

Guidance for holiday dialysis

Department of Renal Medicine

Patient Information Leaflet

Introduction

There will be times when you may wish to have dialysis away from your normal hospital so that you can have a holiday, attend college or university, or go away for work-related reasons. This is known as dialysis away from base (DAFB). Base is the place where you normally have your dialysis.

This leaflet contains guidance on this and includes information on:

- What you need to do if you want DAFB
- Who can have DAFB
- The costs of DAFB
- What the risks of DAFB are
- What happens with the transplant list while you are away
- The forms to complete if you want DAFB

This guidance is for people living in England, or who are registered with an English GP, who are having some form of dialysis treatment. If you do not live in England, or you are registered with a GP outside England, you will need to ask your renal team how to organise your dialysis away from base.

Who can have DAFB?

People wishing to have DAFB need to:

- Have been having haemodialysis for at least six months
- Have the approval of their renal consultant
- Have no infections or open wounds

DAFB may not be approved if:

- The location is not suitable, for example, if the healthcare standards do not match those in the UK
- You have not been attending for regular dialysis
- Your health is getting worse
- Not enough notice is given

Will I have to pay for DAFB?

You do not need to pay for DAFB in an NHS unit in the UK, or in some private units in the UK with which the NHS has an agreement to pay. However you will, of course, have to pay for your travel and accommodation costs. If the unit is private, you will need to check that they have an agreement with the NHS and that the NHS will pay towards the cost of the dialysis.

For outside the UK, the rules on whether you have to pay are different depending on where you travel.

Europe

The European Health Insurance Card (EHIC) card allows you to access state-provided healthcare during a temporary stay in all European Economic Area (EEA) countries or Switzerland. The EHIC is available free of charge at the following website:

<https://www.ehic.org.uk/Internet/startApplication.do>

or by phone on 0300 330 1350.

However, please be aware that in some countries, for example France and Switzerland, **you will need to pay some of the cost of your holiday dialysis.**

It is therefore important to check this before you confirm the booking for your stay. You may need to pay the costs upfront and claim them back.

The following website will have up to date information:

<http://www.nhs.uk/nhsengland/healthcareabroad/plannedtreatment/pages/introduction.aspx>

If the renal unit you will be using within the EEA is not a state-provided renal unit, you will need to pay for the dialysis treatment sessions yourself. However if this is the case, you can apply before you go away, under a European directive known as Article 56, for a partial or full refund from the Cross Border team of NHS England at:

england.europeanhealthcare@nhs.net

Applying before you book your holiday will give you information on the amount that will be refunded. However, it is likely that the amount will not cover the full cost of the holiday dialysis.

This means you will need to pay the rest of the costs yourself, as the cost of the dialysis will probably be more than the NHS will refund you. You will need to forward the original receipts and proof of payment when you come back, in order to receive the refund.

Outside Europe

There are a number of countries outside Europe with which the UK has an exchange (reciprocal) healthcare agreement. Please check the following website link for these countries:

<http://www.nhs.uk/NHSEngland/Healthcareabroad/countryguide/NonEEACountries/Pages/Non-EEACountries.aspx>

Treatment must be arranged in advance, at a state dialysis centre. In most cases, the treatment will either be free or at a reduced cost. However, you will need to check if there are any additional charges before you confirm your booking.

For dialysis in countries without a reciprocal healthcare agreement, you will need to pay the full cost of the treatment.

Do I need travel insurance?

Yes. If you are away from the UK, it is very important that you have comprehensive travel and medical insurance to cover you. The potential charges that you would have to pay, if you need any additional medical treatment while you are away, could easily run into thousands of pounds.

It is important to check the insurance policy small print for any exclusions that may apply for health care abroad.

How do I arrange DAFB?

Please note that it is not the responsibility of the Trust to arrange your travel and accommodation. Staff will help make dialysis arrangements and provide medical details only.

You will need to check that there is a dialysis unit where you wish to travel that will accept you **before** making further arrangements. The Trust is not liable for cancellation costs because dialysis was not arranged before bookings were made.

Many units based at holiday resorts are booked up well in advance and may not be able to accept your requested dates.

We cannot request any specific times for your dialysis sessions. These are allocated by the unit you are travelling to. For this reason, your dialysis sessions may be at different times or days to those you are used to.

If you cancel your trip, you must let staff know immediately in the dialysis unit where you were going so that your dialysis booking can be cancelled. In some cases, there is a cancellation charge which you will have to pay.

Whilst it does take some planning for DAFB to take place, the renal team will be able to help you with organising it. There are some useful websites and telephone numbers at the end of this paper that will help.

It is best to give as much notice as possible before you plan to go away. This is usually a minimum of four weeks if you are travelling within the UK, and three months outside the UK.

Due to the risk of passport-issuing delays, it is also a good idea to make sure you have all the relevant travel documents needed for travelling abroad in plenty of time, before arranging visits to other countries.

DAFB outside of EEA or reciprocal countries may not be regulated by a country's health policy, and you will need to make checks about the quality of the service. Before you book dialysis, you will need to check, for example:

- the type of dialysis service provided
- the number of doctors and nursing staff
- the machines and whether back up machines are provided
- the experience of the renal team in providing dialysis

For some destinations, it may be wise to take some of the items used in dialysis with you, such as dressings and dialysers. This needs to be agreed with your usual renal unit. If you take your repeat prescription form with you, this will prove that the medications and injections you are carrying are for your use.

Transplant list

Please remember to inform your transplant coordinators at the transplant centre of the dates you will be away and your contact details.

What are the risks of DAFB?

The nature of dialysis treatment makes people vulnerable to getting blood-borne viral infections such as HIV, hepatitis B and C. There is a very low rate of infections among patients in UK dialysis units, as the high level of infection control procedures means the risk of transmission is minimised.

However, in some countries the risks are much higher because the infections are more common, facilities are limited and/or infection controls are not so strict.

If you are planning to travel abroad, you will need to be aware of these possible risks. Special precautions may also be needed when you get back, such as testing, monitoring and having dialysis in isolation for some weeks.

What tests do I need before my trip?

Every dialysis unit will require blood tests for the blood-borne viruses:

- Hepatitis B
- Hepatitis C
- HIV

Note: some dialysis units will not accept people whose blood tests show that they have a blood-borne virus.

Dialysis units may also need:

- Negative swab results for MRSA screening
- Negative tests for an antibiotic-resistant bacteria called VRE. The test for this is a rectal swab. This means a swab is taken from a person's back passage. Your nurse or doctor will take the swab and send it to the laboratory for analysis.

What else will the DAFB provider need?

The unit you are going to will require all or some of the following:

- Personal details such as your name, address, age, contact number, next-of-kin contact details, GP details
- Information about your medical condition, medications, your consultant's name and your recent medical history
- Results from an ECG test
- A chest X-Ray

We will ask for your consent to us sending this information to the alternative dialysis unit. If you do not consent to us releasing this information, you will not be able to go there.

What do I need to take when I go?

- Your normal medications.
- EPO – if you are taking this drug, make sure you purchase a small cool bag to keep the injections cool while you are travelling.
- Dialysers – if the unit you are travelling to is in a country where you must bring your own dialysers, you are responsible for keeping them safe while travelling. We will give you one for each session, plus one spare.

Will I get transport to and from the DAFB unit?

You will need to check that there is transport available at the unit that you are planning to use, for the times that you will be having dialysis.

If you meet the eligibility criteria for having transport provided to and from dialysis sessions at your home unit, you may be able to receive this transport free of charge in England only. Your renal team can help find out what the transport arrangements are before you book your DAFB.

Can I use a private dialysis facility in England?

Yes but it will only be free of charge if that private facility has an agreement with NHS England.

Can I have cruise ship holiday dialysis?

Yes, subject to approval from your consultant. If the majority or all of the cruise ports of call are within the boundaries of an EEA country, or a country with which the UK has a reciprocal agreement, you may be able to claim back the cost of the dialysis.

This does mean that you will need to have your dialysis when the ship is in port within an EEA country, as the agreement does not cover dialysis on board a cruise ship. DAFB on a cruise ship is classed as being outside the EEA or a reciprocal country, and therefore it may not be regulated by a country's health policy. This does not stop you from booking your dialysis on board the ship, but you will not get your money back.

You will need to get approval from the renal team for a refund on your return, before you go on your cruise. We will tell you how much of the cost of the dialysis at the cruise ports will be paid back to you. **It may not cover the total cost of the dialysis.** You will need to forward receipts and proof of payment when you return.

You will need to make checks about the quality of the service at the units before you book your dialysis for the cruise. You could check, for example, the type of dialysis service provided, numbers of staff, machines, provision of back up machines, and the experience of the renal teams in providing dialysis etc.

You will need to make sure that the cruise company has your medical information. Also, you will need to update your renal team on the dialysis treatment you received when you get back.

You must have adequate travel insurance to cover you whilst on a cruise ship. NHS England will only pay towards the cost of the dialysis and will not pay for any other healthcare costs.

For cruises outside the EEA or a reciprocal country, you will have to pay the total cost of dialysis yourself.

Can any dialysis patient have DAFB?

No. A decision has to be made whether a person is suitable to have dialysis at another facility and whether they are well enough to travel. For example, a person with complex needs who normally receives haemodialysis at a main renal centre would not usually be able to have dialysis at a nurse-led satellite unit.

Can I arrange DAFB myself?

We advise people to make use of the holiday coordinator at the travel company, or to speak to their renal unit when arranging DAFB. A company called Dialysis Freedom may be able to offer some practical advice, and find a slot within the UK through their swap scheme. Their website is:

<http://www.dialysisfreedom.co.uk/>

The company also provides help and information on DAFB outside the UK.

What if I cannot get dialysis where I want it?

Unfortunately dialysis capacity at some locations is scarce. You may have to consider other destinations. We advise booking as far in advance as possible.

How often can I have DAFB?

There is unrestricted access to DAFB depending on:

- availability
- if you are considered suitable and well enough to have dialysis at another facility

The frequency and length of sessions of DAFB may be different from your normal routine. This is something you will need to find out before you confirm your booking.

Will I be suspended from the transplant list if I go away?

You may be suspended from the transplant list if you travel to a location outside the UK where getting back quickly enough to your transplant centre will be a problem. This may also be the case if the location within the UK makes it difficult to get back quickly, such as the highlands of Scotland. You will need to check this with your renal team.

If you have been away to a country that has a high risk of blood-borne viruses, such as hepatitis B, you will be suspended from the transplant list for three months after you return.

It is important that the transplant coordinator is aware that you will be away and where you will be. It is also important that you update the transplant coordinator if your plans change. When you come back, you will need to make sure you are reactivated on the transplant list. You may need to have general health and infection control checks carried out on your return.

Are there any guidelines in place for infection control?

Yes. In the UK, the Department of Health updated guidelines in 2010, with a specific mention of blood-borne viruses (BBV) and DAFB. In addition, some units and regions in the UK have their own additional guidelines.

Although other countries may have similar guidelines, these may not be as strict as the UK guidelines. There is a particular risk of BBV in South East Asia, Africa and the Middle East. To find out more about this, you will need to see your renal doctor or nurse.

What should I do about medication?

It is advisable to plan the medications you will need, to make sure you take enough to cover your stay. If you are travelling by plane, you should consider putting your medications in your hand luggage. Check with travel providers what their policies are about carrying and declaring medications, and medical equipment.

It is a good idea to carry a repeat prescription sheet with you to prove that the medications and equipment are for your use.

Can I take dialysis equipment on the plane?

Yes. Equipment includes dialysis machines, and also any dialysis consumables such as dressings, you may have to use while you are away.

Under European law, disabled people and other people with reduced mobility for any reason, have legal rights to assistance when travelling **by air**. Regulation (EC) No. 1107/2006 sets out two essential goals:

- preventing unfair treatment. People should not be refused carriage on the basis of their disability.
- guaranteeing free provision of the assistance that passengers with reduced mobility need to have for air travel.

What assistance can I have when travelling by air?

The following services should be available at all European airports for people with a sensory, physical or learning disability that affects mobility when using transport:

- Facilities to summon assistance at designated arrival points, such as at terminal entrances, at transport interchanges and in car parks
- Assistance to reach check-in
- Help with registration at check-in
- Assistance with moving through the airport, including to toilets if required
- Help with getting on and off the plane
- **Free carriage of medical equipment and up to two items of mobility equipment**
- A briefing for you and any escort or companion on emergency procedures and the layout of the cabin
- Help with stowing and retrieving baggage on the plane
- Assistance with moving to the toilet on the plane (some planes will have an on-board wheelchair)
- Someone to meet you off the plane and help you reach connecting flights or get to the next part of your journey

This means that if you are flying within the EEA, you will not be charged for carrying your dialysis equipment with you. If you are flying outside the EEA, you will need to check in advance. This is because companies have different policies and they may charge you to carry your equipment.

Can I find out more?

Here are some useful websites and contact telephone numbers:

British Kidney Patient Association

For assistance with holiday grants.

01420 541424

<http://www.britishkidney-pa.co.uk/>

Dialysis Freedom

For dialysis swap scheme information.

01509 808668

<http://www.dialysisfreedom.co.uk/>

Freedom

For details of holiday destinations with dialysis facilities.

01509 815999

<http://www.holidaydialysis.co.uk/>

Global Dialysis

For information and patient feedback on dialysis units around the world.

<http://www.globaldialysis.com/>

National Kidney Federation

For general advice and information including travel insurance companies.

0845 601 02 09 (Calls to this number from UK landlines are free of charge)

<http://www.kidney.org.uk/>

Other information

Dudley Kidney Patients Association is able to refund some money towards the costs incurred for transport to and from your holiday dialysis unit and holiday accommodation. Forms are available on request from the Renal Unit.

Dudley Kidney Patients Association

Judith Sidaway

01384 424456

Dialysis Freedom

Dialysis Freedom is a travel agency that specialises in holiday dialysis. They can help with many areas of holiday dialysis bookings. However if you are not using them to book your holiday, they do make a charge for this assistance. At the time of writing, this cost was £70.

01509 808668

<http://www.dialysisfreedom.co.uk/>

Dudley Kidney Patients Association will consider refunding this cost on a case by case basis.

Quick checker

Scenario	Responsibility for booking	Responsibility for payment
Going to NHS facility in UK	The Dudley Group NHS Foundation Trust	The Dudley Group NHS Foundation Trust
Going to non-NHS facility in UK	The Dudley Group NHS Foundation Trust	The Dudley Group NHS Foundation Trust
Going to state facility within an EEA country or country with reciprocal agreement	You	You (See NHS England guidance)
Going to a private facility within EEA country or country with a reciprocal agreement, or to a facility that does not accept EHIC	You	You (See NHS England Guidance)
Patient going to a country outside EEA	You	You

You must ensure you have adequate holiday insurance.

References

DoH (2010). *Good Practice Guidelines for Renal Dialysis/Transplantation Units Prevention and Control of Blood-borne Virus Infection. Addendum Guidelines for dialysis away from base (DAFB)*. Department of Health: London.

European Disability Forum (2007). *The regulation (EC) No 1107/2006 on the rights of disabled persons and persons with reduced mobility when travelling by air*. European Disability Forum: Brussels.

Renal Unit contact information

The Renal Unit on 01384 244384

7.30am to 8pm, Monday to Saturday

9am to 5pm, Sunday

Ask to speak to a vascular access nurse (VAN) or a member of the haemodialysis staff, if a VAN is not available.

Out of these hours, ring the hospital switchboard number and tell them you are a renal patient. Ask to speak to the haemodialysis nurse on call.

Remember: the renal team is always willing to give help and advice. Please contact us, however small your query.

Russells Hall Hospital switchboard number: 01384 456111

This leaflet can be downloaded or printed from:

<http://dudleygroup.nhs.uk/services-and-wards/renal/>

If you have any feedback on this patient information leaflet, please email patient.information@dgh.nhs.uk

This leaflet can be made available in large print, audio version and in other languages, please call 0800 073 0510.

للحصول على هذه النشرة بحجم أكبر، وعلى شكل إصدار صوتي و بلغات أخرى، الرجاء الاتصال بالرقم 08000730510.

此宣传单可提供大字版本、音频版本和其它语言版本，请拨打电话：0800 073 0510。

Ulotka dostępna jest również w dużym druku, wersji audio lub w innym języku. W tym celu zadzwoń pod numer 0800 073 0510.

ਇਹ ਪਰਚਾ ਵੱਡੇ ਅੱਖਰਾਂ, ਬੋਲ ਕੇ ਰੀਕਾਰਡ ਕੀਤਾ ਹੋਇਆ ਅਤੇ ਦੂਸਰੀਆਂ ਭਾਸ਼ਾਵਾਂ ਵਿਚ ਵੀ ਪ੍ਰਾਪਤ ਹੋ ਸਕਦਾ ਹੈ, 0800 073 0510 ਤੇ ਫੋਨ ਕਰੋ ਜੀ।

Aceasta broșura poate fi pusă la dispoziție tipărită cu caractere mari, versiune audio sau în alte limbi, pentru acest lucru vă rugăm să sunați la 0800 073 0510.

یہ کتابچہ آپ کو بڑے حروف کی لکھائی، سمعی صورت اور دیگر زبانوں میں مہیا کیا جا سکتا ہے۔ برائے مہربانی فون نمبر 08000730510 پر رابطہ کریں۔

If you would like to apply for DAFB, please complete the following forms and hand them to the ward clerk at the Renal Unit, a minimum of two months before you want to go on holiday.

Please make sure that all the information is completed.

Patient authorisation for disclosure of information for holiday dialysis bookings

I agree that my health records and any personal information can be released to external organisations for the purpose of holiday dialysis, either in the UK or abroad. This personal information will be limited to what is relevant and will only be released to people who need to know it in order to provide dialysis.

Your name (please print): _____

Your signature: _____

Date of birth: _____

Your NHS Number: _____

Address: _____

Date: _____

The Trust cannot accept responsibility for how this information is used by the organisation it is sent to.

Please state what type of booking it is:

- This is a dialysis booking in the UK
 - This is a dialysis booking in the EEA and is covered fully or partially by EHIC. Any additional costs will be paid by me
 - This is a dialysis booking in the EEA but at a private dialysis unit and therefore all costs will be paid by me
 - This is a dialysis booking outside the EEA in a country that does not have a reciprocal agreement with the UK. All costs will be paid by me
 - This is a dialysis booking outside the EEA but in a country covered by a reciprocal agreement. Any additional costs will be paid by me. Please state country and details of reciprocal agreement:
-

The Dudley Group NHS Foundation Trust will not pay for any holiday dialysis costs incurred outside the UK.

Please ensure you understand what costs you may have to pay, and when and how they must be paid.

Please note you may not be able to obtain a refund on some of the costs.

Notification of holiday dialysis booking

I have booked a holiday at the dialysis unit detailed below. Please arrange for the information requested to be sent to the unit.

Unit full name: _____

Address: _____

Telephone number: _____

Fax number: _____

Contact name at the unit: _____

Email address: _____

Last date of dialysis at home unit: _____

First date of dialysis at holiday unit: _____

Last date of dialysis at holiday unit: _____

Date of return to home unit: _____

Number of holiday dialysis sessions: _____

Please advise how your holiday unit expects to receive this information. (You will need to allow 10 working days for the information to be sent to the unit):

(Please tick)

- Fax
- Email
- Post (allow 10 working days)

Information required by holiday unit:

(Please tick)

- Full blood test
- Blood-borne virus tests (Hepatitis B and C, HIV)
- MRSA screening
- Last clinic letter
- Dialysis prescription
- ECG
- X-ray
State type: _____

Please detail any other information requested by holiday unit:

Has the holiday unit asked you to bring your own dialysers?

- Yes
- No

Please ensure you are able to transport the dialysers safely. You will be given one dialyser for each session, plus one spare. The unit will give them to you on your last dialysis session before your holiday.