

# Ambulatory care for adult stem cell transplantation patients

---



## Information pack for patients and carers

This booklet explains ambulatory care for stem cell transplantation, to help you decide if it is right for you. It includes the benefits, the day-to-day routine, what happens at night and weekends, and what happens if you become unwell. If you have any questions or concerns, please do not hesitate to talk to the doctors and nurses caring for you.

### Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

**If we don't ask these questions, then please ask us to check.**

Ensuring your safety is our primary concern.

# Contents

- 3 What is ambulatory care?
- 3 What are the benefits of ambulatory care?
- 4 How will I know if ambulatory care is right for me?
- 5 What should I do if I decided ambulatory care is not for me?
- 6 Who will I see on the Ambulatory Care Unit?
- 6 Where is it and when is it open?
- 6 What is the day-to-day routine on the Ambulatory Care Unit?
- 7 Will I be given meals?
- 8 Things you must do during ambulatory care
- 10 What happens at night and over the weekend?
- 12 What happens if I become unwell during ambulatory care?
- 13 What happens if my carer becomes unwell?
- 14 Staying in the Ambulatory Care Hotel
- 15 Ambulatory care contact numbers



## What is ambulatory care?

It is a way of enabling you to have chemotherapy as an outpatient rather than an inpatient. It means you do not need to stay in hospital overnight while you are having your treatment. It is also called day care.

The Stem Cell Transplantation service at King's College Hospital offers it for certain stem cell transplant procedures through our Leukaemia UK Ambulatory Care Unit (Ambulatory Care Unit).

- **If you live far away from King's:** We can provide you and your carer with free accommodation in our Ambulatory Care Hotel. This means that as long as you remain well, you can stay close to us and visit the Ambulatory Care Unit at King's every day for your treatment.
- **If you live within about a 30-minute car drive of King's:** You may be able to stay at home and travel to the Ambulatory Care Unit at King's every day for your treatment.

## What are the benefits of ambulatory care?

- You will be given the same treatment as on the ward but you will have it between 8am and 8pm. This means you can continue your daily life away from the hospital and spend time with friends and family
- You will still have access to expert medical and nursing care 24 hours a day, seven days a week even though you are not staying on a hospital ward.
- You will have a friend, relative or carer with you 24 hours a day throughout your treatment, which is not always possible if you stay in hospital.
- Most patients who have ambulatory care say it gives them a greater sense of normality and independence.



## How will I know if ambulatory care is right for me?

Our priorities are your safety, your well-being and the quality of your care. It is important to find out if this sort of care is suitable for you. Your haematology consultant, our lead ambulatory care consultant and your pre-transplant key worker (BMT Coordinator Clinical Nurse Specialist) will discuss your ambulatory care options with you.

Here we list what you need to be aware of, understand or agree to before you can have your treatment as an ambulatory care patient.

- You must have a named carer with you 24 hours a day. This can be a relative or a good friend. They will stay with you in the Ambulatory Care Hotel or at home at all times.
- You and your carer must sign a consent form.
- You and your carer must speak and write English well.
- You must agree to come to a morning appointment in the Ambulatory Care Unit every day during your treatment for checks and any treatments you needed. Each visit can take several hours.
- You must agree to stay in the Ambulatory Care Hotel or, if you live close to the hospital, you may be able to stay in your own home with your carer. This will be decided by your haematology and transplant consultant.
- You must agree to take your own medication at the times stated.
- You and your carer must be able to take your temperature and contact the Ambulatory Care team on 02032991382 if your temperature goes above 37.8C.
- You and your carer must agree to contact the haematology team if you feel unwell. We will tell you who and when to call.
- You and/or your carer must be able to record your fluid intake (drinks) each day on the 'Daily fluid intake chart' in your Ambulatory care patient record pack and report show this to your nurse in the Ambulatory Care Unit.



- You must understand the importance of looking after your Hickman or PICC line and keeping it clean and free of infection. Your ambulatory care nurse will flush and redress it every week or more often, if necessary.
- You understand the importance of following the advice we give you and the risks of your treatment.
- You must agree to be admitted to our inpatient transplant unit when advised by the haematology doctor.
- You and your carer must be contactable by phone 24 hours a day. You also need to have and be able to use a mobile phone so you can always contact and be contacted by the Ambulatory Care Unit team.
- You understand that you or your carer can ask for you to be admitted to our inpatient transplant unit at any time.
- You and your carer need to be physically well and able to do everyday activities such as washing and dressing.

## What should I do if I decide ambulatory care is not for me?

- **Before you start treatment:** Please let us know as soon as possible if you decide ambulatory care is not for you. We may be able to give you more information about something that is worrying you or reassure you. Ambulatory care is not suitable for everyone and some patients need to have their treatment in hospital even if we offer them ambulatory care.
- **After you have started treatment:** We will admit you to the ward if you decide ambulatory care is not for you or you feel too unwell to be in the Ambulatory Care Hotel or at home. For more information, please read 'What happens if I become unwell during ambulatory care' on page 12.



## Who will I see on the Ambulatory Care Unit?

It is staffed by senior haematology nurses and doctors who have lots of experience of working with chemotherapy and stem cell transplant patients. A member of the medical team will see you here every day to make sure your care and treatment are progressing as expected. They may make some changes to your treatment and will be able to answer any questions you have.

## Where is it and when is it open?

It is on Davidson Ward and it is open from **8am to 8pm** every day, including weekends and bank holidays.

Outside of these hours, you will have full phone access to medical and nursing advice and support. This is available to you 24 hours a day, seven days a week. See page 16 for contact details.

## What is the daily routine on the Ambulatory Care Unit?

You need to come to the Ambulatory Care Unit at a set time every day. We will let you know your daily appointment time when you come for a discussion and information appointment about ambulatory care before you start your treatment.

You will be on the Ambulatory Care Unit for at least two to three hours every day, depending on the treatment you need. Sometimes you may be here for longer if you are having your conditioning chemotherapy or you need intravenous fluid or a blood transfusion. Treatments can sometimes take longer than expected and you may have days where you feel far more tired than usual, so you need to be flexible about your daily plans.

Your daily care depends on your treatment schedule, your blood test results and how you feel generally, so it can vary from day to day. As



a general guide, each day your ambulatory care nurse will:

- take blood tests from your Hickman or PICC line (and sometimes a vein in your arm)
- check your blood pressure, temperature, weight and pulse rate
- check your fluid intake chart which you have been filling in
- ask you if you are having any side effects from the chemotherapy treatment such as sickness or diarrhoea
- let you know if there any changes to your treatment schedule and appointment times. This will help you to plan your meals, rests, sleep and anything you want to do away from the hospital
- check that you are medically safe to return to the Ambulatory Care Hotel or go home. Your safety is of utmost importance.

In addition, each day a haematology doctor will review you once your blood results are ready and prescribe any medication you need, such as antibiotics or a blood or platelet transfusion.

## Will I be given meals?

When you come into the Ambulatory Care Unit each day, we will give you:

- a snack box at lunchtime
- tea and coffee
- free meal vouchers for your use only. These can be used to buy sandwiches and drinks from the M&S and Costa outlets at King's hospital. We do not provide free meals for your carer.

You can leave the hospital grounds to buy refreshments but you will need to pay for these yourself. Please do not eat at outlets where food is kept warm for long periods of time or it is reheated. You must check that the food you are planning to order is freshly prepared.

**Do not drink any alcohol during your treatment.**



## Things you must do during ambulatory care

Here we explain some of the things you need to do to help avoid infection and complications after chemotherapy, especially if your blood counts are low. It is important that you follow these guidelines and the advice the haematology doctors and nurses give you.

**Take your temperature regularly:** Take your temperature at 7am, 2pm, 6pm and 10pm every day and write the results in the 'Home temperature monitoring chart' in your Ambulatory care patient record pack. Take it at other times if you feel unwell or you are hot or very cold.

**Shower often:** Have a shower every day

**Take care of your Hickman/PICC line:** Your Ambulatory Care Nurse usually redresses your line and flushes it once a week when you come into the Ambulatory Care Unit, but they may change it every day if the area around the line is infected or your dressing becomes wet. They will let you know if you need extra line care out of hospital.

**Do regular mouth care:** It is important regularly to rinse your mouth with water to get rid of bits of food. It is also important to use your mouth washes, given to you by the pharmacy four times a day (after meals and before bed) to help reduce your risk of infections after the chemotherapy. Use a soft baby toothbrush so you do not damage your gums.

Chemotherapy can cause your mouth and/or throat to become inflamed, sore and painful. You may even develop mouth ulcers or little blood blisters. This is a condition called mucositis, and it can also make it difficult for you to eat and drink. You may need to take painkillers to ease the discomfort. Your team will prescribe





these for you. You usually start with soluble paracetamol which you can gargle with and then swallow. You may need to move on to stronger painkillers. The effects of the mucositis may mean you need to be admitted to King's so we can look after you more closely.

Your nurse will check your mouth for signs of mucositis at every appointment in the Ambulatory Care Unit.

**Check for bleeding:** Chemotherapy stops your bone marrow working properly, so your platelet count might be much lower than usual. This can cause bleeding gums and nosebleeds and you might bruise very easily. It is important to tell your team if you have any of these symptoms. They will measure your blood count each day. They will give you platelet transfusions if the count is too low or if you have signs of bleeding.

**Check for signs of infection:** You are more likely to get infections when your white blood cell count becomes low. Your nurse will tell you if yours is low. Signs of infection include a general feeling of being unwell, shivering and feeling cold, or feeling hot and having a high temperature. If you have any of these symptoms, you must contact the Ambulatory Care Unit straight away so you can be started on antibiotics and be checked for possible sources of infection.

**If you think you have an infection, seek medical advice from your team at the Ambulatory Care Unit straight away.**

**Take your medications at the right time:** All the medications we give you prevent infections and reduce the side effects of the chemotherapy. It is important that you are able to take your medications at the right times. The Ambulatory Care Unit team will explain your medications and when and how to take them before you start your treatment.



**Ensure you drink enough and eat the right food:** It is very important that you drink at least two litres of fluid a day. This helps to protect your kidneys against the effects of the chemotherapy. If this is not possible, we will give you fluids through your Hickman line when you visit the Ambulatory Care Unit. **Do not drink any alcohol during your treatment.**

You need to eat a 'clean' diet with foods that have low levels of bacteria. We will give you an information booklet about this.

**Be cautious around pets:** If you are staying in your own home and have a pet, do not let them lick your face and always wash your hands after grooming them. Do not come into contact with their urine (pee) or faeces (poo). You cannot have pets staying with you at the Ambulatory Care Hotel.

**Check whether visitors have infections:** Visitors must not come to see you in the Ambulatory Care Hotel or at home if they have any signs of coughs, colds or stomach bugs such as a runny nose, a sore throat, a cough or vomiting and diarrhoea, or they have been in contact with anyone who has any of these.

## **What happens at night and over the weekend?**

The Ambulatory Care Unit is open seven days a week but closes at night.

You may sometimes feel vulnerable during your treatment, especially when you return to the Ambulatory Care Hotel or go home after your treatment has finished for the day. This is why we ensure the following is in place before you start your treatment.



- You must have a carer with you at all times. This does not have to be the same carer for the duration of your treatment. But if you are planning to change carers you must let your team on the Ambulatory Care Unit know so they can ensure the new person is fully informed and aware of their responsibilities.
- Your carer must read this booklet and be aware of the complications of your treatment so that they know what to do if you are unwell or in an emergency. Each of your carers will be asked to come to an education session with the transplant coordinators and to sign a consent form.
- We record your care notes electronically so the haematology team can access all the information they need if your carer calls the ward with a query or if you are feeling unwell.
- Your name is included in the daily handover list that is given to the doctor on call and the nurse in charge for the evening and then the night shift, so there is always someone who is aware of you.

### **You can get medical advice 24/7, as follows:**

- **During the day, 8am to 8pm:** You or your carer must call the Ambulatory Care Unit on **020 3299 1382** and speak either to a doctor or a nurse who will be able to help you.
- **At night, 8pm to 8am:** You or your carer must contact the haematology registrar. Phone switchboard on **020 3299 9000** and ask the operator to contact the haematology Registrar on call.

There is a full list of contact numbers on page 16 of this booklet and in your Ambulatory care patient record pack.



## What happens if I become unwell during ambulatory care?

It is quite normal to feel unwell during your treatment and you may have a range of symptoms. Although these may not always mean you need to be admitted to hospital, you must always let us know if anything new happens or you feel unwell.

As a rough guide, please look out for the following and let us know straight away if you notice any of them:

- shivers and feeling cold or hot flushes
- temperature close to or above 37.8°C
- persistent vomiting and/or diarrhoea
- shortness of breath or difficulties with your breathing
- painful mouth or throat
- signs of bleeding
- unable to eat enough food or drink enough fluid.

**Please remember:** If you or your carer have cold symptoms such as coughing, sneezing or a runny nose, you must phone the Ambulatory Care unit for advice on **020 3299 1382**.

### If you feel unwell or need advice, 24/7

**During the day, 8am to 8pm:** Phone the Ambulatory Care Unit on **020 3299 1382** and speak to a doctor or nurse.

**At night, 8pm to 8am:** Contact the haematology registrar on call. Phone switchboard on **020 3299 9000** and ask the operator to contact the haematology registrar on call. This doctor will give you advice or arrange for you to be admitted as an inpatient.

If you are not well enough to travel to King's College Hospital by



car, or you need life-saving attention, **call 999 immediately** for an ambulance to bring you to the hospital.

### **What is an emergency?**

It is any urgent situation where you need life-saving medical attention

**If you need life-saving care, you or your carer must call 999**

### **What happens if my carer becomes unwell?**

You must let us know straight away if this happens. Your carer may not be able to help you and if they have an infection this makes you more likely to become unwell.

We will ask you to arrange another carer. If this is not possible, we will admit you to the hospital so your carer can go home to recover.

### **Staying in the Ambulatory Care Hotel**

Remember that you may be admitted to hospital at any time so you need to make sure that your luggage can be taken to King's by you or your carer. If you are admitted to the hospital, your carer must check out of the hotel within 24 hours so your room can be used by another patient.

### **Where is the Ambulatory Care Hotel?**

When you come to the Ambulatory Care Unit on the first day of treatment, your nurse will confirm the hotel where you and your carer will stay. They will give you the address and explain how to get there before you leave the unit.

### **When is check-in/check-out?**

Check-in is at 2pm and check-out is at 11am.



## **What do I need to bring with me?**

- Day clothes
- Nightwear
- Toiletries, including a soft or baby toothbrush
- Mobile phone and charger for personal calls
- Thermometer that measures in degrees Celsius
- Books, magazines, games and so on

## **Hotel and room facilities**

The hotel has a reception desk and free Wi-Fi. Your room includes a shower and toilet, a TV, hanging space, a desk and chair, armchairs and a small table, tea and coffee-making facilities, and a hairdryer.

## **Travelling to King's by car**

The hotel provides a car park for pick-up and drop-off only. It is not available for longer stays. It may charge for use of the car park. Parking is limited at King's and we are unable to provide free parking to our patients.

## **Travelling to King's by public transport**

This is the best way of getting to the hospital. Your hotel will be within easy reach of a bus route which stops directly outside King's. We will let you know the bus route when we confirm your hotel. We will give you an Oyster card which enables you to use all London Transport services. It will be preloaded with £5 credit to enable you to make at least three bus journeys before you need top it up. You can top it up at any newsagent. We cannot give you more than one Oyster card and you must return it to us if you are/when you are admitted to the inpatient ward. You can also use contactless debit and credit cards to pay for travel by public transport.



## **Travelling to King's by taxi**

You may wish to use a taxi for your journeys to and from the hospital although this will be expensive. You can order taxis from a phone in the hospital main entrance. The hotel reception staff will be able to book local taxis, if needed.

## **Can I smoke in the hotel?**

You cannot smoke anywhere in the Ambulatory Care Hotel. If do smoke on the premises, you may not be able to complete your treatment as an outpatient.

## **Can I keep pets with me?**

You cannot have pets staying with you at the Ambulatory Care Hotel.

## **Can I have visitors?**

You can have visitors, including children, but they cannot stay with you. They must not visit if they have any signs of coughs, colds or stomach bugs such as a runny nose, a sore throat, a cough or vomiting and diarrhoea, or they have been in contact with anyone who has these.

## **How often will my room be cleaned?**

It will be cleaned and your bed linen changed every day. Please tell the hotel reception team if your bedding is soiled.

## **Do I get any meals?**

Your breakfast and your carer's is included in your stay at the hotel. The hotel has a restaurant serving food all day, but this is not included in your stay. If you decide to have meals away from the hotel, please do not eat at outlets where food is kept warm for long periods of time or it is reheated. You must check that the food you are planning to order is freshly prepared. Do not drink any alcohol during your treatment.



## Ambulatory care contact numbers

You and your carer can use these numbers for help, advice and assistance.

### Daytime, 8am-8pm

- Ambulatory Care Unit: tel: 020 3299 1382

### Out of hours, 8pm to 8am

- On-call haematology registrar, tel: King's College Hospital switchboard on 020 3299 9000 and ask for the haematology registrar on call
- Davidson Ward, tel: 020 3299 3306/4336/1445
- Derek Mitchell Unit, tel: 020 3299 3611

### 24/7

- Emergency, tel: 999









## **PALS**

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.PALS@nhs.net**

You can also contact us by using our online form at

**[www.kch.nhs.uk/contact/pals](http://www.kch.nhs.uk/contact/pals)**

**If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.**



