Psychological support for CLL patients

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This non-promotional medical educational resource has been organised and funded by AstraZeneca UK.

GB-37598 DOP July 2022

Presentation content:

- Psychological impact of diagnosis
- Psychological impact of treatment
  - Watch and wait
  - Active treatment
- Living with uncertainty in the post-COVID world
- Screening for distress and responding to patients' needs
  - Basic skills
  - Intermediate skills

Psychological impact of a CLL diagnosis

What's (not) wrong with me?

- Most CLL patients are asymptomatic or are concerned with other potential illness at the time of diagnosis. This sudden shift from being 'healthy' to 'having cancer' can be a deeply distressing or disturbing experience[1]

A CLL diagnosis is confusing and overwhelming

- A recent survey found that at the time of diagnosis, **66%** of participants fully understood that CLL was a cancer and only **42%** of respondents fully understood what was wrong with them[2]

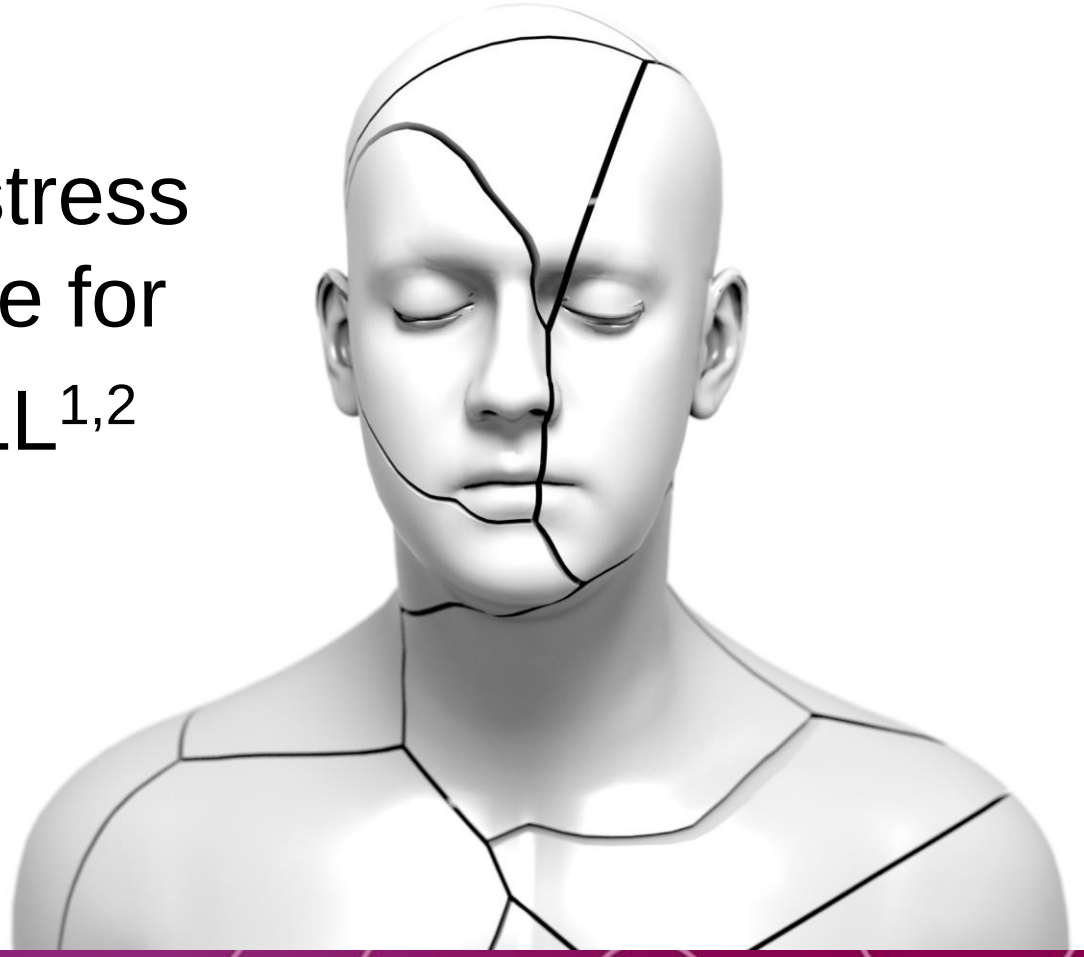
"This can't be true" – "Why me?" – "I should have…" (i.e., shock and denial)

- It's not clear what causes CLL. Although there are some genetic factors that can contribute to disease susceptibility such as having a relative with CLL, there is no proven link to radiation or infections
- In the US, a weak link has been found between CLL and exposure to Agent Orange[3]
- There is no evidence that suggests that dietary or lifestyle factors increase the risk of CLL[4,5]

CLL, chronic lymphocytic leukaemia

1. Holland JC, et al. *Psychosom Med* 2002;64:206–21; 2. Pemberton-Whiteley Z, et al. *Leuk Lymphoma* 2019;3:690–91; 3. Baumann Kreuziger LM, et al. *Leuk Lymphoma* 2014;55:63–6; 4. Kipps TJ, et al. *Nat Rev Dis Primers* 2017;3:16096;
5. NHS. Chronic lymphocytic leukaemia 2019. Available at: https://www.nhs.uk/conditions/chronic-lymphocytic-leukaemia/. Accessed: 15 June 2022

Cancer-related psychological distress is a significant psychosocial issue for at least **25%** of patients with CLL[1,2]



CLL, chronic lymphocytic leukaemia

1. Halilova KI, et al. *J Clin Oncol* 2016;34:201; 2. Shanafelt TD, et al. *Leuk Res* 2009;33:263–70

Defining cancer-related psychological distress

“A multidetermined unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.” (p. 6; National Comprehensive Cancer Network, 2020b).

Understanding patient needs

A CLL diagnosis is a distressing event leading to feelings of loss of control and helplessness. As HCPs working with CLL patients, the first step in responding to their psychosocial distress is to consider how you communicate with them and how you can involve them in their care.

- **Language** – 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.[1,2] Be careful with the use of euphemisms such as, “CLL is the good leukaemia.” Whilst they may be intended to be reassuring, are actually harmful
- **Patient participation and shared decision making** – including the patient in conversations around treatment and decision making enhances personalisation of care, whilst empowering patients to play an active role in composing their cancer care[3–5]
- Learning what are **patients’ values and preferences** – promotes the use of treatment strategy that best fits the patient. Can enhance patient participation in their care whilst minimising distress[3,6]
- **Ask questions**, eg, “What worries you most about your CLL?”

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

1. Arvidsdotter T, et al. *Scand J Caring Sci* 2016;30:687–94; 2. Pollak K, et al. *J Clin Oncol* 2007;25:5748–52; 3. Gentry E, et al. *J Oncol Navig Surviv* 2021;12:182–91; 4. Noteboom EA, et al. *Psycho-Oncology* 2021;30:1663–79; 5. Hack TF, et al. *Psycho-Oncology* 2010;19:606–16; 6 .Marzorati C, et al. *J Multidiscip Healthc* 2017;10:101–6

Psychosocial impact of watch and wait

CLL patients who are on watch and wait report experiencing higher levels of cancer-related distress, despite having what is considered to be a “relatively good prognosis and objectively limited interference in life course.”[1]

This can be for several reasons including:

Delayed or latent processing of their disease – troubles coming to terms with diagnosis

“How can I have cancer? I am so heathy. I just went in for a routine blood test…”

Lack of immediate treatment

“If I have cancer, why I am not getting any treatment? Bob got treatment for his colon cancer right away. What about me?”

Lack of visible disease

“I don’t look like a cancer patient. Am I really ill?”

Lack of information about disease progression

“I don’t know what to do! I feel like I am a sitting duck!”

Living with symptoms

“I was just told to go away and live with it and watch out for symptoms… how can I do that? I didn’t even recognise that I had symptoms in the first place!”

Fears of progression, hypervigilance of perceived physical symptoms

“I know I’m going to need chemotherapy at some point. I just don’t know when. I am so anxious. I inspect myself each day looking to see if I have any new bruises, or if something feels off.”

Feeling forgotten

“I go for my check up a few times a year and that’s it. I’ve been left on my own... with cancer!”

CLL, chronic lymphocytic leukaemia

1. Damen MDC, et al. *Psycho-Oncology* 2022;31:176–84

Psychological impact of active treatment

Common psychological and emotional experiences faced by those on active treatment include:[1]

Delayed or latent processing of their disease

"I can't believe this is/has happened to me."

Adjustment related worry and/or anxiety

"I thought that I was healthy, I had all these plans and now my life is over…"

Increased anxiety related to the treatment regimen

I hope that this is going to work. It's not going to work. I better call my CNS to check to see if it's working."

(New) struggles with physical symptom burden resulting in 'negative' psychological responses

"I am such a failure, I can't even…"

Fears for or perceived loss of future

"I'm a ticking time bomb. I'll never get to see my grandchildren graduate."

Perceived or real psychosocial burden of disease

"I can't work, how am I going to live off UC?"

Relief and sense of control

"I'm doing something about my cancer."

CLL, chronic lymphocytic leukaemia; CNS, clinical nurse specialist; UC, universal credit.

1. Albrecht TA, et al. *J Hosp Palliat Nurs* 2012;14:462–8

Living with (even more) uncertainty

- Established CLL patients are faced with huge amounts of uncertainty in their day-to-day living, from when they will need treatment, to how they will respond to treatment, side effects that might be experienced, and waiting for eventual relapse

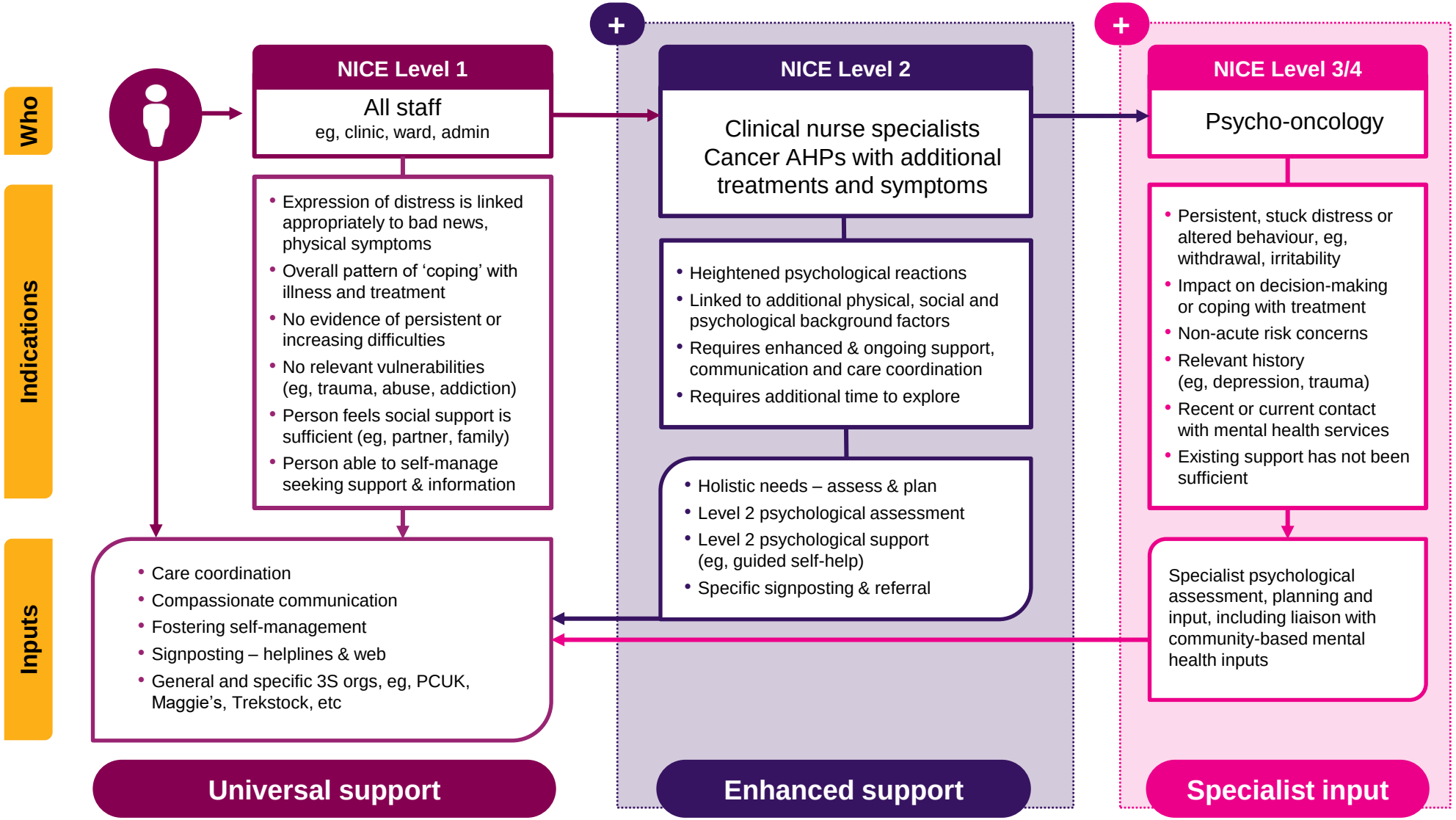
- In the wake of COVID-19, CLL patients have been faced with even more uncertainty as their poor response to vaccines have left this population classed as CEV. As normal social routines are being re-established, people with CLL have reported feeling left behind in an ongoing state of alert, uncertainty and restricted social activity. With many being faced with the difficult task of weighing up the risks vs benefits of staying safe to stay alive vs staying alive but forgoing safety[1]

CEV, clinically extremely vulnerable; CLL, chronic lymphocytic leukaemia

1. Momenimovahed Z, et al. *Front Psychol* 2021; https://doi.org/10.3389/fpsyg.2021.682154

What can **you** do?

Screening for distress and responding to needs



AHP, allied health professionals; PCUK, Pancreatic Cancer UK

King, A. PCUK 2021. Clinical Skills Presentation

Basic psychological skills

Being with patients

Key skills: Being present, compassion, empathy, being non-judgemental, UPR, self-awareness

Active listening

Key skills: Open questions (eg, ‘How are you?’), use silence, listen for emotional content, what is the meaning for the patient (not you), reflecting, summarising, metaphors and analogies, verbal and non-verbal communication

Validation

Key skills: Compassion, UPR, being present, showing you want to understand, being open to and aware of the patient’s context

Normalisation

Key skills: Compassion, empathy, being present with the patient’s lived experience and actively responding without judgement (‘walking a mile in their shoes’)

UPR, unconditional positive regard
Speaker’s own communication

Intermediate psychological skills

Supporting adjustment

Key skills: Understanding what adjustment in cancer looks like

- Emotional turmoil in response to a critical life event
- Complex and multi-faceted
- Threat to life
- Disruption to existing beliefs, assumptions and meanings about health, life, world, future
- Significant losses and changes that need to accommodated
- Disruption to normal routines, life patterns, and roles
- Existential concerns – meaning, purpose, achievements, legacy
- Existential or spiritual distress – fear about death and dying, angst about ‘afterlife’, crisis of faith
- Ongoing process – no neat endpoint

What is needed from our patients to support adjustment:

- Being flexible and varied; changes according to circumstance and needs
- Being idiosyncratic and personal
- Being open to reducing expectations at times

Intermediate psychological skills (continued)

How we can support our patients with coping

Key skills:

- Be **patient-centred** – it's about what works for **them**
- **Look out for current examples** of coping – 'I notice you said that you enjoy spending time with friends – is that a helpful coping strategy for you?'
- Find examples of **previous coping** – 'What worked then?' 'How have you managed this before?', 'What worked well last time you felt so low?'
- **Name and reinforce** the coping – 'I can see that you have a number of resources that seem to be helpful to you when are feeling low…'
- **Reinforce self-belief and a sense of control** in their coping as this reduces distress – 'You mentioned that you only got through last time because of your partner, but I noticed that you did a number of things that seemed helpful – going for walks, getting your sleep, eating well…'
- **Identify protective factors in coping** – "You said having a routine is helpful for you…"