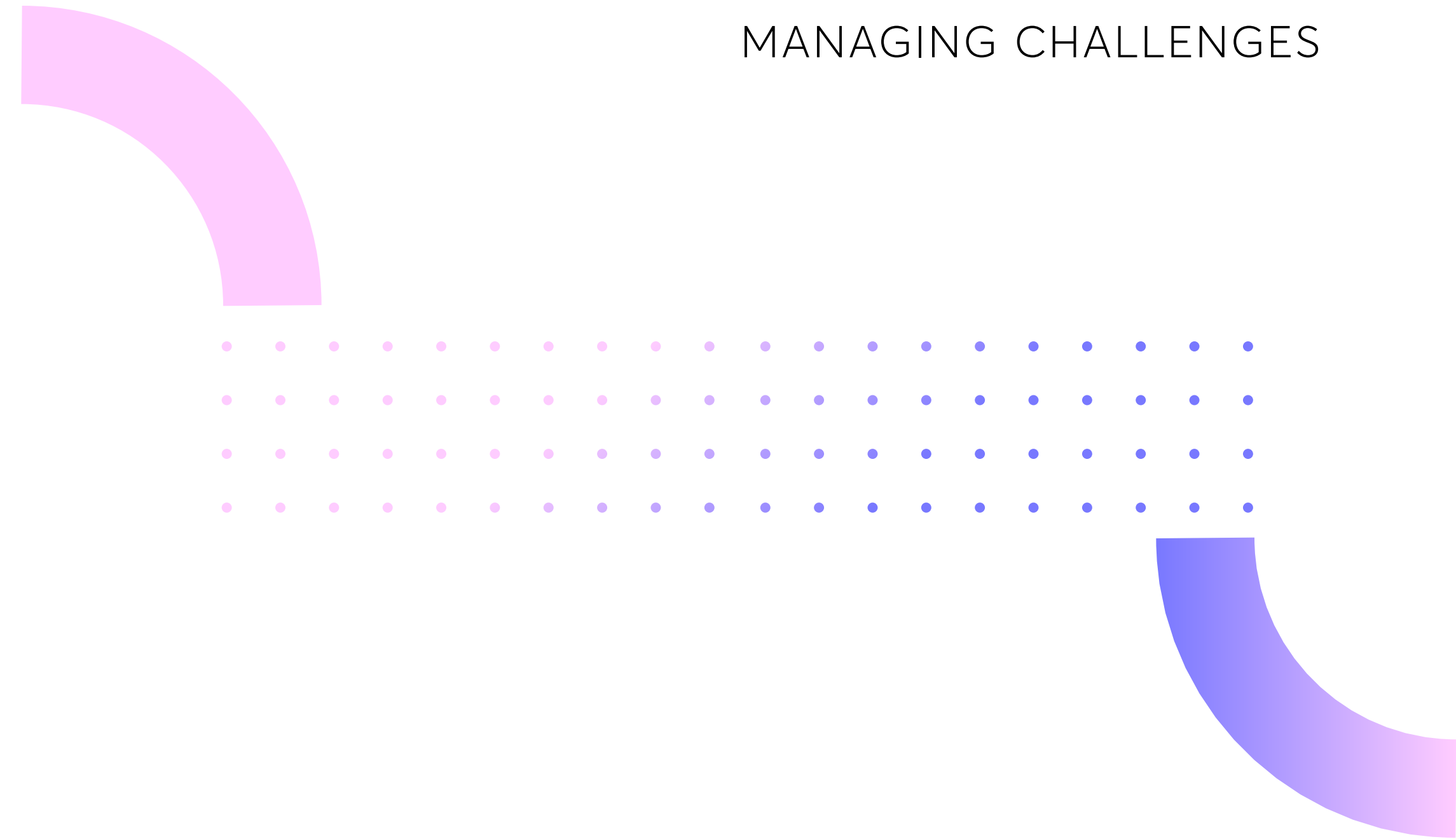
In terms of screening, there are instruments which perform generic quality of life assessments and others that capture patients' disease-specific quality of life. The latter assess the impact of a disease, such as CLL, and its treatments on patients' quality of life.



EORTC QLQ-30

The [EORTC Core Quality of Life questionnaire \(EORTC QLQ-C30\)](#) is a modular instrument. Namely, it consists of 30 core items which measure QoL dimensions for patients with all forms of cancer. There are also supplementary EORTC instruments which encompass specific difficulties of people living with certain types of cancer, such as CLL (see section EORTC CLL17 below).

The core items represent functional scales (physical, emotional, social, cognitive and role functions). There are also several symptom scales (fatigue, pain, nausea and vomiting).



Having a glance at a patient's EORTC QLQ-30 can give you a quick picture of the impact of cancer on your patient's quality of life across several domains. Patient answers can also be converted to total scores for each subscale, and their QoL in general.

In such case, one would need to consult the scoring manual (see <https://cllempowerment.com/tools/>)

EORTC CLL17 QUESTIONNAIRE

[EORTC CLL17](#) questionnaire is an extension of the EORTC QLQ-30, designed specifically for people living with CLL.

Again, it can provide a quick overview into patients' major areas of discomfort, as well as yield more standardized scores.



OVERVIEW

Psychosocial challenges or mental health difficulties are present in almost every person living with cancer.

However, many patients adapt to their changed life conditions and become able to cope with resilience. Others may become overwhelmed by their illness, and its implications, adding up to their existing psychosocial difficulties.



Having the knowledge and the sensitivity to identify and screen for such issues can lift some of their physical and psychosocial burden and greatly improve their QoL.

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