University Hospitals of Leicester
NHS Trust

Medicines after kidney transplant

Renal and Transplant Services

Information for Patients

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Contents

1. Introduction

This leaflet has information to help you understand the medicines you will need to take after your kidney transplant. This is a summary of the most important points about your new medicines. For more information you can read the information leaflets that come with each of your medicines. You can also speak to your pharmacist, doctor or nurse if you have any questions.

This information is also available in a short video format. Use your smartphone to scan this QR code to watch the video or visit this link:

www.youtube.com/playlist?list=PLoaqlhejgAzPbI6DEqYc7oKRl7YFjI2xa

After you have your kidney transplant your medicines will change:

- Some of your medicines may stay the same.
- Other medicines may stop.
- You will need to take some new medicines.

Your medicines or doses may change often. It is very important that you keep an up-to-date list of your medicines. Show it to your doctor, pharmacist and nurse when you see them. If you would like an up-to-date medicines list to be printed, please contact the Kidney Pharmacy Team on the number below.

2. Useful contacts and telephone numbers

- Ward 37 (Transplant Ward at Glenfield Hospital): **0116 258 4126**
- Transplant Clinic Co-ordinator: **0116 258 8024**
- Kidney Pharmacy Team: **0116 258 8177**

3. General information about your medicines

What do I do if I have been given different advice?

The information in this booklet is a general guide and may not apply to everybody that has a kidney transplant. If you have been given different advice by your transplant doctor, follow their advice.

How long do I take my medicines for?

Your anti-rejection medicines are very important because they stop you rejecting your new kidney. If you stop taking your anti-rejection medicines your kidney could be damaged and stop working. You need to keep taking your transplant medicines until the transplant doctor tells you to stop.

What do I do if I miss a dose?

Missing doses of your anti-rejection medicines can make rejection more likely.

- You must make sure that you always take all your medication doses.

- **If you forget a dose, take it as soon as you remember**. If it is nearly time for the next dose, miss out the dose you have forgotten and continue as usual.
- **Do not take 2 doses** at the same time.
- You need to tell your transplant doctor immediately if you miss a few doses (days or weeks) or if you take a higher dose by mistake.

Will I get side effects?

Your new medicines have some side effects but not everybody gets them. Most people feel fine but if you think you have an unpleasant side effect from any of your medicines, tell your doctor, nurse or pharmacist.

How do I get more supplies of my new medicines?

You need to make sure that you get a new prescription before your supply of medicines runs out.

Before you go home from the hospital we will give you enough medicines for at least 14 days.

You will get your anti-rejection medicines from the hospital and the rest of your medicines (like blood pressure or cholesterol-lowering tablets) from your own doctor (GP).

A copy of your hospital discharge letter will be sent to your GP when you go home with an up-to-date list of your medicines explaining which medicines you will get from the hospital. If possible, go and see your GP to talk about the changes to your medicines after the kidney transplant so they can update your records.

Can I drink alcohol?

With most medicines you can drink alcohol in small amounts. Check with your doctor, nurse or pharmacist first.

Can I take other medicines?

New medicines can affect how medicines that you are already taking work. Check with your doctor or pharmacist before taking any new medicines, even over-the-counter, herbal, homeopathic or natural remedies.

If you need to take painkillers, paracetamol is often the best option for people with a kidney transplant. You must not take painkillers called “non-steroidal anti-inflammatory drugs” like ibuprofen. They can harm the kidney transplant.

4. Anti-rejection medicines

Your body has natural defences (your immune system) to protect you. These defences will attack anything that does not belong to your body (like germs). When you have a kidney transplant your defences will know that your new kidney is not part of your body and they will attack it. This would damage your new kidney transplant and stop it from working. This is called rejection.

Some of your new medicines will lower your body’s defences to stop your body rejecting your new kidney. These medicines are called **anti-rejection or immunosuppressant medicines.**

Later sections of this booklet explain the possible side effects of each medicine. But there are some common points that apply to anti-rejection medicines:

- Anti-rejection medicines lower your body's defences to stop you rejecting your kidney transplant. Lower body defences means that it is harder for you to fight infections. You need to tell your doctor if you think you have an infection. For example, if you have a high temperature or a sore throat.
- You should avoid close contact with people who have chickenpox or shingles. Tell your doctor straight away if you do come into close contact with anyone who has chickenpox or shingles.
- If you take anti-rejection medicines there are some vaccines that are not suitable for you. You must avoid live vaccines. You can speak to your doctor, pharmacist or nurse for advice.
- Some anti-rejection medicines can reduce the ability of the bone marrow to make blood cells. Because of this, there can be less blood cells than normal. Too few blood cells can cause anaemia, easy bruising and can weaken the body's defences. Your transplant doctor or pharmacist will check the level of your blood cells to make sure that they do not drop too low. You should always tell your doctor if you have unexplained bleeding or bruising. This could mean that you have low blood cells levels.
- People taking anti-rejection medicines have a higher risk of having some types of cancer like skin cancer and cancer of the lymphatic system. You need to protect your skin with a high SPF (sun protection factor) sunscreen everyday. Protect your skin from sun rays with clothing and a hat. This will prevent skin damage. You must also avoid using sun beds. Tell your doctor if you have any new moles or a mole changes shape or bleeds.
- Some anti-rejection and other transplant medicines are avoided during pregnancy because they can harm the unborn baby. Women of childbearing age must use effective contraception while they are taking transplant medicines. Many people with a kidney transplant have healthy babies. You need to speak to your doctor if you are thinking about having a baby or you are breastfeeding. Men taking anti-rejection medicines may want to speak to their doctor before fathering a baby.

4.1. Prednisolone

Prednisolone is a steroid anti-rejection (immunosuppressant) drug.

How do I take it?

You should take prednisolone tablets once daily (in the morning). Prednisolone is normally taken with food to stop stomach upset. You will normally start taking 20mg of prednisolone each day. This dose will come down slowly over a few weeks.

Are there any side effects?

- Prednisolone can upset the stomach and cause heartburn. We will give you medicines to help stop this.
- Some people find that prednisolone increases their appetite and that they can put on weight. Please make sure you eat well and exercise regularly to maintain a healthy weight.
- A small number of people taking prednisolone have mood swings (feeling high and/or low). They may also feel anxious and have trouble sleeping. Talk to your doctor if this happens.

- Prednisolone can increase blood sugar levels and can cause diabetes. Some people need to take medicines or have insulin injections to control their blood sugars.
- Prednisolone can also increase blood pressure. Some people need to take medicines to bring their blood pressure down. Your blood pressure will be checked regularly in clinic.
- Some people can get flushing of the face or stretch marks on the skin.
- Prednisolone can make bones weaker. The dose of prednisolone is normally reduced over time to reduce this effect.

Is there anything else I need to know?

- You **must not stop taking your prednisolone suddenly** or without telling your transplant doctor first.
- Your **dose of prednisolone will always be reduced slowly.**
- **Always carry your blue steroid card with you**. Show this card to your doctor, dentist, nurse or pharmacist.

4.2. Tacrolimus

Tacrolimus is an anti-rejection (immunosuppressant) drug. There are different brands of tacrolimus available (Adoport®, Prograf®, Advagraf®, Envarsus®, Modigraf®). They all have the same ingredient but they can work in a different way. **You must always take the same brand of tacrolimus unless your transplant doctor or pharmacist tells you to change.** Taking a different brand of tacrolimus may not suit your kidney transplant.

How do I take it?

Always check with your transplant doctor or pharmacist how many times a day you need to take your tacrolimus. This can be different depending on what brand you take. You can take tacrolimus with or without food as long as you always take it the same way. If you are taking the Adoport® brand, you need to take this dose 2 times a day (every 12 hours).

Are there any side effects?

There are several possible side-effects, but not everyone gets them.

- Some people have a headache, feel sick or have an upset stomach. This often gets better and goes away with time.
- Tacrolimus can increase blood pressure. Some people need to take medicines for this.
- Tacrolimus can also increase blood sugar levels and can cause diabetes. Some people need to take medicines or have insulin injections to control their blood sugars.
- Tacrolimus can increase blood cholesterol levels. Some people need to take medicines to bring their cholesterol levels down.
- Some people can get tingling or numbness in their fingertips, toes and/or lips. Some people feel "shaky". Tell your doctor if this happens to you.
- Tacrolimus can sometimes cause hair loss. Avoid harsh treatments that can weaken your hair (like perms) for the first few months after starting tacrolimus.

- Some people have trouble sleeping.
- In some people, tacrolimus can affect the kidney transplant and make it work less well. Some people are given other anti-rejection medicines instead (to stop damage from tacrolimus to the kidney transplant). Your transplant doctor will always check how well your kidney transplant is working. They will tell you which anti-rejection medicines are best for you.

Is there anything else I need to know?

You will have regular blood tests to make sure that the level of tacrolimus in your blood is right for you. Your transplant doctor or pharmacist will decide how much tacrolimus you need to take after looking at the blood test results.

Please do not take your morning dose of tacrolimus on transplant clinic days. Bring your tacrolimus with you to take after your blood sample has been taken. Tell the person taking the blood sample and the transplant clinic staff if you forget to delay your tacrolimus dose. They will arrange a tacrolimus level to be done another day.

Some medicines (like some antibiotics, herbal medicines or supplements) can affect your tacrolimus level. If you are given a new medicine, check with your transplant doctor or pharmacist if the new medicine could affect your tacrolimus levels.

Do not eat grapefruit or drink grapefruit juice while taking tacrolimus because grapefruit can affect your tacrolimus blood level.

4.3. Ciclosporin

Ciclosporin is an anti-rejection (immunosuppressant) drug. There are several different brands of ciclosporin available (Neoral®, Deximune®, Capimune®, etc). They all have the same ingredient but they can work in a different way. **You must always take the same brand of ciclosporin unless your transplant doctor or pharmacist tells you to change.** Taking a different brand of ciclosporin may not suit your kidney transplant.

How do I take it?

You need to take your ciclosporin dose 2 times a day (every 12 hours). You can take ciclosporin with or without food as long as you always take it the same way.

Are there any side effects?

There are several possible side-effects, but not everyone gets them.

- Some people have a headache, feel sick or have an upset stomach. This often gets better and goes away with time.
- Ciclosporin can increase blood pressure. Some people need to take medicines for this.
- Ciclosporin can cause muscle pain or cramp.
- Ciclosporin can increase blood cholesterol levels. Some people need to take medicines to bring their cholesterol levels down.
- Ciclosporin can also increase blood sugar levels and can cause diabetes. Some people need to take medicines or have insulin injections to control their blood sugars.

- Sometimes ciclosporin can make your gums swell.
- Ciclosporin can increase hair growth on the body.
- Some people can get tingling or numbness in their fingertips, toes and/or lips. Some people feel "shaky". Tell your transplant doctor if this happens to you.
- Some people have trouble sleeping.
- In some people ciclosporin can affect the kidney transplant and stop it from working well. Some people are given other anti-rejection medicines and stop taking ciclosporin (to stop damage to the kidney transplant). Your transplant doctor or pharmacist will always check how well your kidney transplant is working. They will tell you what anti-rejection medicines are best for you.

Is there anything else I need to know?

You will have regular blood tests to make sure that the level of ciclosporin in your blood is right for you. Your transplant doctor or pharmacist will decide how much ciclosporin you need to take after looking at the blood test results.

Please do not take your morning dose of ciclosporin on transplant clinic days. Bring your ciclosporin with you to take after your blood sample has been taken. Tell the person taking the blood sample and the transplant clinic staff if you forget to delay your ciclosporin dose. They will arrange a ciclosporin level to be done another day.

Some medicines (like some antibiotics, herbal medicines or supplements) can affect your ciclosporin level. If you are given a new medicine, check with your transplant doctor or pharmacist if the new medicine could affect your ciclosporin levels.

Do not eat grapefruit or drink grapefruit juice while taking ciclosporin because grapefruit can affect your ciclosporin blood level.

4.4. Sirolimus

Sirolimus is an anti-rejection (immunosuppressant) drug.

How do I take it?

You need to take your sirolimus dose once a day. You can take it with or without food as long as you always take it the same way.

Are there any side effects?

There are several possible side-effects, but not everyone gets them.

- Some people get an upset stomach, diarrhoea or stomach pain. This often gets better and goes away with time.
- Sirolimus can increase blood cholesterol levels and some people need to take medicines to bring their cholesterol levels down.
- Sirolimus can also increase blood sugar levels and may cause diabetes. Some people need to take medicines or have insulin injections to control their blood sugars.
- Some people can build up fluid in their body. If this happens they can get swollen ankles.

- Sirolimus can affect the chest. Tell your doctor if you get any breathing problems.
- People taking sirolimus can get mouth ulcers.
- Sirolimus can reduce the ability of the bone marrow to make blood cells. Less blood cells than normal can cause anaemia, easy bruising or weaken the body's defences. Your transplant doctor or pharmacist will check the level of your blood cells to make sure that they do not drop too low. You should always tell your doctor or pharmacist if you have unexplained bleeding or bruising. This could mean that you have low blood cells levels.

Is there anything else I need to know?

Sirolimus can slow the rate at which wounds heal. If you are having a planned (elective) operation, speak to your transplant doctor or pharmacist first. You may need to change your sirolimus to another anti-rejection medication before the operation. After your wound heals (often after a few weeks) you can have sirolimus again.

You will have regular blood tests to make sure that the level of sirolimus in your blood is right for you. Your transplant doctor or pharmacist will decide how much sirolimus you need to take after looking at the blood test results.

Please do not take your dose of sirolimus before coming to transplant clinic. Bring it with you to take **after** your blood sample has been taken. Tell the person taking the blood sample and the transplant clinic staff if you forget to delay your sirolimus dose. They will arrange a sirolimus level to be done another day.

Some medicines (like some antibiotics, herbal medicines or supplements) can affect your sirolimus level. If you are given a new medicine, check with your doctor or pharmacist if the new medicine could affect your sirolimus levels. **Do not** eat grapefruit or drink grapefruit juice while taking sirolimus because grapefruit can affect your sirolimus blood level.

Sirolimus is avoided during pregnancy because it can harm the unborn baby. Women of childbearing age must use effective contraception while they are taking sirolimus and for several weeks after they stop treatment with sirolimus. You need to speak to your doctor right away if you become pregnant, you are thinking about having a baby or you are breastfeeding. Reduced sperm counts have been found in some men taking sirolimus. However, this often returns to normal when sirolimus is stopped.

4.5. Mycophenolate mofetil and Mycophenolate sodium

Mycophenolate is an anti-rejection (immunosuppressant) drug.

There are 2 different types of mycophenolate: mycophenolate mofetil and mycophenolate sodium. Both are very similar but the amount to take (the dose) is different for each type. You must always have the same type of mycophenolate. You may be given a different brand and this is fine as long as it is the same type of mycophenolate and the same dose.

How do I take it?

You will normally take your mycophenolate dose 2 times a day (every 12 hours). Some people take mycophenolate 1, 3 or 4 times a day. Your transplant doctor or pharmacist will tell you the amount of mycophenolate to take that is right for you.

Mycophenolate is normally taken with food to stop stomach upset.

Are there any side effects?

There are several possible side-effects but not everyone gets them.

- Some people get an upset stomach while they take mycophenolate. They can get diarrhoea, sickness and/or heartburn. These side effects normally get better with time and often goes away after a while.
- Mycophenolate can reduce the ability of the bone marrow to make blood cells. Less blood cells than normal can cause anaemia, easy bruising or weaken the body's defences. Your transplant doctor will check the level of your blood cells to make sure that they do not drop too low. You should always tell your doctor or pharmacist if you have unexplained bleeding or bruising. This could mean that you have low blood cells levels.

Is there anything else I need to know?

Do not take mycophenolate during pregnancy because it can harm the unborn baby. Women of childbearing age must use at least 1 form of effective contraception while they are taking mycophenolate and for several months after they stop taking mycophenolate. You need to speak to your doctor immediately if you become pregnant, you are thinking about having a baby or you are breastfeeding.

All women able to become pregnant need to have a pregnancy test before starting mycophenolate to be sure they are not pregnant. This test is repeated after 8 to 10 days.

There is a possibility that men taking mycophenolate can pass on a small amount of drug to their female partner through intercourse/sex. There is no evidence to show this is harmful. As a precaution, the pharmaceutical companies advise that men taking mycophenolate or their female partner use reliable contraception during treatment and for at least 90 days after stopping mycophenolate. Men should not donate sperm whilst they take mycophenolate and for 90 days after stopping mycophenolate.

Men must continue taking mycophenolate to protect their kidney transplant, even if their partner is pregnant. They can talk to a member of the transplant team for more information, to talk about their circumstances and ask questions.

Men and women taking mycophenolate should not donate blood whilst they take mycophenolate and for 6 weeks after stopping mycophenolate.

4.6. Azathioprine

Azathioprine is an anti-rejection (immunosuppressant) drug.

How do I take it?

Most people take azathioprine once a day. Azathioprine is normally taken with food to stop stomach upset.

Are there any side effects?

Azathioprine has quite a few possible side effects but not everybody gets them. They are:

- Some people get an upset stomach while they take azathioprine. They can get diarrhoea, sickness and heartburn. These side effects tend to get better with time and they often go away after a while.
- Azathioprine can reduce the ability of the bone marrow to make blood cells. Less blood cells than normal can cause anaemia, easy bruising or weaken the body's defences. Your transplant doctor or pharmacist will check the level of your blood cells to make sure that they don't drop too low. You should always tell your doctor or pharmacist if you have unexplained bleeding or bruising. This could mean that you have low blood cells levels.

Is there anything else I need to know?

You should speak to your doctor if you are given medication for gout called **allopurinol** while you are taking azathioprine. Tell your doctor or pharmacist before you start taking allopurinol. This combination is normally avoided but sometimes allopurinol can be given with azathioprine under the close supervision of a doctor.

5.1. Co-trimoxazole

Because anti-rejection medicines weaken the body's defences (or immune system), people with a kidney transplant are more likely to pick up infections. Co-trimoxazole is a combination of 2 antibiotics used to prevent a chest infection called Pneumocystis jiroveci pneumonia (PJP) . If you are allergic to either of the ingredients (trimethoprim or sulfamethoxazole), we will give you a different medicine.

How does it work?

Co-trimoxazole is given at a low dose to try to stop the microorganism (Pneumocystis jiroveci) from growing and causing infection.

How do I take it?

Most people will be given co-trimoxazole for the first 6 months after their transplant. You should take co-trimoxazole once daily with or without food.

Are there any side effects?

- Some people get an upset stomach or feel sick. This often gets better with time.
- Co-trimoxazole can reduce the ability of the bone marrow to make blood cells. Less blood cells than normal can cause anaemia, easy bruising or weaken the body's defences. Your transplant doctor or pharmacist will check the level of your blood cells to make sure that they do not drop too low. You should always tell your doctor or pharmacist if you have unexplained bleeding or bruising. This could mean that you have low blood cells levels.
- In very few cases co-trimoxazole can cause a skin rash. If you get a rash after starting co-trimoxazole, stop taking it and tell your doctor right away.

5.2. Valganciclovir

Because anti-rejection medicines weaken the body's defences (or immune system), people with a kidney transplant are more likely to pick up infections. Valganciclovir is an anti-viral medicine used to help prevent infection from a virus called cytomegalovirus (CMV). This is a virus that many people can carry without being ill but it is more likely to make you unwell if you have lower body's defences.

How do I take it?

Not everyone needs to take valganciclovir after their kidney transplant. Your doctor will do some tests and then decide if you need to take valganciclovir. Most people who need valganciclovir will take it for the first few months after their kidney transplant. The dose of valganciclovir is different for each person because it depends on how well the new kidney transplant is working.

Are there any side effects?

- Some people get an upset stomach or feel sick. This often gets better and goes away with time.
- Valganciclovir can reduce the ability of the bone marrow to make blood cells. Less blood cells than normal can cause anaemia, easy bruising or weaken the body's defences. Your transplant doctor or pharmacist will check the level of your blood cells to make sure that they do not drop too low. You should always tell your doctor or pharmacist if you have unexplained bleeding or bruising. This could mean that you have low blood cells levels.

Is there anything else I need to know?

Do not take valganciclovir during pregnancy because it can harm the unborn baby. Women of childbearing age must use effective contraception while they are taking valganciclovir. You need to speak to your doctor right away if you become pregnant, you are thinking about having a baby or you are breastfeeding.

Valganciclovir can damage sperm. Men must use condoms while they are taking valganciclovir and continue for 90 days after stopping it. Talk to the transplant team first if you are thinking about having or fathering a baby. They can advise you about what medicines will work best for you.

5.3. Aspirin

Aspirin is used to thin the blood and prevent blood clots from appearing in the kidney transplant and the blood vessels around it.

How do I take it?

Most people take aspirin for a few weeks after having a kidney transplant. Your transplant doctor will tell you how long you need to keep taking aspirin . Aspirin is normally taken once daily with food to stop stomach upset.

Are there any side effects?

- Some people can get an upset stomach or feel sick. The sickness usually disappears with time.
- Sometimes aspirin can cause a skin rash or make breathing more difficult (especially in people with asthma). If you feel breathless or have a rash after starting aspirin, stop taking aspirin and tell your doctor right away.

5.4. Proton pump inhibitors (like omeprazole, lansoprazole)

Some of the new medicines given after a kidney transplant can cause stomach upset or heartburn. To help prevent this, some people have a medicine called proton pump inhibitor (for example, omeprazole, lansoprazole).

How does it work?

Proton pump inhibitors protect the stomach lining and stop irritation or heartburn. They work by reducing the amount of acid produced in the stomach.

How do I take them?

These medicines are usually taken before a meal or on an empty stomach, usually once a day.

Are there any side effects?

Some people can get an upset stomach (diarrhoea or constipation) or feel sick and have headaches. This often gets better and goes away with time.

6. Paying for your medicines

Some people may have to pay for medicines after having a kidney transplant. You can find out more information on this website: www.nhsbsa.nhs.uk/nhs-help-health-costs

If you pay for your prescription medicines, you could save money by getting a prescription prepayment certificate. This lets you get as many NHS prescriptions as you need for a set price. You can get a prescription prepayment certificate for 3 months or a year.

You can apply for a prepayment certificate by post, by telephone and in some pharmacies. You can also apply online on this website:

www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates

7. More information

- **Patients Know Best**

Patients Know Best is an internet website (www.patientsknowbest.com) where you can see information about your kidney transplant. For example, your contact details, blood test results and your letters from the transplant doctors. All this information is secure and you need a password to see it. You will find the forms to join Patients Know Best in the information pack that you get after your kidney transplant.

- **Leicestershire Kidney Patients' Association** www.lkpa.uk

The LKPA (Charity No. 505795) is a charity which promotes and supports the health and welfare of renal patients (and families). It supports the Leicester Hospitals and its satellite Renal Units and provides education/information on renal disease to the general public. The LKPA aims to support its members through phone, website and newsletters. Also by allocating small grants for basic needs, helping to organise educational sessions, social events and outings. The LKPA also gives funds to enable staff attached to the Renal Unit of Leicester General Hospital to further their research and education into renal problems.

- **Kidney Patients UK** www.kidney.org.uk/kpa

The NKF is a federation of about 70 separate Kidney Patient Associations (KPAs) spread across the UK. These pages contain details of the local contact and activities of each KPA.

- **NHS 111**

NHS 111 can help if you have an urgent medical problem and you're not sure what to do.

Phone 111 or visit www.111.nhs.uk

- **Lab Tests Online UK** www.labtestsonline.org.uk

This website has information to help patients understand tests better.

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net