



Please delete before use		Letter Name	Haem_EoTS_CAR-T_v1_072024 Version 1.0
Ratified by Pathway Board	July 2024	Created	Circa 2020
Consulted	Haematology CNS teams across GM	Reviewed	July 2024
Contact point for amendments	jennifer.roche8@nhs.net Andrea.webber@nhs.net	Review date	July 2026

Please delete this title and box after reading these instructions.

GM Cancer standard template

CAR T cell Therapy –end of treatment summary

Remove all wording that does not apply to a particular patient in order to personalise it to the individual.

If you need to localise this treatment summary, e.g. job titles do not match those used in your Trust or adding your Trust logo, please do so, but please retain all other information.

Remember to ensure sections don't overrun onto the next page or titles separate from the body of the text before sending.

Font should be Arial size 12

For GP use only: please code this letter as cancer treatment completed:

Snomed code 413737006	Cancer hospital treatment completed (situation)	
8BCF.00	Read	Cancer hospital treatment completed

Please take this with you to any planned or emergency visits to hospital. It could help the doctors and nurses with your care.

Patient Name

Hospital Name

Patient Address

Hospital Address

Date of Birth:

Hospital No:

NHS No:

Dear **[INSERT PATIENT NAME]**

Please find below the summary of your diagnosis and ongoing management plan for your haematological malignancy. A copy of this has also been sent to your GP. This plan is specific to your needs and has been designed to increase your knowledge and wellbeing as you move forward in your cancer care.

Please remember that if you do feel anxious or would like further advice or to talk through a concern or symptom at any time you are welcome to contact your treating team. They are there to support you and know about a wide range of resources and services that have been designed to help you.

Your Key Contact Numbers:

Clinical Nurse Specialist	Name: Contact Number:
Cancer Care Coordinator/ Cancer Support Worker	Name: Contact Number:

Please note that there is no haematology service at the weekend/bank holidays. If you require immediate support, please call NHS 111, or the district nurses (if you have a designated district nurse) for advice. If you feel you need more immediate attention, please attend your local Accident and Emergency Department.

Diagnosis and Treatment to Date:

Diagnosis:	Diffuse Large B Cell Lymphoma	Date of Diagnosis:	
BINET Stage:		Treatment aim:	Curative
Summary of Treatment and relevant dates:			
<i>Please be specific and give full information on detail, dates and intent, avoiding jargon.</i> Fludarabine/Cytarabine/CAR-T cells.			

Prophylactic medication post CAR-T:

Aciclovir 400mg bd continue for a year or until CD4 count >200 cells/uL (which ever happens the latest)
Co-trimoxazole 480mg od continue for a year or until CD4 count >200 cells/uL (which ever happens the latest)
Posaconazole 300mg od continue for 6 months post CAR-T
Ciprofloxacin 500mg bd during period of neutropenia

Alert symptoms that require referral back to specialist team:

If you develop any of the symptoms below in-between your regular clinic appointments, you should contact the department for advice:

- Unexplained weight loss
- Severe night sweats (drenching the bed)
- Swelling of your glands
- Itching
- New unexplained pain- especially bone pain
- Unexplained bruising or bleeding
- Recurring/unresolving infections

Secondary Care Ongoing Management Plan (tests, appointments etc) [Delete AS APPROPRIATE]

- You will then be reviewed in a nurse-led clinic at
- 6 months
- 9 months
- 12 months
- 18 months
- 24 months and then yearly thereafter until 15 years post-infusion

At each clinic visit you will need the following blood tests

- FBC, U & E's, LFT's.
- Vit B12 and Folate.
- Thyroid function.
- Calcium, vit D and phosphate.
- Oestradiol (females)/Testosterone (males).
- LH and FSH.
- Immunoglobulins.
- LDH.
- Ferritin (if transfusion/iron overloaded).
- Pro BNP.
- Lipids Screen.
- Glucose.
- Bone profile.

Other service referrals made: (delete as necessary)

District Nurse

Allied Health Professional (AHP)

Social Worker

Dietician

Clinical Nurse Specialist

Psychologist

Benefits/Advice Service

Other

Possible treatment toxicities and/or late effects from the treatment(s) you have had [Delete AS APPROPRIATE]

You may develop some side effects from your treatment which will require ongoing monitoring. In addition, a few people will have some health problems that can affect them after the treatment has finished. These are called 'late effects'. Your treatment summary is designed to help you and your health care professionals monitor these problems, which in some cases can occur several years after your treatment has ended.

Possible treatment toxicities:

Neurotoxicity and Cytokine Release Syndrome.

Possible late effects:

Prolonged cytopenia's

Hypogammaglobulinemia

Risk of secondary malignancies, neurological and autoimmune diseases

Infection

Your follow up plan is designed individually. You may not need all the tests listed below and your specialist team will recommend which you may require, either as part of your hospital follow up or with your GP.

Late effects screening (please delete where not relevant)

Heart - cardiac monitoring required	Details: Echo at 1 year then 10 years. We recommend that patients cardiovascular risk factors including HbA1c, and lipid profile will be monitored at each clinic appointment.
Lungs – lung function tests required	Details:
Kidneys - eGFR monitoring required	Details:
Thyroid –	Details: TFT monitoring required
Fertility -	Details:
Other organs -	Details: Bone Density (DEXA) scan at 1 year post CAR T infusion

Summary of the consultation about your cancer and future progress

Please avoid medical jargon.

You will need to attend for regular cancer screening (breast, cervical, prostate, bowel as appropriate) and to have regular dental visits.

Please be alert to possibility of new symptoms.

General Information relating to your lifestyle, wellbeing and support needs:

People who have had treatment for haematological cancers are at a higher risk of developing other cancers. This can be related to chemotherapy and radiotherapy but also lifestyle, age and family history can be important. Patients with myeloproliferative neoplasm's are also at increased risk of developing blood clots.

Your specialist team will advise if you need any specific monitoring but in general:

Stopping smoking

If you are a smoker, giving up smoking will improve blood circulation, lower blood pressure, reduce the risk of a stroke, improve your immune system (ability to fight infection), and help to improve your breathing or stop it from getting worse.

Take care in the sun and keep your skin covered or use a high SPF sunscreen.

Looking after yourself in good times and bad

We can all struggle on a day-to-day basis. Dealing with a diagnosis of cancer and undergoing treatments can be particularly challenging and it may add an additional level of complexity in looking after yourself when you are not feeling your best. You may notice that you are more worried and stressed than usual, or you may feel sluggish and low. Adjusting and adapting to everything you have been through can take time, and sometimes it needs a bit of extra support and effort to figure out how to be okay when life is proving challenging.

Exercise and Physical Activity:

It has been proven that engaging in regular exercise or physical activity (ideally 3 times a week) can address feelings of anxiety, experience of fatigue and low mood. It can also improve heart health, muscle strength and maintaining a healthy weight. Even a small amount of physical activity is helpful if you are able. You may need to change the type of activity you do to your specific needs and limitations, so we advise talking to your GP before you start. Please visit www.prehab4cancer.co.uk for more information and helpful resources.

Eating Well:

Eating a healthy balanced diet is an important part of maintaining good health and can help you feel better. This means eating a wide variety of foods in the right amounts and maintaining a healthy body weight. Depending on the surgery you have had on your bowel you may need additional advice and support to achieve this.

Reducing alcohol to within safe limits:

The current UK guidelines to keep health risks to a low level for both men and women are to avoid or not to regularly drink more than 14 units a week (6 pints of average-strength beer or 10 small (125ml) glasses of low-strength wine).

Cancer Screening Programmes

Please partake in national cancer screening as appropriate i.e., mammogram, cervical smears and bowel cancer screening

If you would like more help and advice, please speak to your Haematology Team.

Treatment Summary Completed by:	
Copy sent to GP:	<input type="checkbox"/>
Copy sent to consultant:	<input type="checkbox"/>
Copy sent to other Health Care Professional(s):	[INSERT DETAILS]

Personalised Care and Support Plan <input type="checkbox"/> (attached)	
Prescription Charge exemption certificate <input type="checkbox"/>	Free prescription reminder <input type="checkbox"/>
Health and Wellbeing Information and Support given	See referral advice given on services available
Advice given to apply for benefits assessment if required	Yes/No/Not applicable
Advise entry onto primary care palliative or supportive care register?	Yes/No/Not applicable
SR1 application completed?	Yes/No/Not applicable

Required GP actions (e.g. ongoing medications/ osteoporosis screening, Cancer Care Review Date(s) due)

Please see any request above for late effects monitoring by GP.

Annual flu vaccination

COVID vaccination as per national protocol

Re-vaccination (Vaccination Procedure for Adult Patients Post-Stem Cell Transplant or CAR-T Cell Therapy)

All treatment summaries are subject to review in light of evidence-based changes to clinical protocols and treatment toxicity.

Additional resources and information for primary care staff are available through www.gatewayc.org.uk