

Monitoring yourself or your friend or whanau member after CAR T-Cell Treatment

After you are discharged from hospital following CAR T-cell treatment you should **check your temperature at least twice per day for at least 4 weeks after CAR T-cell treatment**. If you measure a **temperature of 38°C** or higher **OR** you have a **two temperatures above 37.5 °C** (taken an hour apart) please telephone:

- Day ward: 8am – 4.30pm Monday to Friday – XXXX
- Ward 5 North: 4.30pm – 8am and weekends – XXXX

Here is a list of symptoms/ problems for you and your friends or whanau to look out for and what to do about it if they occur:

Problem	Symptoms	What to do
Fever	Feeling hot or cold and shivery	Ring immediately if temperature above 37.5 °C on two separate occasions (taken an hour apart) or if you are feeling unwell. Ring immediately if temperature 38°C or above. Do not take Paracetamol.
Drowsy, confused or headache	Inability to wake up or speak	Ring immediately.
	Difficulty in finding the right words or following simple instructions	Ring immediately
	Confusion	Ring immediately.
	Feeling disorientated or agitated	Ring immediately.
	Severe headache	Ring immediately.
	Dizziness or light headed	Ring if symptoms persist after drinking more, after 4 hours.
Eye Changes	New onset of blurred or double vision	Ring immediately.
Cold Symptoms	Shortness of breath	Ring immediately.
	Cough	Ring within 24 hours
	Sore throat and runny nose	Ring within 24 hours
Bleeding	Blood in vomit or bowel motion	Ring immediately.
	Bleeding nose	Administer first aid measures (eg pinch nose, apply ice pack to nose) and ring immediately
	Blood in the eye	Ring immediately.
	Bruises	Ring within 24 hours.
	Blood in the urine	Ring immediately.
	Vaginal bleeding	Ring within 24 hours
Diarrhoea (liquid motion that is watery and without form)	Stool contains blood or appears to be black, tarry or maroon coloured	Ring immediately
	Increase in amount and/or frequency	Ring within 24 hours
Chest pain	Pain in the mid chest	Ring immediately.

If you have other symptoms that you are concerned about, but which are not listed above please telephone one of the numbers provided above. We recommend that you avoid driving or operating heavy machinery for 8 weeks after receiving CAR T-Cells.

Summary Sheet to give to your doctor if you are unwell after CAR T-Cell treatment

Please note that _____ has received Chimeric Antigen Receptor (CAR) T-Cell therapy on a Phase 1 Clinical Trial at Wellington Hospital on DD/MMM/YYYY.

CAR T-Cell therapy is a type of immunotherapy where patients' immune cells are genetically modified to recognise cancer cells and then re-infused back to them.

There are some specific toxicities that should be considered when assessing patients that have received CAR T-Cell therapy including:

Cytokine Release Syndrome: CRS is triggered when modified immune cells (CAR T-cells) bind to their targets on tumour cells and become activated. This releases inflammatory cytokines, causing fever or a sepsis-like syndrome. It can present with fevers (usually the first sign), rigors, arthralgia, hypotension, headaches or hypoxia. CRS requires prompt recognition and management as complications can be severe and life threatening. CRS usually occurs within 4 weeks of CAR T-Cell administration but can occasionally occur later than this.

If you suspect that this patient may have CRS please immediately contact one of the CAR T-cell treating clinicians at Wellington Hospital (details provided at the bottom of this page).

Immune effector Cell-Associated Neurotoxicity Syndrome (ICANS): ICANS is caused by infiltration of immune cells into, and release of pro-inflammatory cytokines within, the central nervous system. Typical features include expressive and receptive dysphasia, language disturbance, dysgraphia, disorientation and altered level of consciousness. ICANS requires prompt recognition and management as complications can be severe and life threatening. ICANS usually occurs within 4 weeks of CAR T-Cell administration but can occasionally occur later than this.

If you suspect that this patient may have ICANS please immediately contact one of the CAR T-cell treating clinicians, with details provided at the bottom of this page.

Infections : Patients treated with CAR T-cell therapy are likely be immunosuppressed for a long period of time after treatment. There should be a low threshold to recognise and treat infections in this patient.

Cytopenias: Patients treated with CAR T-Cell therapy may have prolonged cytopenias including anaemia and thrombocytopenia which may require blood product transfusion support. Patients may also have neutropenia for a prolonged period of time after CAR T-Cell therapy. *Please do not administer Granulocyte Colony-Stimulating Factor (GCSF) without consulting a CAR T-cell treating clinician at Wellington Hospital, as GCSF may exacerbate CRS.*

Graft versus host disease (GVHD): Patients who have received an allogeneic stem cell transplant prior to CAR T-Cell therapy treatment may be at risk of GVHD after receiving CAR T-cell therapy. If you suspect GVHD in this patient, please contact the bone marrow transplant physician looking after this patient.

CAR T-Cell treating clinicians at Wellington Hospital contact details:

Telephone Wellington Hospital on XXXX and connect via switchboard to:

Consultant Haematologist on-call OR XXXX (Consultant Haematologist and Principal Investigator of Phase 1 CAR T-Cell Trial) **OR** XXXX (Clinical Research Fellow on Phase 1 CAR T-Cell Trial)