

Ambulatory care for adult stem cell transplantation patients



Education pack for patients and carers

This booklet lists the requirements that you and your carer must meet to ensure that your ambulatory care is as safe as possible. If there is any other information about you that you think is important, please talk to your transplant coordinator. The booklet also explains how to do certain things such as record your temperature and fluid intake and complete your self-medication chart.

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.

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Requirements for having ambulatory care

You must be:

- 18 or over
- fluent in spoken and written English
- able to care for yourself and live independently. This means you are fully active and able to do normal daily activities without any restrictions or, if you cannot do strenuous activities, you must be independently mobile and able to do light work such as light housework, office work and so on.
- a non-smoker
- willing to comply with the requirements of ambulatory care
- able to take medications by mouth.

You must not have:

- any active or presumed fungal or bacterial infections.

You must have:

- adequate organ function including creatinine clearance (>30ml/min)
- an adequate increase in your platelet count with transfusions
- a mobile phone and be able to use it
- a designated adult carer.

Your carer must be:

- willing and capable of supporting you during ambulatory care.

You and your carer must:

- successfully complete the ambulatory supportive care education programme.

Using a thermometer

- How to take your temperature
- How to record your temperature
- Normal and abnormal temperatures



Recording fluid intake

You should aim to drink between 2 litres and 3 litres of fluid every 24 hours. This includes waters, tea, coffee, fruit juice, fizzy drinks and so on.

You must not drink any alcohol.

If you cannot drink enough fluids, we may need to give you extra fluids intravenously when you come to the Ambulatory Care Unit.

- What to record
- When to record
- How to record

Record all drinks you have and roughly how much of each.

Write this down as close to the time you have the drinks so you do not forget.

Also note when you have been to the toilet to pee/pass urine.

Example;

Date	Time	Fluid type	Volume (ml)	Comment
03.04.17	0830	Coffee	200	
03.04.17	1030	Cola	330	Can of cola
03.04.17	1200	_____	_____	Peed/passed urine



Filling in your self-medication chart

It is very important that you keep an exact record of all the medicines you should be taking. This includes any medicines that you were taking before your transplant as well as the new medicines that you have been prescribed.

You must take every prescribed medication at the correct time and note this on your self-medication chart straight away. This medication chart will be provided by the pharmacist.

You must bring your self-medication chart with you every time you come to the Ambulatory Care Unit so your nurse can check you are taking your medicines correctly.

If you find it hard to take your medicines, please talk to your nurse. Your self-medication chart will have the name of each drug and the time that you need to take it.

Once you have taken each medicine, put your initial in the box for that date and time, and the time you took it in the box next to that.

Understanding and reporting side-effects and symptoms

You can have a lot of different symptoms. It is important that you understand these and let your ambulatory care team know if something new is happening to you. Read the 'Symptom tracker for patients and carers' for more information.

- Fever
- Pain
- Nausea and vomiting
- Diarrhoea
- Constipation



- Malnutrition and weight loss
- Skin problems and rashes
- Problems passing urine
- Fatigue
- Breathlessness

Adherence questionnaire

The scale below is used to work out how you feel about taking medications. Your nurse will go through this with you.

1. Do you sometimes forget to take your medicine?	No = 1, Yes = 0	
2. People sometimes miss taking their medicine for reasons other than forgetting. Over the past 2 weeks, were there any days when you did not take your medicine?	No = 1, Yes = 0	
3. Have you ever cut back or stopped taking your medicine without telling your doctor because you felt worse when you took it?	No = 1, Yes = 0	
4. When you travel or leave home, do you sometimes forget to bring your medicine?	No = 1, Yes = 0	
5. Did you take all your medicine yesterday?	No = 1, Yes = 0	
6. When you feel like your symptoms are under control, do you sometimes stop taking your medicine?	No = 1, Yes = 0	
7. Taking medicine every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?	No = 1, Yes = 0	
8. How often do you have difficulty remembering to take all your medicine? (A) Never/rarely (B) Once in a while (C) Sometimes (D) Usually (E) All of the time	A = 4, B = 3, C = 2, D = 1, E = 0	Divide score by 3
Score: <6 = Low adherence; 6-<8 = Medium adherence; 8 = High adherence		



Checklist

Your ambulatory care nurse will go through this checklist with you and your carer.

It is important to talk to your nurse if there is anything that you do not understand or are concerned about.

	Patient	Carer	CNS/Keyworker
Using a thermometer			
<ul style="list-style-type: none"> • Taking your temperature • Recording your temperature • Normal and abnormal temperatures 			
Recording fluid intake			
<ul style="list-style-type: none"> • What to record • When to record • How to record 			
Completing self-medication chart			
Comment			
• Understanding and reporting side effects and symptoms			
<ul style="list-style-type: none"> • Pain • Nausea and vomiting • Diarrhoea • Constipation • Malnutrition • Skin problems • Problems passing urine • Fatigue • Breathlessness 			
Adherence questionnaire			
Comment			



Questions

Use this section if you have any questions for your doctors or nurses or to make extra notes to remind you.

Ambulatory care contacts

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 Hambleden 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

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



