



Please delete before use		Letter Name	Haem_EoTS_Myeloproliferative_Neoplasm_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	<u>jennifer.roche8@nhs.net</u> Pathway Board Manager <u>Andrea.webber@nhs.net</u> Personalised Care Manager	Next Review date	July 2026

Please delete this title and box after reading these instructions.

GM Cancer standard template - Myeloproliferative Neoplasm

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:		Date of Diagnosis:	
Summary of Treatment and relevant dates:			
<i>Please be specific and give full information on detail, dates and intent, avoiding jargon.</i>			
Current medications			

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

Your Haematologist will discuss your out-patient follow up with you. You can usually expect to have follow up in the nurse led clinic every 3 months for assessment and with your consultant once a year. You may need to see them less or more frequently dependant on your disease status.

At these appointments you will have some blood tests, an assessment of any new symptoms and a physical examination if indicated.

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

You are now established on your treatment for your myeloproliferative neoplasm (MPN). Your Haematologist is satisfied your disease is now well controlled. You do however require regular monitoring to assess for any signs of disease progression and any side effects from your treatment. 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 to monitor for any of these problems, which in some cases can occur several years after your treatment has ended.

Am I at risk of late effects?

The risk of late effects depends on a number of different things including the types of drugs used, dose of drugs and the number of cycles. It can also be affected by things like your general health and lifestyle, e.g. smoking will put you at more risk of several types of late effects. 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.

Heart - cardiac monitoring required		Details: Patients with a Myeloproliferative disorder are at increased risk of developing both venous and arterial blood clots. We recommend that they have their cardiovascular risk factors managed aggressively irrespective of Q-RISK score. HbA1c and lipid profile will be monitored annually in haematology clinic.
Lungs - Lung function tests required		Details:
Kidneys - eGFR monitoring required		Details: will be monitored every 2-3 months in haematology clinic.
Thyroid – TFT monitoring required		Details:

Fertility		Details:
Other organs -		Details:

High potassium results – If your platelet level is high when testing your blood, this can sometimes give a false high potassium reading. A repeat in a lithium heparin tube is all that is required to confirm a spurious result.

High MCV and MCH – Medications such as hydroxycarbamide can cause an increase in Mean Corpuscular Volume (MCV) and Mean Corpuscular Haemoglobin (MCH). There should be further testing taken before starting medications such as folate, to confirm deficiencies.

Alert Symptoms that will require investigation.

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

- New bone pain or worsening of pain or back pain
- Repeated infections
- Worsening tiredness or breathlessness
- Unexplained bleeding/bruising
- Night sweats
- Leg ulcers
- Weight loss
- Change in appetite

Summary of the consultation about your cancer and future progress

Please avoid medical jargon.

You will need lifelong blood parameter monitoring and the need for treatment will be an ongoing assessment. We have made you aware that this disease carries a small risk of transformation to a more serious bone marrow condition.

Personalised Care for Cancer:

Access to Health and Wellbeing Information and Support is a continuous element of your care. Your Support Plan can be reviewed at any point if you feel your needs have changed. Please contact your Clinical Nurse Specialist for information on support available or if you have any questions or concerns.

Referral/advice given on services available

- | | | | |
|---|--|--|--|
| <input type="checkbox"/> Allied Healthcare Professional | <input type="checkbox"/> Benefits Advice Service | <input type="checkbox"/> Lymphoedema service | <input type="checkbox"/> Complementary Therapist |
| <input type="checkbox"/> Dietitian | <input type="checkbox"/> District Nurse | <input type="checkbox"/> Macmillan Cancer Information & Support Centre | <input type="checkbox"/> Occupational Therapist |
| <input type="checkbox"/> Physical Activity | <input type="checkbox"/> Physiotherapist | <input type="checkbox"/> Sexual Dysfunction | <input type="checkbox"/> Therapist |
| <input type="checkbox"/> Social Worker | <input type="checkbox"/> Speech & Language Therapist | <input type="checkbox"/> Prehab for cancer and Recovery Programme (please continue engaging in rehabilitation) | <input type="checkbox"/> Support Group |
| <input type="checkbox"/> Vocational Rehab | | | |

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 the chemotherapy and radiotherapy you have had, but also a number of lifestyle choices can affect your ongoing health and wellbeing. 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.**

Managing your wellbeing: 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).

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. <ul style="list-style-type: none"> • Annual flu vaccination. • Cancer care review 	

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