Barts Health
NHS Trust

Patient information

Skin care after an organ transplant

Also for those who have a suppressed immune system

Dermatology Department
The Royal London Hospital

Please bring this booklet with you to all clinic visits

The production of this updated skin care booklet was undertaken as part of a Mary Seacole Award

BSSCII
British Society for Skin Care In Immunosuppressed Individuals

Endorsed by the British Society for Skin Care in Immunosuppressed Individuals (BSSCII)

BARTS CHARITY

The original skin care booklet was funded by Barts Charity

Contents

Introduction

After an organ transplant you will need to take immunosuppressive (anti-rejection) drugs which suppress your immune system and help to prevent your organ being rejected. These medicines mean that you are more likely to suffer from certain skin conditions as you are less able to fight infections. Immunosuppressive drugs can also increase your risk of developing some skin cancers, depending on the type of skin that you have.

This booklet has been produced to help you look after your skin following an organ transplant. Much of the advice is also appropriate for people who have a suppressed immune system due to other causes such as chronic lymphocytic leukaemia (CLL) and HIV, and for those awaiting an organ transplant.

The booklet gives you information about what signs and symptoms to look out for, and describes the treatment for a variety of skin conditions. There is also a useful chapter on skin cancer prevention including how to examine your skin and protect yourself from exposure to the sun.

At the back is a patient diary for you to write down the outcome of your clinic visits and any comments about the condition of your skin.

Please bring this booklet with you when you come to the transplant skin clinic.

About the transplant skin clinic

The transplant skin clinic is part of the Dermatology Department at Barts Health NHS Trust. Located on the second floor of The Royal London Hospital, it is run by dermatologists for monitoring, preventing and treating skin problems in patients who have had an organ transplanted or who are immunosuppressed for other reasons. It is one of the biggest centres for this specialty in the UK.

Doctors and specialist nurses from the clinic aim to see you routinely following your transplant to alert you to any possible skin problems that might arise, and to assess your individual risk for skin cancer. They will give you advice and guidance on how to look after your skin.

Depending on your risk factors and individual needs, you will be advised how frequently you need to be seen thereafter – usually between one and five years.

An important part of the work of the clinic is the study of skin disease and skin cancer after a transplant, with a view to preventing and improving treatment for these conditions.

We may ask you whether you would be willing to participate in one of the research studies being undertaken by the clinic.

How often will I be seen in the clinic?

This will depend upon your risk of developing skin problems. Our aim is to detect new or suspicious skin lumps early so that we can treat them as soon as possible.

At your first appointment we will assess your risk of developing skin cancer. This is based on:

- Your age
- Your age at transplantation
- How easily you burn in the sun
- Your history of sun exposure
- How often you have suffered sunburn
- Any pre-existing skin problems

Follow-up appointments

For some of you the risk of developing skin problems is so low that we will not need to see you routinely. We ask only that you self-examine your skin and request a referral back to us if there are any concerns.

Other patients will need to be seen at regular intervals. This may be as little as once every five years, every 18 months or as much as every three months. We will let you know when your appointments should be made.

The frequency of your visits may change over the course of your care. If you develop a skin cancer you will need to be seen more often.

Between appointments

For everyone regular self-examination of the skin is essential so that problems, especially skin cancer, can be detected early and treated. How to examine your skin is described on pages 30–32.

If you have a skin lesion that changes over time, or develop a new skin mark, please ask a health professional for advice or ring us. Our contact numbers are on page 37.

Common skin conditions after a transplant

These are the skin conditions most commonly seen after transplant surgery. Each of these skin problems is described with a photograph on the pages shown below. Do look through them to familiarise yourself with the skin conditions.

Throughout this booklet any skin condition that requires urgent medical assessment has been indicated by a red asterisk ✻

If you develop any skin problem that you are worried about you can:

- Contact the Dermatology Department
- Speak to one of the transplant nurses if your transplant was carried out at this Trust
- Make an appointment with your GP
- Call NHS 111 if you are feeling very unwell
- Go to your local A&E department if your symptoms are severe

Delayed wound healing and fragile skin

Some patients may notice thinning of the skin with increased bruising. This is usually due to medication, in particular the use of steroids. Cuts and abrasions may take longer to heal.

Acne

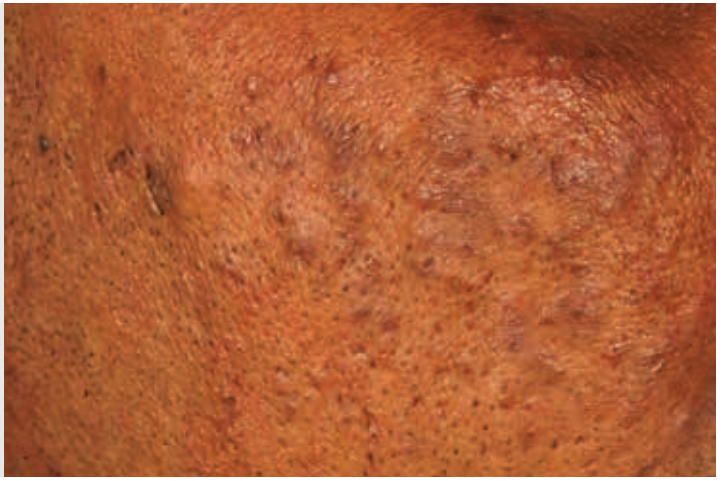
Spots are common in the first 12–18 months after transplantation, particularly in younger patients. They usually settle down as the dosage of immunosuppressive drugs is lowered.

Treatment for acne

Creams or gels may be all that is needed. Some of these can be obtained from a pharmacy and others can be prescribed by your GP.

If creams or gels do not control the acne, antibiotics may be required from your GP or dermatologist. For very severe acne a dermatologist may prescribe tablets such as isotretinoin.

Acne on the cheek



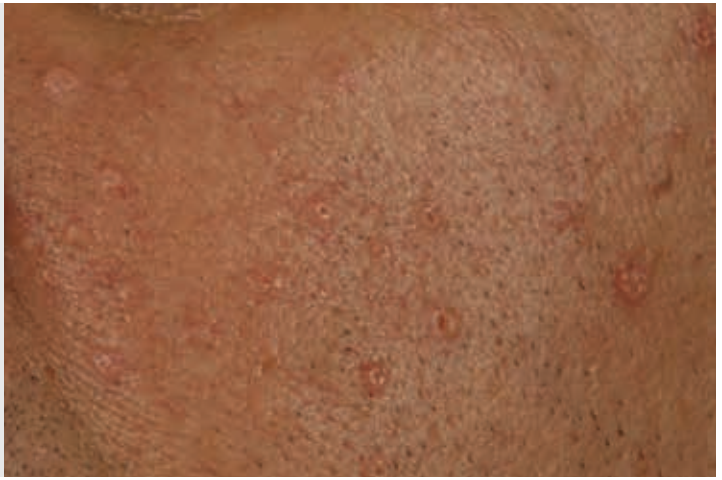
Sebaceous gland hyperplasia (SGH)

SGH is very common after an organ transplant. As shown in the photograph, it appears as small (2–4mm in diameter), raised, whitish/yellowish bumps on the skin, especially on the forehead, nose and cheeks.

Treatment for SGH

This is a benign condition and usually no treatment is required unless the appearance of SGH is a significant cosmetic problem.

Sebaceous gland hyperplasia on the cheek



Fungal infection of the skin and nails

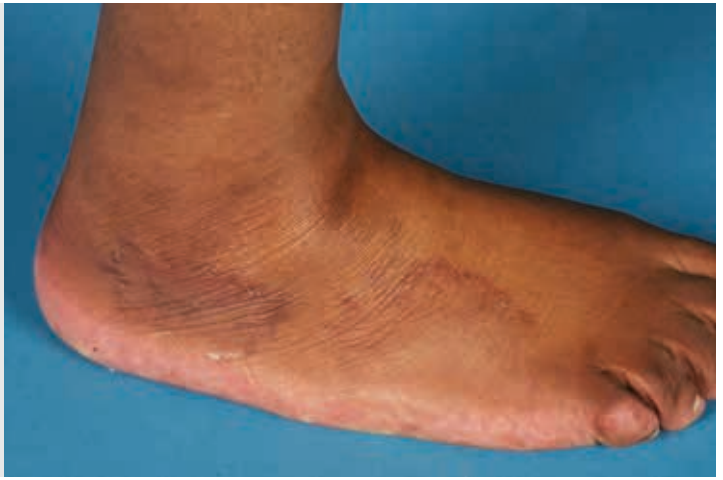
Fungal infection of the skin on the feet (tinea pedis or athlete's foot)

This is a very common condition that usually appears as scaly patches on the feet and a red/white rash between the toes, both of which can be itchy.

Treatment for athlete's foot

Creams are available over the counter from your pharmacist or can be prescribed by your GP.

Athlete's foot



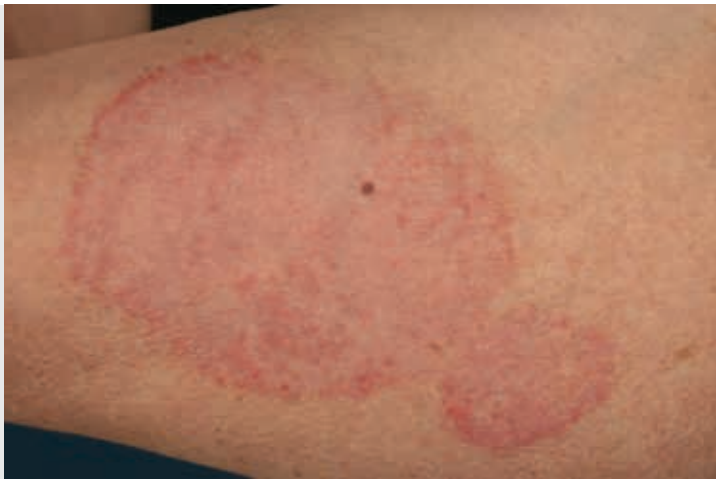
Fungal infection of the skin elsewhere (tinea corporis or ringworm)

This appears as red, scaly, itchy patches on the body. It can start anywhere but is especially common on the trunk and in the groin region.

Treatment for ringworm

It is important to have a diagnosis from a doctor before beginning treatment so if you think you have ringworm contact your GP in the first instance. Treatment is usually the application of a cream or shampoo.

Ringworm on the arm



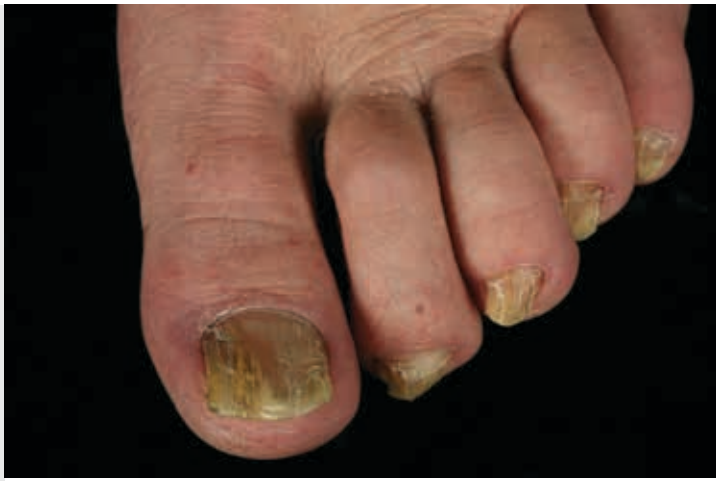
Fungal infection of the nails (onychomycosis)

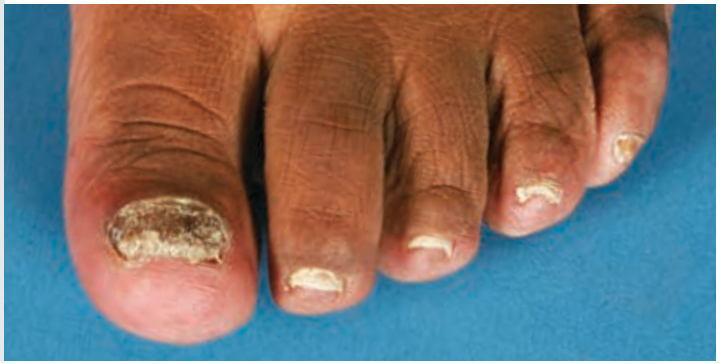
Infection first appears as yellow or white patches under and within a toenail; it can push the nail up off the bed and cause the nail to become thicker. The infection usually starts in one toenail and then spreads to the others.

Treatment for onychomycosis

You may be given a lacquer (nail paint) by your GP but if your nails are very thick this can take up to a year to remove the infection. For severe infection you may need a course of tablets from your dermatologist to be taken over several months.

Fungal infection of the toenails





Pityriasis versicolor (yeast infection)

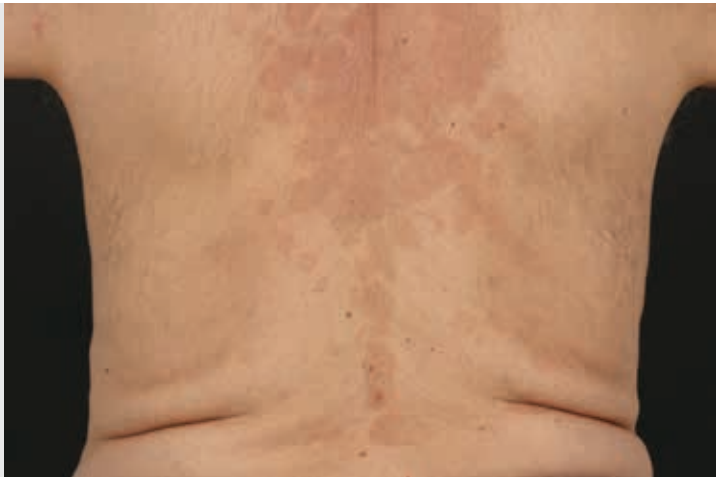
This common yeast infection of the skin often affects the chest and back. It usually appears as pink or brown patches, darker or lighter than your normal skin tone, and may be scaly and itchy.

Treatment for yeast infection

Treatment usually involves washing with an anti-fungal shampoo and using an anti-fungal cream for several weeks which can be obtained from your GP.

Sometimes it may be necessary to see your dermatologist who can prescribe an anti-fungal tablet as well.

Pityriasis versicolor on the back



Other infections

Shingles and chickenpox (herpes zoster and varicella)*

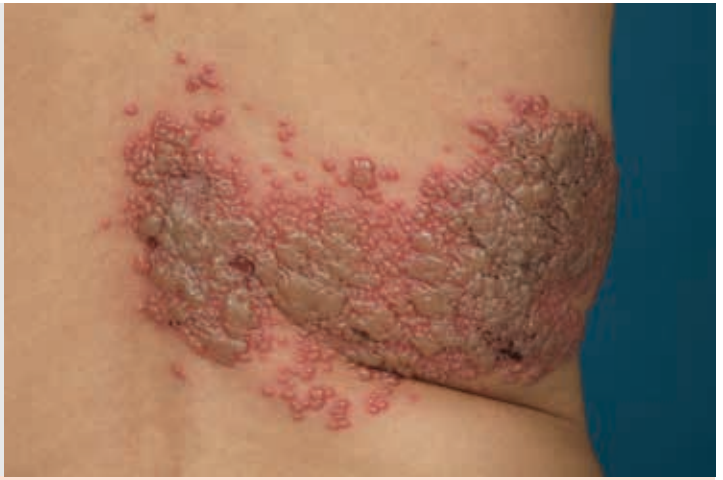
Shingles and chickenpox are caused by the same virus. Both can be more serious in people who have had a transplant.

Shingles usually appears as a painful, blistering rash on a particular area of the body, for example one side of the chest, the arm or on one side of the face. Chickenpox is usually associated with feeling unwell and a more widespread rash which eventually blisters.

Treatment for shingles and chickenpox

Treatment mainly involves antiviral medication but it is not always required.

Shingles on the right side of the back



* If you think you may have developed either shingles or chickenpox, especially if you have any form of blistering rash, you should seek medical attention immediately. Both are contagious and people with shingles can cause chickenpox in those who have not previously had it.

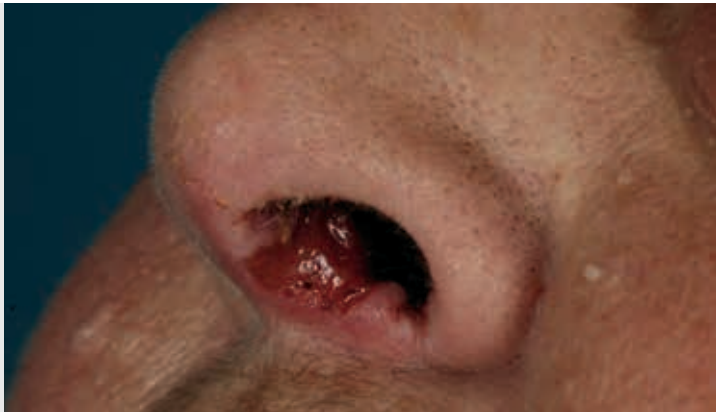
Cold sores (herpes simplex)

The herpes simplex virus causes cold sores which are very common but they may be more of a problem after a transplant. They usually appear as painful blisters or ulcers that come back in the same part of the body such as on the lips, nose or buttocks.

Treatment for cold sores

Cold sores may need treatment with antiviral creams available over the counter from a pharmacist. If they are still causing a problem go to your GP, who might prescribe tablets, and if they become very troublesome contact your dermatologist.

Cold sore in the nose



Viral warts

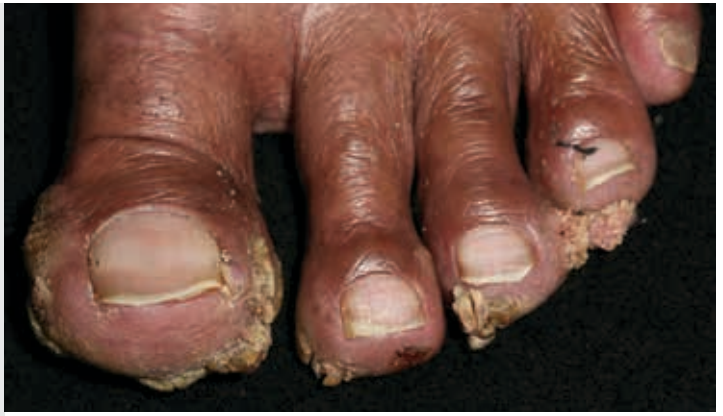
These are very common after transplantation and are caused by the human papillomavirus (HPV). Some people develop just one or two warts – often on the hands or feet – while others can develop large numbers that need specialist care. On the feet they are known as verrucas.

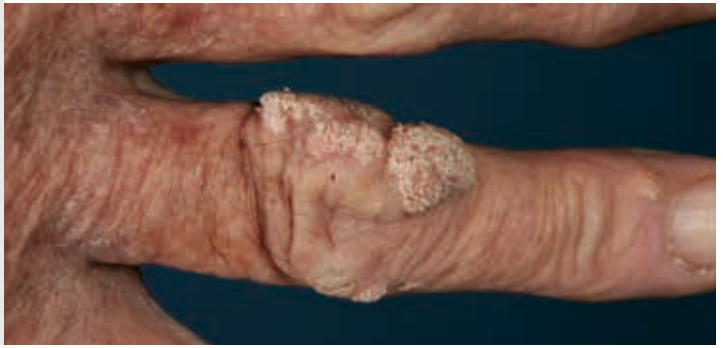
Treatment for viral warts

Warts and verrucas can be difficult to treat in organ transplant patients but your GP or dermatologist will usually recommend a salicylic acid preparation such as Verrugon or Occlusal.

If one or more of these treatments don't work, more aggressive therapy such as freezing (cryotherapy) or other creams may be recommended.

Warts on the toes and fingers





Benign (harmless) skin lumps

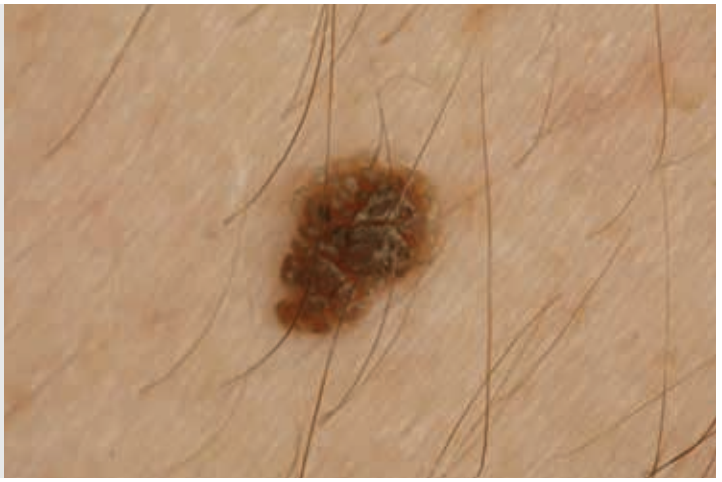
Seborrhoeic warts (seborrhoeic keratoses)

These are harmless lesions with a warty appearance although they are not warts and are not caused by a virus like true warts. Seborrhoeic warts often appear on the back and chest but they can erupt anywhere on the skin, and there may be many of them.

Treatment for seborrhoeic warts

Seborrhoeic wards do not usually require treatment but if they are causing problems the warts can be frozen off or removed surgically.

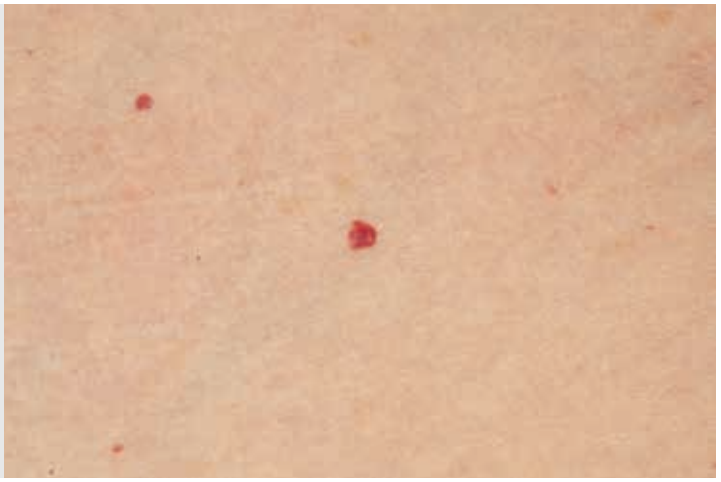
Seborrhoeic wart



Campbell de morgan spots (cherry angiomas)

These are harmless overgrowths of blood vessels and do not require treatment. They look like tiny, red, raised spots and are common on the chest and abdomen, but can appear on any part of the body.

Campbell de morgan spots



Pre-cancerous skin lesions

Actinic keratosis (AK)

This is also known as solar keratosis as it tends to occur on sun-exposed sites such as the hands, face and scalp. It appears as small, dry, flaky patches of skin, some of which can have a crust. Sometimes this crust falls off leaving a red area underneath.

Solar keratosis is usually painless but may be slightly itchy. If you develop any tenderness or pain in the area you should seek medical advice from your dermatologist.

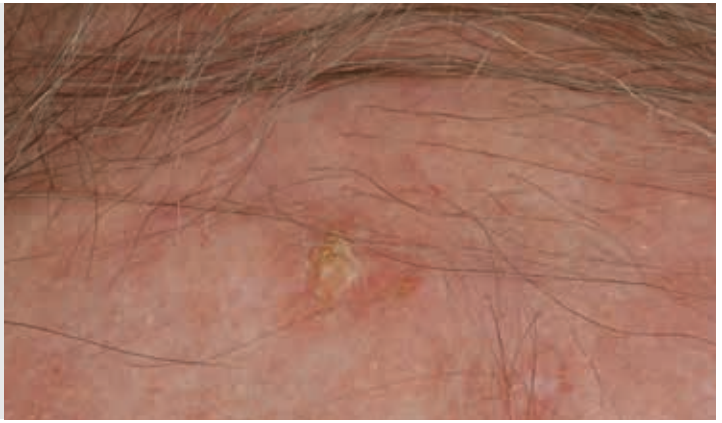
The presence of actinic keratosis may be a sign that you are at increased risk of skin cancer, and the condition has the potential to develop into skin cancer. It is usually assessed and treated, if necessary, within the Dermatology Department.

Treatment for actinic keratosis

Treatment includes the following options:

- Observation (watchful waiting)
- Freezing (cryotherapy)
- Solaraze (hyaluronic acid) gel
- Efudix (5-fluorouracil) cream
- Aldara (imiquimod) cream
- Surgical removal
- Photodynamic therapy (PDT)

Actinic keratosis



Bowen disease (carcinoma in situ)

Bowen disease, or squamous cell carcinoma in situ (CIS), is commonly found on the lower legs, hands, forearms and face. It appears as crusty/scaly areas of reddened skin which can sometimes ulcerate. These areas can range in size from small lesions the size of a pea to large areas almost covering the back of a hand.

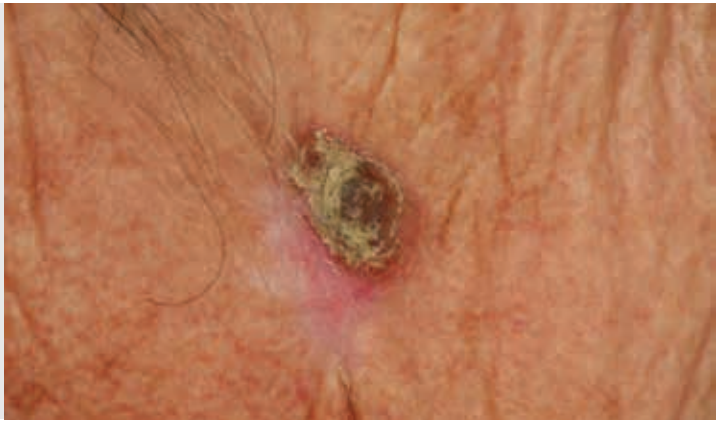
The presence of Bowen disease may be a sign that you are at increased risk of skin cancer, and these lesions have the potential to develop into skin cancer.

If you suspect the condition please contact the Dermatology Department for advice.

Treatment for Bowen disease

Bowen disease is usually assessed, diagnosed and treated within the Dermatology Department.

Bowen disease



Porokeratosis

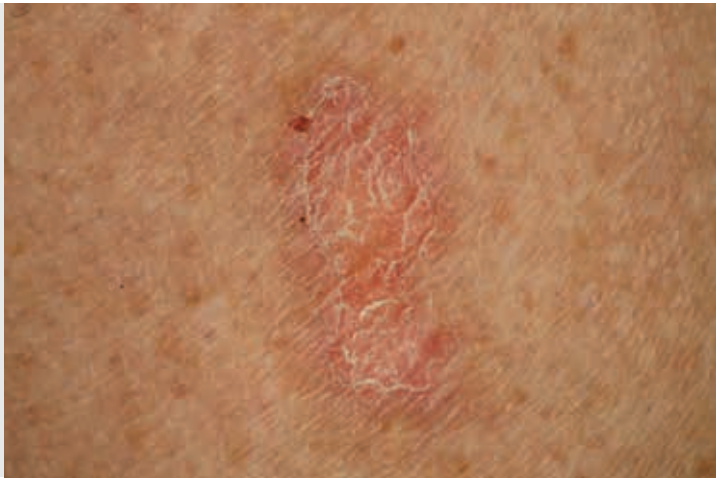
Porokeratosis appears as raised, sometimes scaly, red rings or patches which are often found on the lower legs.

Very rarely porokeratosis can develop into skin cancer, so if you suspect that you have the condition let your dermatologist know at your next appointment.

Treatment for porokeratosis

Porokeratosis is usually assessed, diagnosed and treated within the Dermatology Department.

Porokeratosis on the lower leg



Skin cancer

These four types of skin cancer are most commonly seen after an organ transplant:

- Squamous cell carcinoma (SCC)
- Basal cell carcinoma (BCC)
- Melanoma
- Kaposi sarcoma (KS)

The main cause of skin cancer is a combination of exposure to the sun, which may have happened many years earlier, and immunosuppressive drugs used to stop the transplanted organ from being rejected.

The major risk factors for skin cancer are:

- The length of time you have had your transplant: the longer you have had your transplant, the greater the risk
- Receiving your transplant after the age of 50 years
- Having light skin which burns easily and freckles in the sun
- High levels of sun exposure in the past
- Having a precancerous lesion such as actinic keratosis, Bowen disease or porokeratosis

Squamous cell carcinoma (SCC)*

Squamous cell carcinoma is the most common skin cancer in transplanted patients, especially those with fair skin.

SCCs appear as red, crusty, raised lumps, bumps or ulcers. Sometimes they may look like warts with a red base. They can be tender or painful and they may bleed. SCCs can grow quite quickly, for example double in size within two to three months, but this is not always the case.

SCC is most common on areas of the body that are regularly exposed to the sun, such as the face, ears, hands, and lower legs in women. Transplant patients will often go on to develop more SCCs after the first one appears.

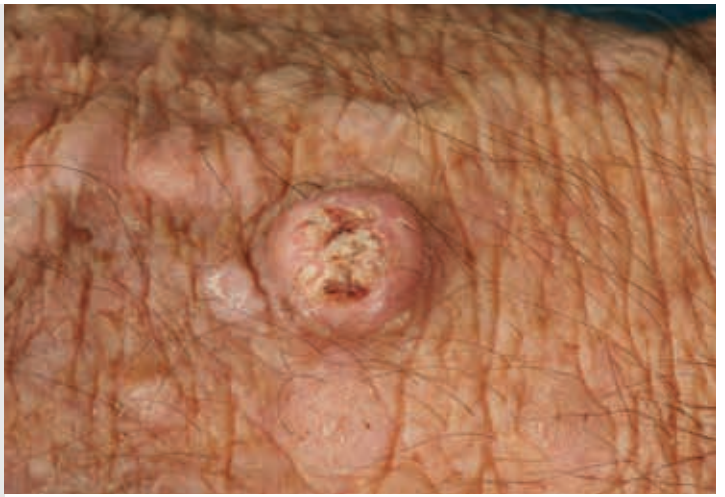
People from South Asian or African/Afro-Caribbean backgrounds are at a lower risk of SCC, but it may still occur – particularly in the genital region. If you see any non-healing lumps or bumps in this area you should let your dermatologist know.

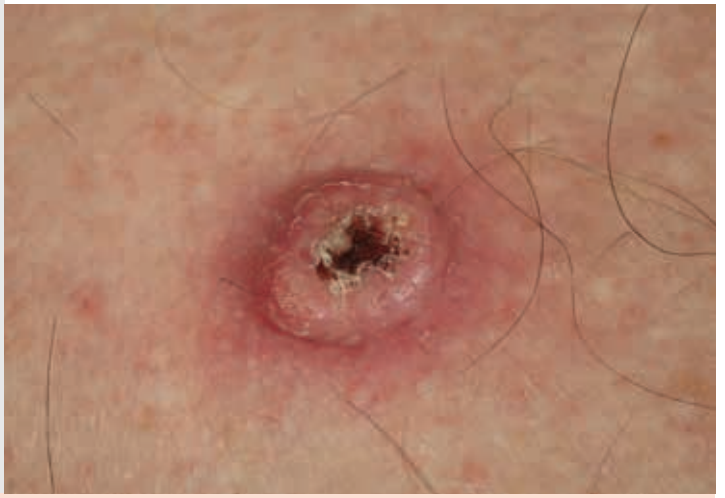
Treatment for squamous cell carcinoma

There are four treatment options:

1. Surgical removal. These lesions can usually be removed by surgery in the Dermatology Department. If the skin cancer is big, or in a difficult area such as the ears or eyes, plastic surgery may be necessary combined with skin grafting. If left to grow, SCC can infiltrate deeper and spread to the lymph glands.
2. Radiotherapy. This is occasionally used as an alternative, or in addition, to surgery.
3. A reduction in immunosuppressive drugs. Sometimes organ transplant patients can develop multiple squamous cell carcinomas. If this occurs the dermatologists may find out from the transplant doctors whether it would be possible to reduce the dose of immunosuppressive drugs.
4. Acitretin. In some cases a drug called acitretin may be prescribed to slow down and prevent the development of these skin cancers.

Squamous cell carcinomas





* If you think that you may have a squamous cell carcinoma, telephone either of the Dermatology Department contact numbers given on page 37 as you will need to see a dermatologist.

Basal cell carcinoma (BCC)*

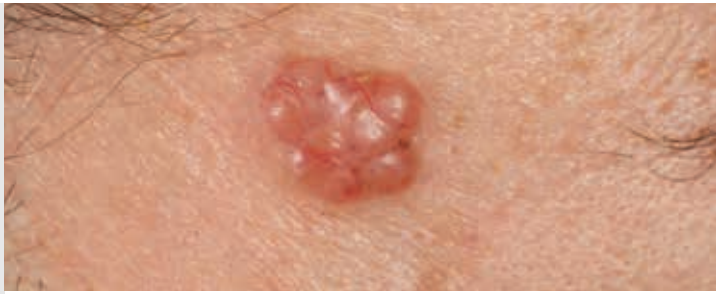
Basal cell carcinoma lesions usually appear as shiny/pearly lumps and are commonly found on the upper body and face, but they can develop elsewhere. Occasionally they appear as crusting, sore areas of skin that do not heal. The majority grow slowly and can take up to a year to double in size.

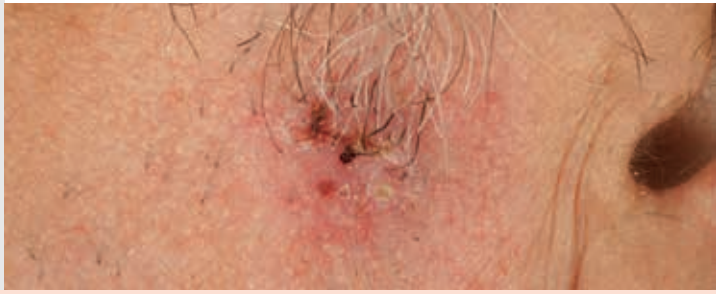
Treatment for basal cell carcinoma

The treatment options are:

- Surgery
- Aldara (imiquimod) cream or Efudix (5-fluorouracil) cream
- Cryotherapy
- Radiotherapy

Basal cell carcinomas





* If you think that you may have a basal cell carcinoma, telephone either of the Dermatology Department contact numbers given on page 37 as you will need to see a dermatologist.

Melanoma*

Melanoma is an uncommon tumour in organ transplant patients but it is important to catch it early as melanoma can spread. Melanoma can arise from a longstanding mole, or from a new mole that wasn't there before.

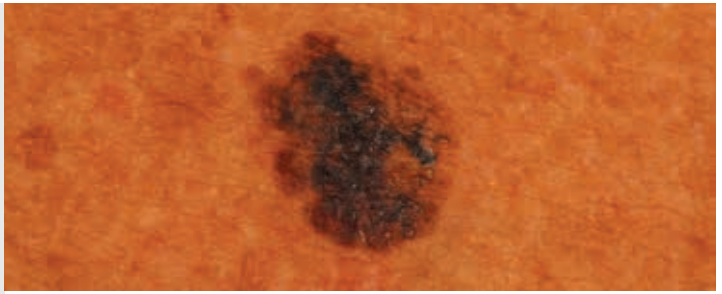
If you notice any change in the shape, size, or colour of a longstanding mole, or if you develop a new mole, it should be examined by a dermatologist.

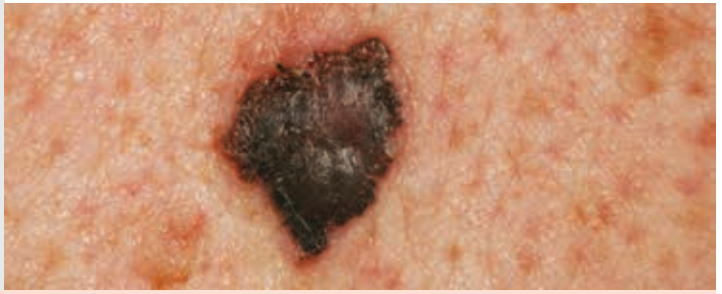
In people with darker skin, melanoma is more commonly seen under the nails and on the feet

Treatment for melanoma

Melanoma is usually treated with surgery in the first instance.

Melanoma





* If you think that you may have melanoma, telephone either of the Dermatology Department contact numbers given on page 37 as you will need to see a dermatologist.

Kaposi sarcoma (KS)*

People from Africa, the Middle East, the Mediterranean and Caribbean have a higher risk of developing a type of skin cancer known as Kaposi sarcoma. It is caused by human herpes virus (HHV8), which is very common in these areas.

The virus is often picked up in childhood and lies dormant in the body but can be reactivated when the immune system is suppressed with immunosuppressive drugs. This sarcoma can appear at any time after a transplant but usually develops in the first three to five years.

Most often KS appears on the skin but it can also affect organs inside the body such as the lymph nodes, lungs, the bowels or inside the mouth. Changes on the skin appear as small, flat areas of discolouration, spots, or larger, raised bumps or ulcers. Colours range from red, brown and purple to deep purplish blue. To confirm the diagnosis a skin biopsy, a small piece of skin removed under local anaesthetic, is taken from the lesion.

Other symptoms can occur before any skin lesions appear; one of the commonest is swelling in one leg. There may be swelling of the arms and legs accompanied by pain if the lymph nodes are involved. It is important to have these symptoms investigated by the Dermatology Department as soon as possible.

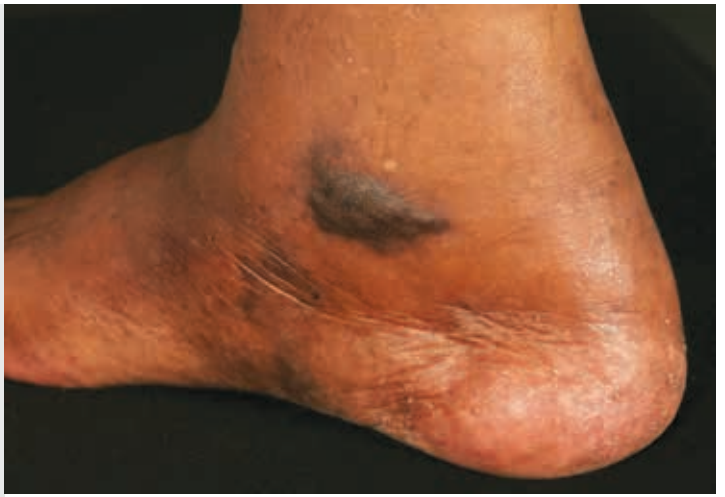
Treatment for Kaposi sarcoma

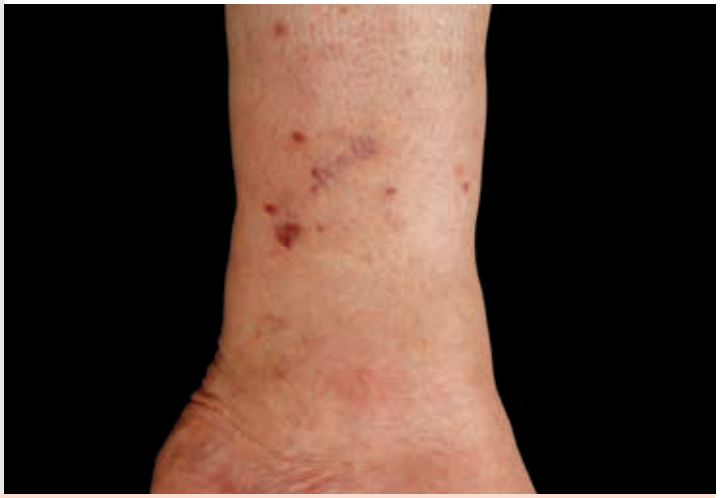
Sometimes all that is needed is a reduction or change in immunosuppressive drugs; this can take several months to have an effect.

Additional treatments such as surgical removal of the lesion, radiotherapy and chemotherapy are occasionally required.

If you have had a transplant, decisions on treatment for KS will be made in consultation with your transplant doctors as it is important to monitor the function of the transplant organ throughout treatment.

Kaposi sarcoma on the ankle and shin





* If you think that you may have Kaposi sarcoma, telephone either of the Dermatology Department contact numbers given on page 37 as you will need to see a dermatologist.

Skin cancer prevention

It is important that you can recognise the early signs of skin cancer so that the appropriate treatment can be given. The earlier these skin growths are detected, the better the outcome.

Skin self-examination

We recommend you examine your skin regularly, ideally at least once a month. This means that if you notice any new lumps, bumps, marks or growths on your skin they can be checked by a dermatologist and, if necessary, treated early. Early detection can help to reduce the risk of developing a larger, more serious skin cancer that may need extensive surgery or treatment.

You should be looking for:

- New skin lumps, spots, ulcers, scaly patches or moles that weren't there before
- Marks (including moles) on the skin that have changed shape, colour, texture or size
- Sores that do not heal
- Any areas on the skin that are itchy, painful or bleed

How to examine your skin

Ideally you should examine your skin in a warm, well-lit room with the following equipment:

- A chair
- A full-length mirror
- A hand-held mirror
- A comb
- A tape measure or ruler
- A digital camera or mobile phone to record any skin marks that you are not sure about

To make sure that you check all your skin, we suggest you examine yourself from head to toe following these steps. Use a mirror to check difficult-to-see areas or ask a friend or relative to help you.

Head

Beginning with your head, examine your scalp using a comb to part your hair so you can check all over your scalp. Go on to look over your face and neck. Don't forget to check behind your ears and the back of your neck.

Upper body

Check your shoulders, chest and abdomen, again using a comb to part any hair to examine the skin underneath. Don't forget to examine under your breasts and in the groin area.

Arms and hands

Examine each arm in turn beginning with the hands. Look at both the front and back of your hands and check between your fingers (the web spaces) and your fingernails. Examine all around your upper and lower arms (remember to use a mirror for places you can't see) and raise your arms above your head to check each armpit.

Back

If you have someone who can look at your back for you that is the easiest method of examination. If you want to do it yourself, use a full-length mirror in conjunction with a hand-held mirror. Look at the whole of your back starting at the top. Examine both shoulders to the middle of your back. Working from each side to the middle, traversing your back as you go, move down past your hips to your bottom.

Legs and feet

Sit down to examine the front and sides of your upper and lower legs. Remember to look at your groin area including the genitals. Look at your feet, paying particular attention to the soles and between your toes. Remember to check your toenails.

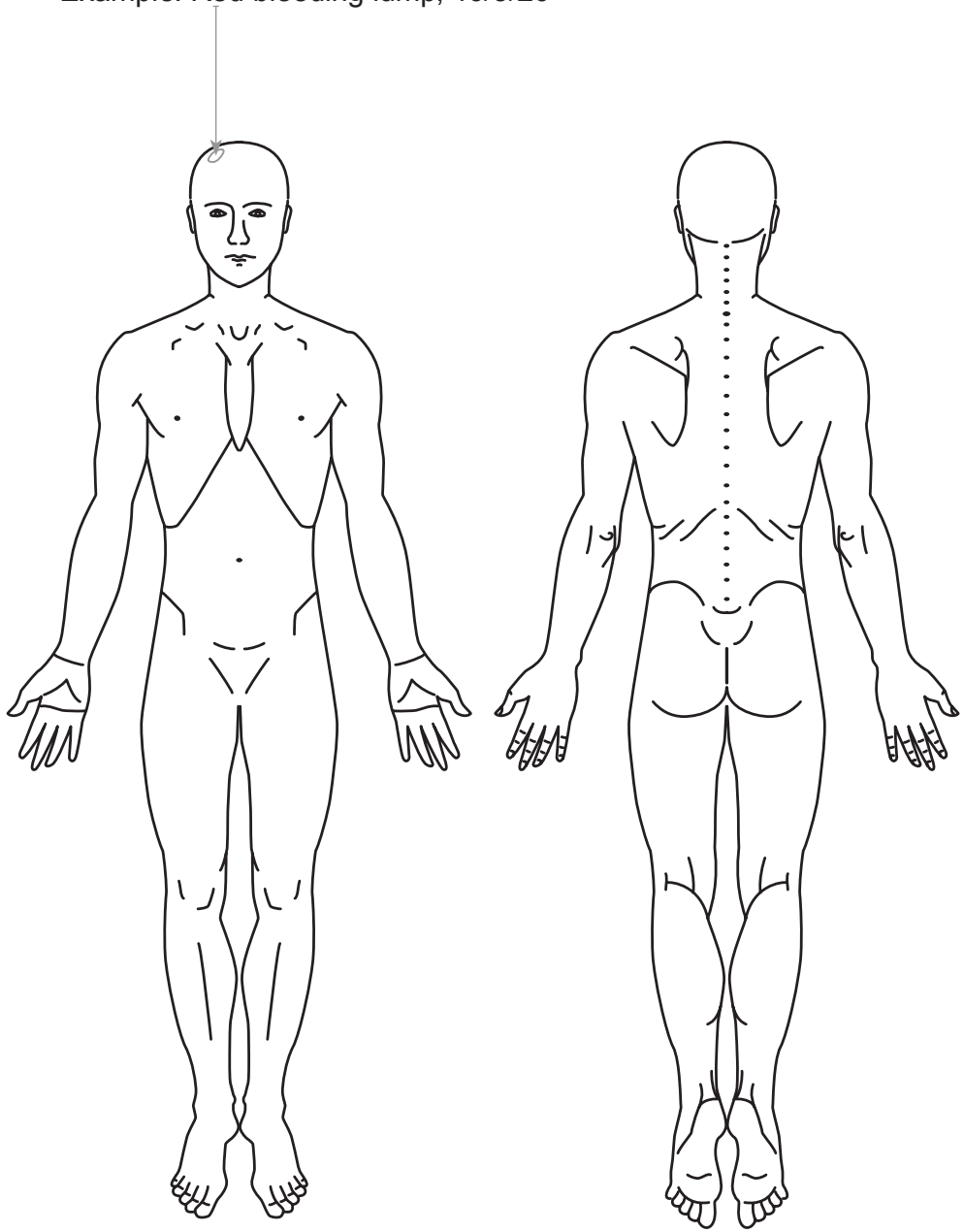
Recording what you find

You might find it helpful to keep a photographic record of any skin marks that you notice to see if they get any bigger, or change in any way.

You can also record any skin changes that you are worried about on these diagrams of the front and back of the body. As shown in the example here, draw a small circle on the diagram in the approximate position you found the skin problem. Write down the date that you noticed it, and any other remarks such as ‘bleeding’ or ‘itchy’. This will help remind you and assist the dermatologist when they see you at your next visit.

If you notice any new lump, bump, ulcer, sore, scaly patch or changing mole that lasts for longer than 2–3 weeks, contact your dermatologist for advice.

Example: Red bleeding lump, 16/5/20



Sun protection

It is important to protect your skin from excessive sun exposure. This includes when you are undertaking outdoor activities such as gardening, walking and sports.

The three golden rules are:

1. Prevent yourself from burning in the sun
2. Avoid sunbathing
3. Do not use artificial tanning beds

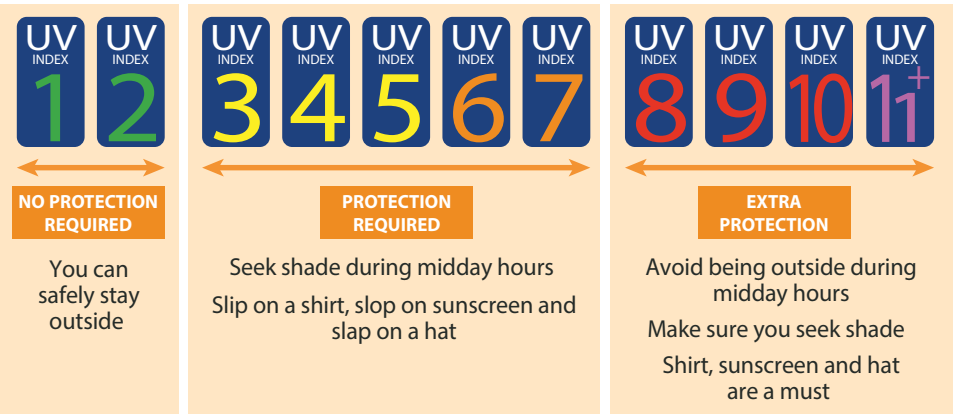
From April to October you should cover your body as much as possible by using a hat, long-sleeved clothing and sunglasses.

Use a good quality sunscreen with at least SPF 30 and a 4-star rating (this information can be found on the product) and stay in the shade. Note that between 11am–3pm the sun is particularly intense.

The UV index

You can find out how damaging the sun is at different times of day and in different parts of the world by using the ultraviolet (UV) index. The index is widely available in weather reports, online, and you can also download an app and receive alerts.

The higher the UV index number, the higher the risk of skin and eye damage. Although people with a darker skin are more protected, a UV index of 7/8 or above puts them at risk of sun damage. Very light skinned people are at risk with a UV index as low as 3.



World Health Organisation (WHO) UV index

Vitamin D

People who need to take extra precautions to reduce sun exposure may become deficient in vitamin D which is important for the healthy function of the body.

At least 90% of the vitamin D that the body needs is produced in the skin after sun exposure; vitamin D is quite hard to obtain through diet alone. Only a few foods are rich in vitamin D including oily or fatty fish such as salmon, sardines, tuna, mackerel and also cod liver oil.

Certain foods can be fortified with vitamin D including some types of cow's milk, soy milk, orange juice, cereals and oatmeal.

If you think that you may be at risk of vitamin D deficiency because you are being careful about sun protection talk to your GP or transplant doctor. If a blood test shows that your vitamin D level is low it is easy to treat with vitamin D tablets.

Further information

British Association of Dermatologists (BAD)
Information about skin care for pre-transplant and transplant patients.

www.bad.org.uk

British Society for Skin Care in Immunosuppressed Individuals (BSSCII)
This organisation, linked to the BAD, was founded in 2011.

www.bsscii.org.uk

International Transplant Skin Cancer Collaborative (ITSCC)
Information on skin care and transplant medication.

www.itscc.org

Cancer Research UK
Information about cancer and cancer care.
General enquiries 0300 123 1022

www.cancerresearchuk.org

Macmillan Cancer Support
Cancer information and support charity.
Support line 0808 808 0000

www.macmillan.org.uk

Skin Care in Organ Transplant Patients Europe

www.scopenetwork.org

Dermatology Department
The Royal London Hospital

Contact numbers

Dermatology skin cancer CNS	Michelle Marshall michellemarshall1@nhs.net 020 3594 2102 07934 904089

Patient diary

Please use this diary to keep a record of your clinic visits

Visit date	**Outcome** (treatment etc)	**Comments** Write down anything you want to mention at your next visit	**Next appointment**	
			Date	Time

Large print and other languages

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. For more information, speak to your clinical team.

এই তথ্যগুলো সহজে পড়া যায় অথবা বৃহৎ প্রিন্টের মত বিকল্প ফরম্যাটে পাওয়া যাবে, এবং অনুরোধে অন্য ভাষায়ও পাওয়া যেতে পারে। আরো তথ্যের জন্য আপনার ক্লিনিক্যাল টিমের

Na żądanie te informacje mogą zostać udostępnione w innych formatach, takich jak zapis większą czcionką lub łatwą do czytania, a także w innych językach. Aby uzyskać więcej informacji, porozmawiaj ze swoim zespołem specjalistów.

Macluumaadkaan waxaa loo heli karaa qaab kale, sida ugu akhrinta ugu fudud, ama far waa weyn, waxana laga yabaa in lagu heli luuqaado Kale, haddii la codsado. Wixii macluumaad dheeraad ah, kala hadal kooxda xarunta caafimaadka.

Bu bilgi, kolay okunurluk veya büyük baskılar gibi alternatif biçimlerde sunulabilir, ve talep üzerine Alternatif Dillerde sunulabilir. Daha fazla bilgi için klinik ekibinizle irtibata geçin.

یہ معلومات متبادل فارمیٹس میں دستیاب کی جا سکتی ہیں، جیسا کہ پڑھنے میں آسان یا بڑا پرنٹ اور درخواست پر متبادل زبانوں میں بھی دستیاب ہو سکتی ہیں۔ مزید معلومات کے لیے، اپنی کلینکل ٹیم سے بات کریں'۔

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