

Psychological support during CAR T

This document is designed to guide those providing Level 2 psychological support (those who have had training in identifying and providing simple psychological self-management skills), for patients undergoing CAR T treatment and their carers/families. This document is not a substitute for appropriately qualified professionals but may be helpful for the multi-disciplinary team working from a psychological perspective.



Why does psychological assessment and support matter?




- The process of CAR T is psychologically demanding; the patient has awareness of potentially significant risks of the treatment, recovery after discharge can take time and may not be fully achieved. Rates of anxiety, depression and PTSD can be significant
- Not everyone will need psychological support, but all patients should know it is available and be screened. Psychological pre-hab may be useful to help people think about what their challenges during treatment may be, and to identify useful strengths and strategies to draw on


Pre-CAR T

Psychosocial assessment should aim to cover:



- Current mood/well-being, social support and coping strategies
- Adjustment to diagnoses and coping with treatment to date
- Psychological history (including any significant depression, anxiety, or other psychiatric diagnoses, substance misuse)
 - A history of significant psychological or psychiatric difficulties, suicidal ideation, or issues that would predict difficulties during the hospital admission would strongly suggest referral to specialist services.
- Understanding of CAR T process, awareness of risks and benefits
- Specific challenges anticipated with the admission e.g. needle phobia, claustrophobia
- Exploration of other stressors (e.g., housing), any learning difficulties, neurodivergence, language or cognitive difficulties

Measures such as [Patient Health Questionnaire \(PHQ\)](#) , [Generalised Anxiety Disorder Assessment \(GAD\)](#)  and [Functional Assessment of Cancer Therapy \(FACT\)](#)  can be useful to ascertain current coping and quality of life but are not a substitute for a clinical interview and do not detect all people who would benefit from further assessment and support.

[Guidelines for the role of psychological specialists in the assessment of adults undergoing Haematopoietic Stem Cell Transplantation.](#) 

These Guidelines are not specifically related to CAR T but you may find these helpful for your practice.



Value of empathy

It can feel tricky to talk about psychological difficulties, especially if we feel we don't know how to help. It's helpful to be aware of your professional competencies. However, a lot of the time there isn't a quick "fix" or solution, the most valuable thing to do is to listen, empathise and validate, which we can all do – and refer on to specialist help if needed.



Self-care

Caring for people having CAR T, and their families, can be demanding, especially if they do not respond well to treatment and become unwell – it's important to take care of yourselves and your colleagues. Many hospitals have links to reflective practice, staff support and informal debriefs.

During CAR T:

Psychosocial support during CAR T treatment



All patients will likely benefit from Level 2 psychological support skills during their admission. Specific concerns may relate to physical symptoms (including CRS and iCANS), isolation and anxiety about the process. Listening and validation, as well as provision of accurate information, is likely to be helpful.

If the patient is reporting significant low mood, hopelessness, or anxiety that is impacting their functioning then this would warrant referral to specialist psychological services.

Family members and carers can also find this stage very difficult, and so assessing their psychological well-being and own source of support is important.

Post CAR T:

Psychosocial support after CAR T treatment



Difficulties that commonly arise after treatment and what might be helpful

Identify	Action	Refer
Fatigue	Normalising, advice on pacing can be helpful, also explore sleep as this can exacerbate fatigue if disrupted.	Direct to resources for improving sleep if appropriate (e.g. Cancer Research UK - Difficulty sleeping).
Cognition	Patients can experience prolonged difficulties with cognition post CAR T – with mild difficulties, normalise and provide advice on strategies to manage (such as using external memory aids, minimising distractions etc). Impairments to cognition may also be a symptom of delayed or recurrent Immune effector cell-neurotoxicity syndrome (ICANS).	If ICANS is suspected, refer on to haematology team. If ongoing or not within normal limits, refer onward (e.g. to neurology/ neuropsychology).
Mood	Reduced activity and isolation can lead to feelings of worthlessness and low mood. It can be helpful to explore ways to reconnect with valued activities.	If mood remains low, refer on for psychological support.
PTSD	PTSD can occur post CAR T, especially if ICU admission was involved, and may occur as nightmares or flashbacks. Helpful to assess, monitor, normalise, and provide information about likely improvement over time (e.g. Worry after Critical Illness).	Refer for specialist psychological treatment if symptoms persist.
Anxiety and worry about relapse	It is common for people to feel anxious after CAR T – for example about relapse or the uncertainty of their situation. Being able to discuss these concerns in a supportive environment is very helpful.	If prolonged and impacting day-to-day life, refer on for psychological support.
Changes in body image, identity, relationships	Patients may not raise issues with body image, intimacy and sexual functioning unless directly asked – doing so sensitively can lead to helpful conversations for the patient.	Refer on for support to psychology or psychosexual services as needed.

Sources of further psychological support for patients and families:

- Hospital based psychology team (may be based within oncology)
- [Maggie's](#)
- Local/diagnosis specific charities e.g. [Lymphoma Action](#) or [Blood cancer UK](#)
- [Anthony Nolan helpline and telephone emotional support](#)
- [Talking Therapies – NHS psychology in the community](#)