

Patient information factsheet

Ambulatory care for people with acute leukaemia

We have given you this factsheet because you are due to have chemotherapy treatment or follow-up care in an outpatient setting at University Hospital Southampton NHS Foundation Trust (UHS). This is known as ambulatory care.

This factsheet explains more about what ambulatory care is and what it involves in relation to your cancer treatment, so you know what to expect. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What is ambulatory care?

Ambulatory care means having your treatment at the hospital without having to stay in hospital overnight.

This means you may have certain tests and treatments during the day at the haematology day unit in the hospital, such as:

- chemotherapy
- fluids
- transfusions
- monitoring blood tests and observations for several days after chemotherapy

If you feel well after the tests and treatments, and live near to the hospital, you will be able to go home overnight. If you do not live locally, we can arrange for you to stay in a nearby apartment or hotel. If this is the case, we will discuss overnight arrangements with you in more detail.

If appropriate, some people are able to have their treatment delivered via a computerised ambulatory delivery device (CADD) pump. If this is the case for you, it will mean that you can have your chemotherapy safely at home. The pump delivers medication to you continuously or at specific times depending on your needs (as prescribed by your doctor). When you begin your treatment, your nursing team will explain how to use and care for the CADD pump. For more information about using a CADD pump, please read our 'Going home with a CADD pump' patient information leaflet which can be found on our website: www.uhs.nhs.uk/for-patients/patient-information-leaflets

Where will I receive my care?

Our ambulatory care service is based on C7 ward (haematology day case unit), C level, West Wing at Southampton General Hospital.

What are the advantages of ambulatory care?

There are several advantages of ambulatory care, including:

- a reduced number of overnight stays in hospital
- a greater degree of privacy, independence and normality to your treatment experience
- a more comfortable environment in which to rest between daily treatments
- your partner, or a relative or friend can stay with you during your treatment (this is not always possible in hospital)
- fewer interruptions to your daily life (for example, if you are having chemotherapy, we may give you a portable pump which will deliver your treatment wherever you are)

Is ambulatory care suitable for everyone?

Ambulatory care is not suitable for everyone. To be able to stay at home overnight you must:

- live within a 30-minute travel time to Southampton General Hospital at rush hour
- have a local family member or friend available to drive you to the hospital at any time (day or night)
- be able to take your medications independently and record your fluid intake accurately

To stay at a nearby apartment or hotel, you will need to have a friend or relative stay with you.

You must also have the following equipment:

- a thermometer (preferably an electronic one)
- a mobile phone (so we can always contact you)
- a hospital bag that is packed in case of emergencies (this should ideally be cabin-sized or smaller)
- all your daily medications (in their original packaging)

What will happen during the ambulatory care stages?

Before you start your treatment, we will give you a letter containing your daily treatment appointment times, along with a separate patient information factsheet about the intended chemotherapy treatment.

In addition to this, if part of your treatment plan includes you having to stay in hospital (known as a 'planned inpatient admission') we will let you know the date of this in advance. However, if you become unwell before your planned inpatient admission date, you may need to come into hospital earlier. If this is the case, we will discuss this with you.

Each day that you come into hospital for tests and/or treatment during the ambulatory care stages, we will:

- assess your general wellbeing and record your temperature, pulse, blood pressure and weight
- assess you to see if you are experiencing any side effects from the treatment
- perform daily blood tests and/or give you the treatment as prescribed
- let you know how long we expect you to be in hospital for (this will depend on the tests and/or treatment you are having and whether you experience any side effects)

If you feel well after your tests and/or treatment, you will be able to go home. Occasionally, treatments can take longer than expected, so please take this into account when planning your day.

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What are common side effects of chemotherapy?

Chemotherapy can cause some side effects. You may notice these during your treatment or after the course of treatment is complete.

Common side effects include:

- nausea (feeling sick)
- vomiting (being sick)
- diarrhoea or constipation
- fatigue (extreme tiredness)
- hair loss
- infection
- rashes

For more information about the possible side effects, please read the separate chemotherapy patient information factsheet.

If you experience any side effects while receiving treatment, please let us know. We will give you preventative medicines to take to help minimise and manage your symptoms.

It is also important that you let us know if you are running low on any medicines you are taking, so that we can order more for you ahead of time.

What should I do if I become unwell?

Call our acute oncology 24-hour emergency phone line on **023 8120 1345** immediately for advice if you have any concerns about your health or develop any of the following symptoms:

- shivers or hot flushes
- a high temperature (37.5°C or above) or a low temperature (below 36°C)
- persistent nausea, vomiting and/or diarrhoea
- shortness of breath or difficulties with your breathing
- a cough, sore throat or flu-like symptoms
- feeling dizzy or faint
- feeling generally unwell or 'not right'
- redness and pain around your Hickman or PICC line (a narrow flexible plastic tube that is inserted into a vein in the upper arm)

Do not wait until the morning to contact us if you develop any of the symptoms above.

Depending on your symptoms, we may ask you to come to the hospital for an assessment. If this is the case, please remember to bring all of your daily medications (in their original packaging) with you.

Please let us know before coming into hospital if you have any COVID-19 symptoms, such as:

- a continuous cough
- a runny nose
- a loss of taste or smell
- sneezing
- headaches

If you have any of the symptoms above, this may affect where you will need to go for your assessment (this is so that we can minimise the risk of infection spreading to other people).

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After our assessment, we may then need to admit you for closer monitoring and/or additional treatment, such as fluids or antibiotics, that cannot be managed outside of the hospital. Please note that your consultant will remain the same whether you are being treated as an inpatient or as an outpatient.

Will I need any follow-up care?

Most people will have a low blood count for several weeks during their treatment for acute leukaemia due to the effects of the treatment.

When your blood count is at its lowest level (usually 7 to 14 days after starting treatment), we will admit you to our inpatient haematology ward. You will need to stay in hospital until your blood count recovers to a safe level. This is to minimise your risk of infection and to ensure you receive timely supportive care.

Once your blood count has returned to a safe level and your haematologist decides you are well enough, you will be able to go home.

We will let you know the planned date for your next block of treatment. We will also arrange any blood tests or central line care as needed.

How can I help myself?

To help yourself stay well during treatment, you should:

- take your temperature regularly:
 - four times a day when you are **not** neutropenic (being neutropenic is when you have a low number of white blood cells called neutrophils in your blood)
 - every four hours (day and night) when you are neutropenic (for more information about being neutropenic, please see the 'What happens if my blood counts are low?' section below)
- avoid people who have cold symptoms (this also applies to anyone staying with you during your treatment, such as a relative, friend or carer)
- avoid crowded places
- wash your hands regularly
- maintain a high level of personal hygiene (for example, washing or showering)
- take good care of your teeth and gums
- follow the neutropenic diet (for more information about this diet, please visit: www.bloodcancer.org.uk/understanding-blood-cancer/blood-cancer-side-effects/neutropenia/neutropenic-diet)

Frequently asked questions

Will meals be provided?

We will offer you snacks and drinks throughout the day.

Is hospital transport available?

We do not provide hospital transport for everyone. If you think you are entitled to hospital transport, please ask the nurse caring for you.

Will I receive any assistance with car parking fees?

While you receive treatment on the haematology day unit, you are entitled to a subsidised parking ticket. Please speak to a member of our reception team who will be able to arrange this for you.

What happens if my blood counts are low?

When you have low levels of neutrophils (a type of white blood cell) in your blood, your immune system is weakened, making it harder for your body to fight infection. This is called neutropenia or being neutropenic. Your specialist nurse or doctor will provide you with more information about this and explain what symptoms to look out for and what you should and shouldn't do when your blood counts are low. They will also inform you when you are neutropenic and will give you blood products or extra fluids if needed when you come into hospital for treatment.

Contact us

If you have any questions or concerns, please contact us.

For non-urgent queries

Acute haematology clinical nurse specialists

Telephone: **023 8120 6293** (Monday to Friday, 9am to 5pm)

Myeloid clinical nurse specialists

Telephone: **023 8120 2738** (Monday to Friday, 9am to 5pm)

If you are feeling unwell

Call our acute oncology 24-hour emergency phone line for advice on: **023 8120 1345**.

If you need urgent medical attention

- Call **999** immediately and ask for an ambulance.
- State your symptoms and location.
- If you have a carer, relative or friend with you, they should call our acute oncology 24-hour emergency phone line on **023 8120 1345** to let us know.

Useful links

Macmillan Information and Support Centre (Southampton)

Telephone: **023 8120 6037**

Website: www.macmillan.org.uk

Maggie's Southampton (Cancer Support Centre)

Telephone: **023 8212 4549**

Website: www.maggies.org

Macmillan Hampshire Citizens Advice

Telephone: **0344 847 7727**

Email: macmillan.cahampshire@cabnet.org.uk

Blood Cancer UK

Website: www.bloodcancer.org.uk

Leukaemia Care

Website: www.leukaemiacare.org.uk

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MDS UK Patient Support Group

Website: mdspatientsupport.org.uk

Cancer Matters Wessex

Website: cancermatterswessex.nhs.uk

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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