

| Please delete before use     |   | Letter<br>Name | Haem_EoTS_AML_HighRiskMDS_v1_072024  Version 1.0 |
|------------------------------|---|----------------|--|
| Ratified by<br>Pathway Board | July 2024                                     | Created        | Circa 2020                                       |
| Consulted                    | Haematology CNS teams across<br>GM            | Reviewed       | July 2024  |
| Contact point for amendments | jennifer.roche8@nhs.net Andrea.webber@nhs.net | Review<br>date | July 2026  |

Please delete this title and box after reading these instructions.

**GM Cancer standard template** 

Acute Myeloid Leukaemia (AML) & High Risk Myelodysplasia (MDS) – Post Treatment

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 h | ospital 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    | <b>Hospital Name</b> |
|-----------------|----------------------|
| 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:**

| Haematology Triage Line   | Contact Number: |
|---------------------------|-----------------|
| Open 24 hours a day       |                 |
| Clinical Nurse Specialist | Name:           |
|                           | Contact Number: |
| Cancer Care Coordinator/  | Name:           |
| Cancer Support Worker     | Contact Number: |

#### **Diagnosis and Treatment to Date:**

| Diagnosis: (delete as appropriate)   | Acute Myeloid Leukaemia<br>(AML) | Date of Diagnosis: |  |  |  |
|--|----------------------------------|--------------------|--|--|--|
|  | High Risk Myelodysplasia (MDS)   |                    |  |  |  |
| Treatment aim:   |                                  |                    |  |  |  |
| Summary of Treatment and relevant dates:   |                                  |                    |  |  |  |
| Please be specific and give full information on detail, dates and intent, avoiding jargon. |                                  |                    |  |  |  |

### Alert symptoms that require referral back to specialist team:

Your Haematologist is satisfied your disease is now well controlled and additional treatment currently is not required. You do however require regular monitoring to assess for any signs of relapse disease.

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

- Unexplained weight loss
- Recurring/unresolving infections
- Unexplained fevers, sweats
- New unexplained pain- especially bone pain

Oral symptoms- gum hypertrophy (excessive growth of the gums) or bleeding

# GP to monitor and refer if appropriate

- Worsening anaemia
- Unexplained bruising or bleeding with low platelet count
- Changes in blood counts

# 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 see your doctor or a member of the team at regular intervals for five years:

- 2-3 monthly in the first year
- 3 monthly in the second year
- 4 monthly in the third year
- 6 monthly in the fourth year
- 12 monthly in the fifth year
- After 5 years disease recurrence is rare and you will be discharged back to your GP.

At these appointments you will have some blood tests undertaken and a physical examination if needed.

Additional investigations may be required if there are signs of recurrence or late effects of your treatment.

In addition, your doctor will advise if you need to continue any medications in the short or long term.

# 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.

#### 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.

#### Late effects screening

| <b>Heart</b> - cardiac monitoring required | <b>Details:</b> We recommend an echocardiogram at 5 years post |
|--|--|
|  | chemotherapy   |

| Other organs -     | Details:                                     |
|--------------------|--|
| Optician -         | Details: Every 1-2 years                     |
| Dentist -          | Details: 6-12 months as per dental follow up |
|                    |  |
| Cancer screening - | Details:                                     |

# Summary of the consultation about your cancer and future progress

Please avoid medical jargon.

You will have routine follow ups and blood checks until you are 5 years post chemotherapy. At that time point you will be discharged from haematology and will require an annual full blood count check in primary care.

# 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 you have had but also a number of lifestyle choices can affect your ongoing health and wellbeing.

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 <a href="www.prehab4cancer.co.uk">www.prehab4cancer.co.uk</a> 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**

Annual flu vaccination

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:                                |                  |
| Copy sent to consultant:                        |                  |
| Copy sent to other Health Care Professional(s): | [INSERT DETAILS] |
|   |                  |

| Personalised Care and Support Plan   (attached)  |   |  |  |  |
|--|---|--|--|--|
| Prescription Charge exemption certificate  | Free prescription reminder                      |  |  |  |
| 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.  |   |  |  |  |

COVID vaccination as per national protocol

Continue regular medications

Shingles (non-live) vaccination. Shingrix is recommended for immunocompromised patients

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