

Ambulatory care for adult stem cell transplantation patients



Symptom checker for patients and carers

This booklet explains a range of symptoms that you might have while having your treatment at King's. It includes a checklist for each symptom to help you describe how you are feeling or what is happening. It also tells you when and how to seek advice.

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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Pain

Pain is an uncomfortable and unpleasant physical and emotional feeling that happens when tissues in your body are damaged. It can be short-term (acute) or long-term (chronic). It can last a long time and feel very strong and intense.

It is quite common to have mouth pain when you are given high doses of chemotherapy before a stem cell transplant. This is caused by a condition called mucositis, which is a side effect of the treatment. It can be mild, moderate or severe.

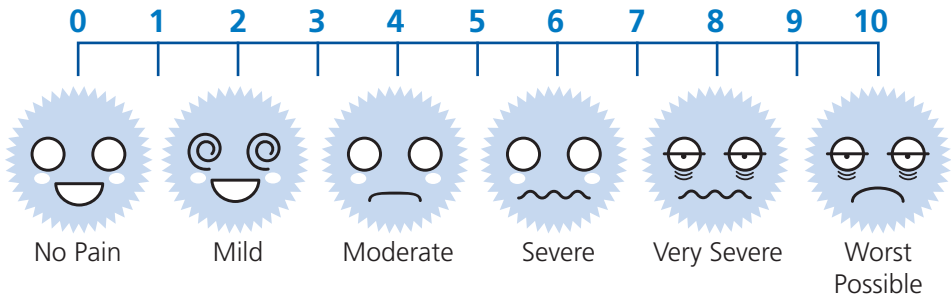
You can also have pain in other places, too. For example, you can have headaches or bony aches and pains during the G-CSF injections used to help the new stem cells to grow.

It is important to tell your team on the Ambulatory Care Unit if you have any pain or discomfort so they can help you.

Common words used to talk about pain:

- ache
- discomfort
- soreness.

Your team may ask you questions about your pain to work out what is causing it and the best ways of easing it. You can use the pain scale below to help you describe your pain.



Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19.

- the pain is sudden and acute
- you have a sudden increase in previous pain levels
- you have weakness with the pain.

Pain checklist

- Where is the pain?
 - One area or more than one area?
 - Does it start in one place and spread over time?
 - Is it an old pain or a new one?
- Is the pain there all the time?
- Is it near the surface of your body or deep inside?
- Does the pain last for seconds, minutes or hours?
- How long has the pain been there?
- What words would you use to describe the pain?
 - Aching, annoying, biting, blinding, burning, constant, cramping, dull, intermittent (comes and goes), nagging, niggling, pins and needles, stabbing, throbbing.
- Can you score your pain on a scale of 0-10? 0 = no pain and 10 = the worst pain imaginable.
- Have you taken any medication?
 - What and how often?
 - Did it work and, if so, for how long?
- Does anything other than medication make it better?
 - Lying down
 - Sitting down
 - Heat or cold
 - Distraction (music, tv, reading)
- Does anything make it worse?
 - Moving or walking



Sitting/ standing/ lying down

Eating

Time of day (when)

- Does it keep you awake at night?
- Does it affect your daily life?
- Do you have any other symptoms with the pain?

Nausea and/or vomiting

Constipation

Numbness/ tingling

Inability to pass urine

Breathlessness

Nausea and vomiting

Nausea is an unpleasant feeling that ranges from a lack of appetite and indigestion to vomiting.

Vomiting is when the contents of your stomach are forced up and through your mouth; it can include retching without actually bringing up anything.

Common words used to describe nausea and vomiting:

- sick to my stomach
- pressure in my stomach
- no appetite
- feels like flu
- retching
- gagging
- indigestion.

Your team may ask you questions about your appetite, nausea and vomiting to work out if it is a problem, how bad it is and best ways of easing it.



Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if:

- your vomit has blood in it or it looks like ground coffee
- you have any tummy pain or a headache
- you feel weak, dizzy, confused or drowsy
- you have not been able to eat for 24 hours.

Nausea and vomiting checklist

- Are you having or have you had chemotherapy?
- Are you having or have you had radiotherapy?
- Nausea:
 - When did it start and how long has it gone on for?
 - How often do you get it and how strong is the feeling?
 - Does anything make it worse?
 - Does anything make it better?
- Vomiting:
 - Colour?
 - How much?
 - How often?
- Are you taking anti-sickness medication?
- Does anything make it better?
- Does anything make it worse?
- What food have you eaten in the past 24 hours?
- What fluids have you drunk in the past 24 hours?
- Is your tummy swollen?
- Are you passing urine (peeing) normally?
- Are you opening your bowels (passing stools/poo)?
- Do you feel?
 - Dehydrated
 - Feverish
 - Weak



Diarrhoea

Diarrhoea is where you do frequent runny or liquid poo. You often feel discomfort, need to go to the loo urgently and you **may have incontinence** might not always make it in time.

Common words used to describe diarrhoea:

- loose stool
- loose bowel motions
- runs
- squits
- trots
- funny tummy

Your team may ask you questions about your diarrhoea to work out if it is a problem, how bad it is and the best way of easing it. You can use the Bristol Stool Chart on page 19 to help describe what your poo looks like.

Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if you:

- have pain in your tummy or rectum (bottom)
- have to poo three – five times a day
- have mucous in your poo
- have nausea and vomiting
- are unable to drink
- have blood in your poo
- are dehydrated.



Diarrhoea checklist

- When did your diarrhoea start?
- What does it look like?
 - How runny is it?
 - What colour is it?
 - How much poo are you doing?
- Is there any mucus or blood in your poo?
- Do you have any tummy cramps?
- How often do you normally have a poo?
- Have you changed your diet or eating pattern?
- Have you started taking any antibiotics recently?
- How much are you managing to drink?
- What sort of fluid are you drinking?
- What colour is your pee?

Constipation

Constipation is where your poo is hard and dry, you cannot go very often and you usually have to strain to do a poo.

Common words used to describe constipation:

- bloated
- bowel problems
- bugged up.

Your team may ask you questions about your constipation to work out if it is a problem, how bad it is and best ways of easing it. You can use the Bristol Stool Chart on page 9 to help describe what your poo looks like.








Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if you:



- have tummy pain
- are vomiting
- have a swollen tummy.

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

Constipation checklist

- When did you last do a poo?
- Was it hard like nuts?
- How often do you normally have a poo?
- What colour was/is your poo?



Constipation checklist *continued*

- Are you passing wind (farting)?
- Are you feeling nauseous?
- Have you been vomiting?
- How much fluid have you been drinking?
- Are you eating at the moment?
- Are you moving around?
- What medications are you taking?

Strong painkillers

Chemotherapy

Anti-sickness medicines

Fatigue

Fatigue is an unusual sense of tiredness that you cannot shake off and that makes it hard to do – or stops you from doing – your usual activities.

Common words used to describe fatigue:

- tired
- worn out
- weak
- wasted
- exhausted
- no energy
- cannot concentrate on anything

Your team may ask you questions about your fatigue to work out if it is a problem, how bad it is and best ways of easing it. The scale at the bottom of this page may help you to talk about your fatigue.

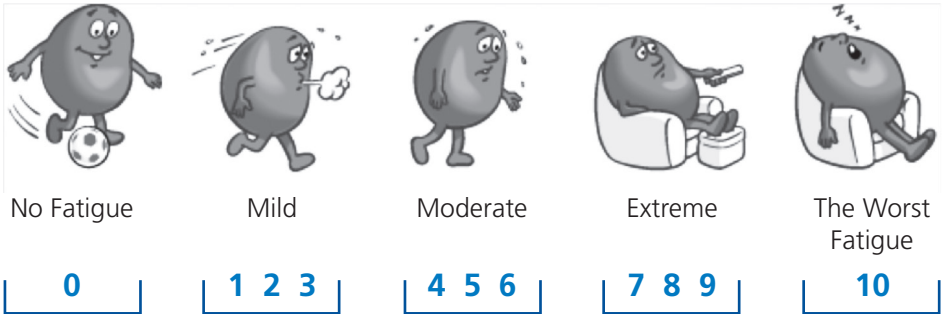
Advice

Seek advice **immediately** from your team on the Ambulatory Care



Unit contact number on page 19 if you:

- have chest pain
- have a fast heartbeat
- suddenly feel fatigued
- feel breathless when you are resting
- think you are bleeding
- score more than 6 on a scale of 0 to 10 on the fatigue chart below.



Fatigue checklist

- When did your fatigue start and how long has it lasted?
- Can you still do normal activities?
 - Bathing and showering
 - Cooking
 - Walking
- Are you still able to eat and drink normally and regularly?
- Are you getting enough sleep?
- Do you feel rested after a night's sleep?
- How much time have you spent in bed in the past 24 hours?
 - Has this changed yesterday?
- Does anything make the fatigue better; if so, what?
- Are you able to concentrate during a conversation?
- Are you able speak and make decisions?
- Are you able to remember things?



Fatigue checklist *continued*

- Do you feel sad, anxious or distressed?
- Are you feeling more emotional than usual?
- Can you score your fatigue on a scale of 0-10, where 0 = no problem and 10 = total exhaustion?
- Do you have any other symptoms?
 - Signs of bleeding
 - Feeling cold
 - Feeling faint
 - Dizziness
 - Breathlessness when resting or active
 - Rapid heart rate
 - Chest pain
 - 'Heavy' legs
 - Nausea and/or vomiting

Fever

Fever is where you have a temperature of 37.8°C or more, or you are shivery and shaky with or without a high temperature.

It is important to contact your team on the Ambulatory Care Unit immediately if your temperature is 37.8°C or more. If it is, do not take any paracetamol or medication with paracetamol in it.

Common words used to describe fever:

- burning up
- sweats
- shivers
- aching
- rigors.

Your team may ask you questions about your temperature, but they



are likely to tell you to go straight to the hospital so you can have treatment without delay.

Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if you:

- have a temperature of 37.8°C or above one or more times
- have a temperature of less than 37.8°C but have shivers or rigors
- feel unwell with or without a high temperature.

Skin reactions

Skin reactions are where you have a change in your skin colour or texture, or it becomes damaged in some way.

Common words used to describe skin reactions:

- rash
- blisters
- lesions
- dermatitis
- cracking
- peeling
- burns
- pimples
- inflammation
- redness
- itchy
- hot.

Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if you:

- have been in contact with anyone with an infection
- notice any rashes, swellings or pain.



Skin reactions checklist

- When did you first become concerned about your skin?
- What colour is it?
- Is there any swelling?
- Is there any itching?
- Does it feel warm to the touch?
- Is it bumpy or smooth?
- Is there any pain or tenderness?
- Is there any smell?
- Has this been exposed to the sun?
- Do you have any fever?
- Do you have any known allergies?
- Have you had anything new or different to eat or drink?
- Have you used any new skin care or cleaning products?
- Have you recently been in contact with anyone with an infection?

Urine problem symptoms

There are several different problems you can have when you pee:

- dysuria – where it is painful or difficult to pee
- nocturia – where you do a lot of pee or pee often at night
- haematuria – where you pass blood in your pee.

Common words when talking about problems peeing:

- hurts to pee
- peeing all the time
- burning when I pee
- feeling like I need to pee but cannot
- feels like I cannot empty my bladder properly.



Advice

Seek advice immediately from your team on the Ambulatory Care Unit contact number on page 19 if you:

- cannot pee
- you are concerned about the how often you pee or what the pee looks like
- you see blood in your pee.

Urine problem symptom checklist

- When did your peeing problem start?
- How often do you usually pee and how much do you do?
- What is it like now?
 - How often?
 - Do you need to go urgently?
 - Is it difficult to go or do you find you stop and start while peeing?
- When did you last pee?
- What did it look like?
 - Colour?
 - Clear or cloudy?
 - Any blood or mucous?
- How much pee did you do last time?
- Do you have any pain?
 - Where is it?
 - What sort of pain is it?
 - How long have you had it?
- Have you noticed anything else?
 - Fever
 - Tiredness/fatigue
 - Dizziness
- How much have you drunk in the past 24 hours?
- Have you had a urine infection before?



Breathlessness

Breathlessness or shortness of breath is where you have an uncomfortable and unpleasant awareness of your breathing or your need to breathe

Common words used to describe breathlessness:

- hard to breathe
- feeling smothered
- tightness in the chest
- need more air
- cannot get breath.

Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if you:

- feel distressed when breathing
- have chest pain.

Breathlessness checklist

- When did your breathlessness start?
- Do you have any known breathing conditions such as asthma or emphysema?
- Are you taking any medication for breathing?
- Describe your breathlessness.
 - What does it feel like?
 - Is it painful to breathe?
- Does anything make it worse?
 - Speaking
 - Walking up a slight incline
 - Walking in level ground
 - Activity
 - Climbing stairs



Lying down
The weather

- Does anything make it better?
- Do you have a cough?
- Are you coughing any spit/phlegm?
- If you are, what colour is it?

Malnutrition and weight loss

Malnutrition is where you develop a medical condition because you do not get enough nutrients from your diet (your food and drink) to keep you healthy. It can be caused by what you eat and drink not containing the right nutrients (unbalanced diet), problems with your digestion, problems with your body not absorbing the nutrients, or other medical conditions.

If you lose lots of weight over a short period of time you might need help with what you eat and drink (nutritional support) to help your treatment be successful.

Common words used to describe malnutrition:

- do not feel like eating
- cannot stop losing weight
- feel weak all the time
- too tired to eat
- lost muscles.

Advice

Seek advice **immediately** from your team on the Ambulatory Care Unit contact number on page 19 if you:

- have not eaten or drunk any fluid in the past 24 hours
- feel dehydrated
- keep vomiting



- cannot swallow anything because of pain
- feel too weak to do anything for yourself.

Malnutrition and weight loss checklist

- Have you lost weight?
How much?
Over how long a time?
- Are you eating less?
- What are you eating?
What sort of food – how much and how often?
Are you taking any nutritional supplements?
- Do you have any nausea or vomiting?
- Do you have any constipation or diarrhoea?
- Do you have a sore mouth, mucositis or altered taste?
- Do you feel dehydrated?
Are you more thirsty than usual?
Is your mouth dry?
Are you peeing less than usual?
Do you feel weak?
Do you feel dizzy?
Any confusion?
- Do you feel low in mood?
Is this affecting your appetite?
- Is pain affecting your appetite?
Are you taking pain medication?
- Are you able to do your normal activities?
- Has your muscle strength changed?



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 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.





