

B.U.G.S.



Mission Statement

To support and encourage people as they move out into the community who are under the care of the Odstock Centre for Burns, Plastic and Maxillofacial Surgery, by providing the opportunity for friendship, information, as well as practical and professional help and advice.

Objectives

- To support and encourage these patients and their families/carers.
- To gather and impart relevant information to survivors and their families /carers.
- To provide public education through the media and programmes to help reintegration into society.
- To fund raise to support the work of B.U.G.S.
- To provide grants to help a patient return to their community or access specialist support.
- To support relevant research that will benefit B.U.G.S. members.



INTRODUCTION

The idea for this booklet originated from the one produced by the McIndoe Burns Support Group based at The Queen Victoria Hospital, East Grinstead. The Burns Unit Group Support (B.U.G.S.) would like to thank them for allowing us to use their booklet as the basis for this one.

We hope that our information will help you and support you through any difficulties you may find you have to face now you have left the hospital.

Unfortunately, for many patients, burn care does not stop once you leave the Burns Unit and the hospital. The length of your recovery depends on the extent of your injuries, the need for surgery and your body's natural healing processes.

On being discharged from hospital you may feel worried and anxious about how you are going to cope and you may find it difficult to return to your old routine.

We hope our booklet will help you during this time.

We have tried to follow a logical sequence by starting at the beginning of the day with washing, skin care and dressing, then progressing on to more general information around everyday activities and needs.

You may find it useful to dip into individual sections as required.

Though you have been discharged from the Burns Unit, please do not hesitate to contact the nurse-in-charge if you have any questions concerning your care once you are at home.

Telephone number: 01722 345507.

There is a video/DVD available from the Burns Unit called 'The Vital B.U.G.S. Video'. It covers some sections from this booklet in more detail.

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Patient Representatives

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WHAT IS B.U.G.S. - THE BURNS UNIT GROUP SUPPORT?

B.U.G.S. was originally set up as a charitable support group for people who have been burned and their families/carers. B.U.G.S. (Registered Charity Number: 1052284 B.U.G.S. Fund 1223) was founded in May 2000 by staff trained in burn care and an ex-patient.

What does B.U.G.S. do?

We offer support, friendship, practical information and advice.

Help from B.U.G.S. is offered to all current and previous patients and their families. They do not have to have been treated in Salisbury District Hospital.

The group's logo is a red ladybird, which you will see on the tabards that the volunteers wear.

B.U.G.S. volunteers visit patients on the Burns Unit. You, your family or carers are welcome to come and have a chat over refreshments.

B.U.G.S. can give information about a variety of things that you may find useful and help you to link into professional help, therapy and treatment. We can recommend national organisations for additional support.

More recently, B.U.G.S. has widened its scope and now supports patients who are under the care of the plastic surgeon in Salisbury.

B.U.G.S. provides 2 newsletters a year which describe its activities during the year. It also sponsors children and young adults to attend Burn Camps held each year.

Occasional formal meetings are organised and everyone is welcome to attend these.

Membership is free.

For further information please contact the Sister on the Burns Unit.



SHOULD I BATHE OR SHOWER?



It is important that you bathe or shower every day. This helps to prevent a build up of the moisturising cream, which you will be using on your skin.

If you do not feel confident to have a bath or shower alone, make sure that you have someone with you.

The bath must be cleaned and rinsed before you use it as part of normal good hygiene. This should be done with a clear liquid or foam cleaner. A more abrasive cleaner may leave bits in the bath, which you may find irritate your skin.

You will find that your skin is more sensitive to hot and cold temperatures. For this reason it is important that you test the water temperature in the bath or shower with an area of unburnt skin before you get in. You should aim for pleasantly warm water.

You should remove your dressings or pressure garments before you bathe. However, if they are stuck to your skin you may find it helpful to soak them. You can do this by getting in the bath or shower for a few minutes before you try to remove them.

(See section - 'Washing')



WASHING

When you wash you need to use a mild or pure non-perfumed soap, such as 'baby' soap. This will help to reduce the chance of your skin being irritated, which can happen with more perfumed soaps.

You need to clean your skin as you have been advised by the staff on the Burns Unit.

Dry yourself gently with a clean towel.

You will find that your skin will feel more supple after being warmed and after being in water.

WASHING YOUR HAIR

If your head has been burnt, wash your hair with a gentle shampoo such as a 'baby' shampoo. This will reduce the likelihood of irritating your unhealed or newly healed areas.

Wash your head with gentle pressure from your fingertips rather than with your nails. Make sure that you rinse your hair thoroughly to remove all of the shampoo.

(See section - 'Should I bathe or shower')

HOW DO I LOOK AFTER MY SKIN?

It is important to moisturise your skin after you have had a wash. The oil and sweat glands are often damaged in a burn injury, making the scar area drier than normal skin.

New skin will benefit from massage with a moisturising cream to improve its quality. This will help to make the area supple and less dry and also help to reduce itchiness.

You need to use a non-perfumed moisturising cream. This hospital uses sunflower oil cream. The cream that you use should be light and non-greasy.

You will not need to use too much cream. It is more important that you massage the cream into your skin well.

(See section – ‘Should I bathe or shower’)

SKIN CARE - throughout the day

Your skin will benefit from massage and moisturising a minimum of 2 – 3 times a day. This needs to be fitted in with your lifestyle.

Wash your skin carefully before a session of applying your moisturising cream. This will help to prevent build up of the cream, which can lead to blackheads or pimples.

I STILL HAVE DRESSINGS. WHAT SHOULD I DO ABOUT THEM?

If you have been discharged from the Burns Unit and are still having dressings you should keep them in place until your next appointment at the hospital or with your family doctor, unless: -

- fluid oozes through the dressing
- the dressing becomes accidentally wet
- you experience worsening pain or discomfort
- you feel unwell

If any of these happen you should contact the Burns Unit to seek advice. You may need to be seen sooner than originally planned.

Some dressings can seem to trap or produce extra fluid and may have a different smell. If you are concerned about this, contact the Burns Unit for advice.



WHAT KIND OF CLOTHES WILL BE BEST?



You will feel more comfortable if you wear loose or easy fitting clothing made of natural fibres such as cotton, linen or silk rather than man made fibres like polyester. Try clothes with an elastic waistband.

You may be more sensitive to extremes of temperature and should dress so that you are comfortable.



WHAT SHOES SHOULD I WEAR?



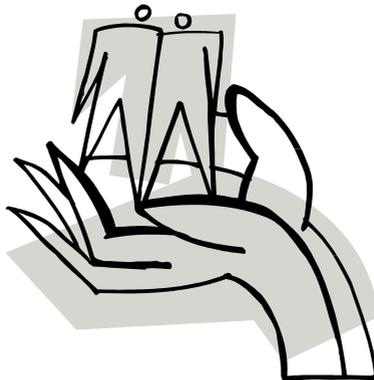
If your feet have been burnt it is important that your shoes are comfortable and do not rub the newly healed skin. You may need to wear different styles of shoes to normal. You may find that you need a larger size than usual and you will need to make sure that the style of shoe does not cause problems to your skin. Slippers are often a good choice of footwear in the beginning.



WHAT IF I GET STARED AT?

Sadly people will stare, so you may feel more comfortable in clothing that covers you more, e.g. long-sleeved shirts if your arms are scarred. You may find that your confidence grows over the course of time and being looked at may not bother you in the long term. You may then find it easier to dress in your normal style of clothes.

With the help of others it is possible to develop your strategies for coping with other people's reactions to you. It is worth mixing with friends and other people so that they can get used to seeing you as you are. If you need help with this you could discuss it with your G.P., who can arrange any necessary support or training that may be available to you. If you would like to talk to a psychologist, please talk to the Burns Unit or B.U.G.S. volunteers.



EATING AND DRINKING

When you are recovering from burns it is important to eat well to help the burn to heal. You need to eat a well balanced diet including a variety of different foods at each meal to give you all the energy and nutrients required for wound healing.

Use the 'Balance of Good Health Plate Model' to help you plan your meals.

(See the next page)

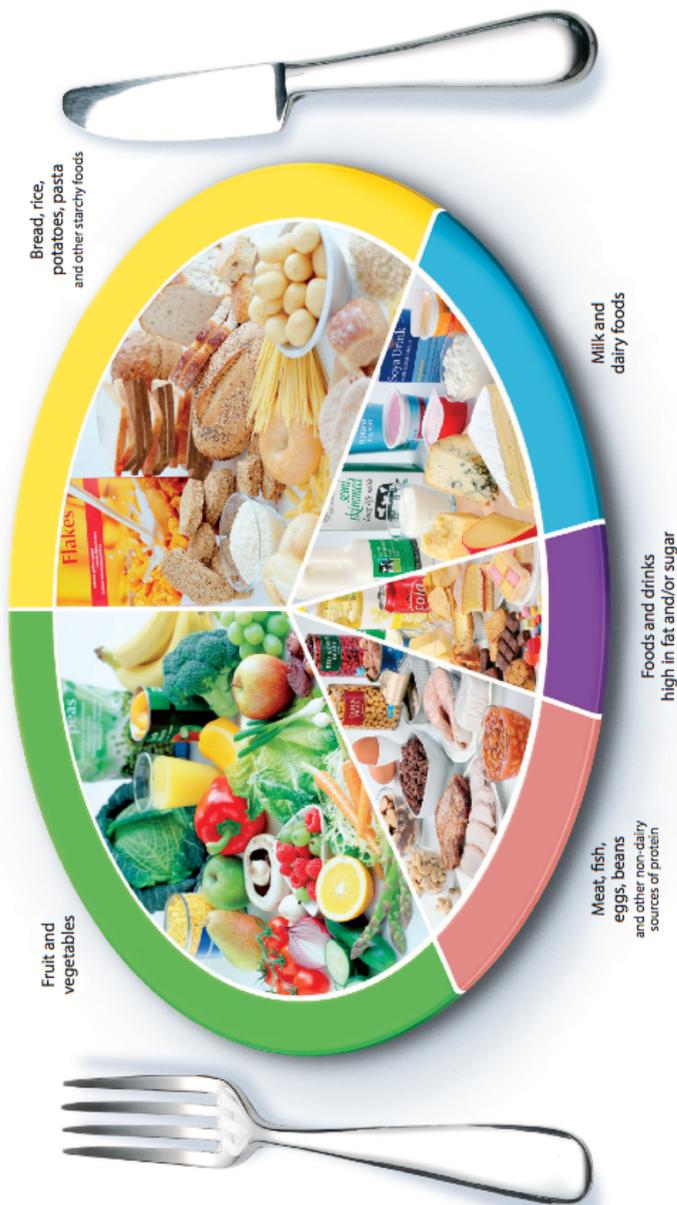
Try to eat something from each of the food groups at every meal.

It is important to remember to drink plenty of fluids, such as water. Having been in hospital, where drinking is encouraged, it is easy to forget to drink once you are home.



The eatwell plate

Use the eatwell plate to help you get the balance right. It shows how much of what you eat should come from each food group.



WHAT DO I DO IF I HAVE PAIN?

- Take any pain killers that you have been given as you have been instructed. However, you should contact the Burns Unit or your family doctor for advice if you feel that your pain has become a problem.
- Doing an activity can help distract you from your pain. It is important to try to do something. You will need to work out how much activity you can manage. You may need to pace your activity level according to how you feel. If you break a task into smaller chunks rather than one big chunk, you are more likely to complete your task, which will give you a sense of achievement.



WHEN CAN I BEGIN NORMAL DAILY ACTIVITIES?

It is normal to feel more tired than usual when you first go home from hospital. One way to manage the day is to pace yourself. This involves doing a task and having breaks little and often. You could try to do different types of activities that need different types of physical abilities. Your aim is to be able to reach the end of the day having achieved something without feeling too exhausted because you have tried to do too much.

Remember – preparing for the day will take longer than before your injury as you have more personal needs. At times this will be frustrating, but it is important to remember that the end result is worthwhile. Do not be discouraged if you cannot manage all your normal daily activities immediately.

Whilst you may not be able to get back to your usual activities straight away, it can be helpful to try to get into a routine of sorts. Have a 'wake up' time to start the day and try not to get stuck in front of the TV all day. Include a range of different activities in your day and try to do things outside the home too. You may find it easier to try small amounts of activity at first, gradually building up as you feel able.



It is very easy to feel isolated and lonely. Try to get out and about and go back to your previous activities when you can. Try not to be demoralised if you do not achieve things as quickly as you would like.

If you had an inhalation injury with your burn (injury to your throat, lungs or breathing airways), you may have some periods of shortness of breath or wheezing even after a small amount of activity. You may also have some hoarseness in your voice or have colds and coughs more often than usual. You may need to see your G.P. if you do not recover from colds or coughs as quickly as you used to.

WHY DO I FEEL SO LOW?

Although the return home is easy for some, it is not uncommon to feel anxious or depressed. Getting back to family and community life requires patience and understanding from both yourself and those around you.

Periods of feeling down, restless, problems with sleeping, reliving the accident, worries over finances, worries over other people's reactions and how you look are not unusual. You can expect to have days when you feel you have returned to normal as well as days when you are overwhelmed by what has happened to you and are unable to cope.

Remember that these emotional feelings are normal

If you find that you are feeling low for several days you may find it helpful to discuss your feelings with someone you can trust such as your G.P. Your G.P. may be able to put you in touch with someone with whom you can discuss your particular problem, in confidence.



MAKING TIME FOR YOURSELF

It is important that you make time for yourself and do things that you find relaxing and enjoyable. For example, by getting back to former leisure activities. However, your ability to do this will be dependent on what you enjoy doing and your injury.

Doing things which you enjoy will tend to lift your spirits.



RELATIONSHIPS AND SEXUAL ACTIVITY

Relationships will be different for all concerned i.e. friends, children, partner, parents and colleagues, essentially anyone with whom you have a relationship.

Some people may have concerns about sexual activity. This might be because of physical discomfort, pain, skin sensitivity or tiredness. It might also be due to anxiety, depression, low self-esteem or worries about how your body looks. It is important to talk to your partner about your concerns and try to address them together. With time and understanding sexual difficulties can be resolved.



This again is quite normal. You will all need time to adjust. If you are experiencing difficulties it is worthwhile trying to talk things through and, if necessary, seek help from your G.P., who may recommend counselling sessions for anyone concerned.

SKIN CHANGES

With a burn or scald injury it is probable that there will be some scarring. This depends on the depth of the burn and the length of time that it takes to heal.

It is difficult to predict the severity of the scarring that will occur. It depends on:

- depth of the burn
- how long the burn takes to heal
- your skin type
- your age
- location on the body

Scar tissue undergoes changes in colour (red/purple/blue), texture and flexibility over time. In addition, you will notice changes in colour related to changes in temperature. This is perfectly normal (also see pages 24-26). Eventually, most of the scar will become pale, soft and supple.

To help control scarring and skin tightness we recommend that you:

- Exercise and stretch as you have been taught
- Keep active
- Massage and cream your scars as you have been advised
- Wear any splints that you have been given as advised and make sure that they are well fitting. Contact your therapist or orthotist if they do not seem to fit.
- Wear any pressure garments that you have been given and make sure that they are well fitting. When your garments are new, you may find that they are quite tight and you might need to wear them for short periods to begin with, gradually increasing the wearing time until you are able to wear them all day.

CHANGES IN BODY TEMPERATURE

It is not unusual to find that your body does not regulate temperature in the same way as it used to before your injury. You may feel hot when you would not expect to do so. You may also find that you sweat differently.

Patients have said, “I cannot regulate my temperature. I find that I am the same temperature as my surroundings. If the house is cold, then I feel very cold. If the room is warm I feel that I want to step outside to cool down”.

No one can predict how long these changes will last. We advise that you wear layers of clothing that you can take off or put on as you feel necessary. It is important to remember to drink enough water if you have a tendency to feel hot.

(See section – ‘What kind of clothes will be best?’)

WHY DO MY SCARS CHANGE COLOUR?

Scar or donor areas may appear dark pink, deep red or purple. Discolouration of burn or scald areas is normal because of changes in the blood circulation and the make up of the newly healed skin.

The change in colour may be more noticeable at different times of the year, especially in colder weather when your body temperature changes or when you are doing activities that increase your heart rate.

The skin's natural colour might return to areas that have superficial or partial thickness burns after several months. Deeper burns may have some permanent discolouration. Skin that has had a deeper burn will always be a different colour compared to the surrounding skin.



SKIN CAMOUFLAGE

Skin camouflage is the application of specialist cover creams to improve the appearance of scarring and other disfiguring skin conditions, including scarring from burns.

The daily creams are used to conceal blemishes and they provide effective, long lasting, waterproof cover on any area of the body. They are appropriate for men and children as well as women.

We have a “Changing Faces” skin camouflage volunteer in the hospital that will discuss camouflage if required.

For more information visit

<http://www.changingfaces.org.uk/skin-camouflage>

Or

Telephone: 0300 0120276.

E-mail: skincam@changingfaces.org.uk.

(As of 2013)

This is also provided privately.

MEDICAL TATTOOING

Medical Tattooing is a technique that can be used to improve your appearance in particularly on the face. This will need to be discussed with your consultant.

More information can be found at:

<http://www.katiepiperfoundation.org.uk/medical-tattooing/>

SKIN PROBLEMS

Blisters

Your newly healed skin will be quite delicate for several months and will have a tendency to develop little blisters which may seem to appear for no specific reason. At other times, they may occur as a result of rubbing from clothes or pressure garments or after you have bumped yourself.

It is important not to pop the blisters if they appear normal i.e. not infected. Keep the area clean. You can expect the blister to pop or get smaller by itself.

The tendency for blisters to form gradually disappears over time.

Do not wear pressure garments until your blistered area has healed.

Do continue to use your cream but do not apply cream to any open areas and massage delicate skin with care.

There may be other skin problems which are described in the table on the next page.

If you are worried about your skin contact the Burns Unit for advice.

QUICK CHECK TABLE FOR SKIN PROBLEMS

PROBLEM	WHY MIGHT THIS HAPPEN
Blisters may occur on the burn or scalded areas as well as on donor sites. They are common for the first few months.	Rubbing from clothing or pressure garments or from accidental knocks to the skin.
Skin breakdown that can happen over a long period of time.	Small knocks, rubbing, scratching or infection.
Whiteheads and blackhead care a common problem which decreases over time.	They can be caused by such things as cream, dirt or soap collecting in the uneven scar tissue.
Cysts may occur in the first six months and can be very uncomfortable. They may appear as red, black or yellow raised lumps under the surface of the skin.	Cysts can occur as a result of small areas of skin, or dirt becoming trapped under the graft leading to a localised infection.

TREATMENT	HOW COULD IT BE PREVENTED
<ul style="list-style-type: none"> • Leave the blister alone • Do not pop it • Use a dressing to protect the blister under your clothing and garments • If the blister becomes larger or infected contact your practice nurse or the Burns Unit for advice 	<ul style="list-style-type: none"> • Follow your skin care instructions carefully • Make sure that your pressure garment fits well • Change your pressure garments daily • Wash pressure garments daily • Avoid tight fitting clothing
<ul style="list-style-type: none"> • Contact the Burns Unit for advice • Your pressure garments may be causing the problem 	<ul style="list-style-type: none"> • Follow the above information • Try not to knock your vulnerable area • Do not scratch
<ul style="list-style-type: none"> • Gently wash the area with a soft sponge and soap in warm water 	<ul style="list-style-type: none"> • Good skin hygiene is essential • Careful washing of your skin to remove old cream before applying the new is very important
<ul style="list-style-type: none"> • Soak in warm water and then gently wash the area with a circular motion using a soft sponge 	<ul style="list-style-type: none"> • Good skin hygiene is essential

WHAT CAN I DO ABOUT MY ITCHING?

This is a common problem affecting burn, scald and donor areas. This is a result of nerve endings, which are often damaged through the injury or surgery, growing back. Unfortunately, there is no complete cure for this distressing problem. It is usually worse in the Summer and at night when you will be warmer. It can cause loss of sleep and appetite. As time passes itching should decrease.

To minimise the problem: -

- Good skin care is essential i.e. bathing and proper use of moisturising creams. Keeping your cream in the fridge and using it cold can increase the relief obtained through moisturising.
- Bathing the area with cool water or placing a flannel soaked in cold water may bring some relief or, if your skin condition permits, frequent cool baths.
- Careful washing of your pressure garments is important. Avoid strong washing powder. Ensure that soap powder is thoroughly rinsed out of your garments.
- It is best to wear cotton clothes and sleep in cotton sheets. Wool and nylon will tend to increase skin temperature and therefore increase itching.
- Do not scratch as this might cause the skin to break down.

- Your doctor may be able to prescribe medication that might help.
- Once your skin is well healed you may want to try other products, such as different moisturisers, to try to help minimise the itching.
- Laser treatment may be beneficial. This will need to be discussed with your consultant.
- Some people find portable air-conditioning units are helpful when the weather is hot.



BURNS SCAR MANAGEMENT CLINIC

If you are at risk of scarring following your burn injury you will be given an appointment for the scar clinic; usually within 1 month of being healed.

The aim of the clinic is to help you care for your newly healed skin and provide information and treatment. This will help to improve the suppleness of the scars. A therapist may also assess your movement, function, and suggest ways to improve this if necessary.

A decision will be made as to whether you would benefit from having pressure garments or any other scar management products. This will all be discussed with you during the clinic appointment.

You may receive support from the clinic for up to two years. This depends on how your scar matures. You are likely to have appointments every three to four months.

The clinic is held on the burns unit every other week. It is a nurse led clinic with access to a physiotherapist, occupational therapist, consultant, psychologist and B.U.G.S., who are able to refer to other specialists as required.

WHAT ARE PRESSURE GARMENTS?



These are close fitting garments made of Lycra. They are either off the shelf garments for use when your skin is delicate, or made to measure garments, which you will be encouraged to wear for up to 23 hours a day.

Scars are improved by the pressure put on them from these garments, which flatten and soften them more quickly than if pressure is not used.

The staff in the clinic will explain about the garments and their use and will also advise you about when to wear your garments, particularly if you have small, unhealed areas of skin.

(See section - 'what can I do about my itching')

WHAT CAN I DO IF MY LIMBS ARE SWOLLEN?

This may continue to be a problem for some time. To help control swelling: -

- Wear your pressure garments
- Exercise regularly
- Rest your arms and legs propped up on pillows when you are sitting or resting, as you have been shown
- Put your feet up.



CAN I GO OUT IN THE SUN?



Do not sunbathe during the two years following a burn injury because your skin is likely to burn and this can worsen the appearance of your scarring due to increased pigmentation (it will go darker than normal).

It is essential for you to protect your skin from the sun.

Follow these directions carefully: -

- Avoid direct sunlight on the affected areas for **at least** two years after healing has occurred.
- Wear cotton, silk or linen clothing over your pressure garments. Your pressure garments will not protect your skin from the sun as they allow 60% of the sun's rays through. There are companies who specialise in sun protective clothing. B.U.G.S. can give you

information about these companies, or you can type, “sun-protective clothing” into a search engine.

- Always use total sunblock (for sensitive skin) on areas you are unable to protect with clothing, even on a cloudy day. Sunblocks need to be re-applied according to the manufacturer’s instructions and particularly after swimming.
- Schedule activities to take place in the cool of the day if possible. Avoid the hottest time of day between 11.00am and 3.00pm for outdoor activities.
- You can still get sunburnt through sitting under sun canopies and on cloudy days.
- If you swim in the sea we recommend that you apply sunblock, wear a shirt and only stay in the water for half an hour at a time. Try to rinse your skin thoroughly and apply more sun block, afterwards.



UVA & UVB PROTECTION

It is important that you wear a sun cream which provides good protection for both UVA **AND** UVB exposure. Recent scientific experiments by RAFT suggest that it is important to look at UVA as well as UVB factors. UVB causes burning, but now UVA is believed to play a greater role in skin cancer than previously thought although it does not cause burning to the same extent as UVB.

Although sunscreens do not provide the same protection against UVA as they do against UVB it remains important to wear a high factor sun protection.

Sunscreen UVB continues to be indicated by a factor rating e.g. 20, 30 etc. A star rating indicates UVA protection. The highest star-rated cream available is 5-star.

The usual guidelines for sun exposure, such as covering up, seeking shade and avoiding the midday sun still apply.



EXERCISES

You will have been given advice while you were on the Burns Unit about the importance of exercise to regain and maintain movement. You may have been advised on a specific programme for your injury.

It is important that you do any exercises that you have been given regularly, as well as maintain your general fitness and stamina. You need to continue to do these exercises until you feel that you are able to maintain your movement through your normal everyday activities. Even then you may find that you need to do your exercises occasionally.

It is easier to exercise when your tissues are warm, e.g. after a bath. It is better to do your exercises little and often throughout the day.

You can be flexible in your approach to doing your exercises and vary them depending on how you are feeling and what you are able to do.



STRETCHES

If your burn is to skin that goes over a joint you will need to do stretches to maximize your movement. As your skin heals it will tend to get tighter and limit the joint moving through its full range. You will be taught stretches by the physiotherapists to help minimise this problem. It is important you do these stretches regularly as long as is required.

Please contact your therapist if you are having difficulties with this.



DO I HAVE TO WEAR MY SPLINTS?

Splints are very useful in helping to maintain or improve range of movement in joints. If you have a problem with keeping movement in a joint you may be given a splint made from a plastic material. A physiotherapist, orthotist or maxillo-facial technician will specifically make your splint for you. You will be advised when to wear your splint and its use will be explained to you.

After you have been discharged from the hospital you will need to check that your splint always fits properly. If it does not fit, or it is not doing its job properly, contact your physiotherapist and arrange for your splint to be altered.

It may be necessary to wear a splint for several months as advised by your therapist.



WHEN CAN I RETURN TO MY LEISURE ACTIVITIES?

Getting back to your former leisure activities will depend on your injury and your sport.

If you do a physical sport, do some stretches before and afterwards.

You may find that you get more overheated during physical activity, so remember to drink enough water to compensate for fluid loss. It is also important to make sure your clothing is not going to cause problems by being too tight or of the wrong fabric.

(See section – ‘What kind of clothes will be best’)

You may also find that you sweat differently after your burn.

Once the burn has healed you can return to swimming. Shower thoroughly at the end of your swimming session. If you are swimming in an outdoor pool it is important that you wear a waterproof sun block over the burned areas.

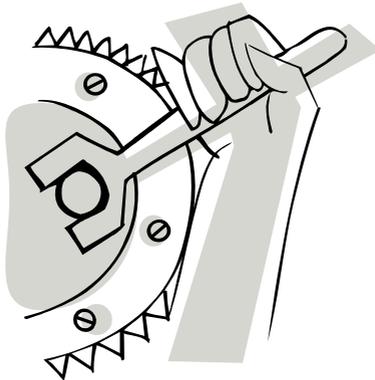


WHEN CAN I RETURN TO WORK?

You need to seek advice from your hospital doctor or nursing staff about when you could return to work.

We would encourage you to return to work as soon as you feel able in order to help you regain a normal pattern of life.

You will probably need to discuss your return to work and any special needs you may have with your employer to help your return to work be as smooth as possible.



REFERENCES

Home at Last! - Published by McIndoe Burns Support Group, East Grinstead

Burns Scar Management Clinic (formerly the Tissue Support Clinic) Patient Information Leaflet – Salisbury District Hospital

RAFT, Leopold Muller Building, Mount Vernon Hospital, Northwood, Middlesex. HA6 2RN

Jobskin Ltd, Unit 13a, Harrington Mill, Leopold Street, Long Eaton, Nottingham, NG10 4QG

