

MANAGING FATIGUE RELATED TO CANCER

What is Fatigue?

Fatigue is the feeling of extreme tiredness or exhaustion all or most of the time. It can feel overwhelming and unrelenting and it is often not improved by rest. Some people describe fatigue as feeling “weary”, “exhausted” or “washed out”. It is a common symptom of cancer and its treatments. It can affect anybody at any time irrespective of their age or type of cancer they have.

Common Features

For some people fatigue is very mild and does not interfere much with daily life. For some people it can be very disruptive. If you experience fatigue you may experience one or more of these symptoms:

- Feeling impatient with those around you, affecting relationships with family and friends
- Lacking in motivation, feeling you can't be bothered. Avoiding socialising because it is too much effort
- General tiredness and a feeling of having no energy. You may feel as if you could spend whole days in bed, unable to complete the smallest chore
- You may find it difficult to remember things and have trouble thinking, speaking or making decisions
- Judgement may be impaired and decision making may be more difficult or slow
- You can experience difficulty getting to sleep
- Loss of sex drive
- You may feel sad and upset

Causes of fatigue

Cancer

Cancer itself can cause fatigue. It is unclear whether the type of cancer a person is diagnosed with means that they experience more or less fatigue than a person with a different cancer.

There are many factors which make a difference and they are individual to you.

Pain

Pain can make fatigue seem worse and fatigue can make pain seem worse. Let the health professional who is looking after you know if you have any pain. It is important to be honest so that the right treatment can be given.

Treatment

Chemotherapy, Radiotherapy, Hormone Therapy, Immunotherapy and Surgery can all increase the amount of fatigue you can feel. It is important to tell your doctor or other health professional what affect fatigue is having on your everyday life.

Anaemia

Red blood cells contain haemoglobin which carries oxygen to all the cells of the body to provide energy. If the haemoglobin level is low this is called anaemia. You may be offered a blood transfusion or other treatment if anaemia is making you very tired or if you have other symptoms such as breathlessness.

Eating Problems

Poor appetite due to cancer and/or treatment can mean that you have less energy. Problems such as sickness, having a sore mouth, difficulties in swallowing or changes in your bowel movements can reduce the amount you feel able to eat. Help and advice can be provided by your health professional and you may be referred to a dietitian.

Medication

Some medication can cause fatigue and/or drowsiness. You may be warned about this and it is important to report this to the health professionals looking after you if it persists.

Psychological Effects of Cancer

Anxiety, depression, stress and tension can combine to increase fatigue.

How long will it last?

- Everyone is affected differently and the length of time fatigue lasts depends on its cause
- Some people find that levels of fatigue can affect them in peaks and troughs
- The fatigue itself may continue to affect you even if the cause of it may have stopped

Please talk to a health professional if you are worried.

What can I do?

Exercise

Not being physically active at all can make fatigue worse. But there are things you can do to help you feel better.

It is important to conserve energy, but light, gentle exercise can gradually be built up over time.

Usual everyday activities may be enough exercise but it can be difficult to get the balance right – find your own level. This may vary from day to day. Regular light exercise such as walking is one of the best and safest ways to exercise. Walk at a steady pace and gradually increase the distance. Try and walk everyday, even if is indoors. Even walking, standing and going up and down stairs at home can be enough to help.

Ensure you are able to take a rest after you have done any exercise to allow time for recovery. Physical activity can improve your emotions as well.

Talking

Fatigue is a very real symptom which your health professionals need to know you are experiencing in order to help you. Talking about it may give some relief from emotional tiredness.

Talk to family and friends so they know how you feel. Be honest about how much fatigue is affecting your life. Some people have found it useful to keep a diary which can be useful when discuss how you have been feeling.

Energy Levels

It is important to find a balance between gentle exercise and not overdoing things.

To conserve energy, try doing a task using the least amount of energy possible, or combine activities and taking frequent rests. Try sitting instead of standing and use a relaxing activity afterwards such as listening to music.

If friends and family are able to help with chores – consider letting them.

Planning and Prioritising

Plan periods of activity and rest - doing things 'little and often'. If you are feeling particularly well one day, take care not to do too much as you may suffer from more tiredness the next day. It is difficult to get a balance between doing things and taking enough to rest. Sometimes this is learnt by trial and error.

Decide what is most important and if you need help with chores, ensure you ask. Remember, you may well have good and bad days.

It is difficult but you may have to accept that you cannot do everything you used to. It is important that you do not use all of your energy to do tasks. Try to find time each day to do something you enjoy as well. Do not feel guilty about asking for help.

It may be helpful to plan activities around treatment. Let friends and family know that visits, although welcome, can be tiring and need to be planned.

Rest and sleep

- Try and keep to a normal sleep pattern. A regular wake-up time in the morning can strengthen your sleep routine
- Try to establish a regular routine to help you to wind down before bedtime
- A daytime nap can be beneficial (early in a day). If it interferes with how well you sleep at night, try setting an alarm clock so that you only sleep for 30-40 minutes each nap. This has been found to be helpful, as you don't sleep as deeply during this time
- Make sure that your bed and bedroom are comfortable – not too hot, not too cold, not too noisy
- Take some time to relax properly before going to bed
- If there is something troubling you and there is nothing you can do about it right away, try writing it down before going to bed and then tell yourself to deal with it tomorrow
- Many people believe that alcohol can aid falling asleep. However it can disrupt normal sleep patterns, resulting in increased fatigue
- If you cannot sleep, get up after 15 minutes and do something you find relaxing such as reading, watching television or listening to quiet music. After a while you should feel tired enough to go to bed again to sleep
- Caffeine can act as a stimulant and it may be helpful to avoid this late at night

Working

- Some people with cancer are able to continue to work. Others find they need to cut down their hours or stop altogether. Ask your doctor or other health professional what they think is realistic

Talk to your employer, human resources or occupational health department. Things you may need to consider are:

1. Changing your hours of work.
2. Asking your colleagues to be supportive and help with some of your work.
3. Arrange to do some work from home if possible.
4. Ask your employer about lighter work if you find it too tiring.
5. If you do work – take plenty of breaks, especially at mealtimes.

You may benefit from referral to an Occupational Therapist and/or Physiotherapist.

Helpful Diet Tips

You may feel that you have a reduced appetite and that it requires a lot of effort to eat when you have fatigue.

Try to prepare meals in advance if possible or ask others to help.

- Ask friends and family to help with shopping and stock up on foods that will last for some time
- Cold meals can be as good for you as hot meals and quicker to prepare
- Softer foods may take less effort to eat (e.g. shepherds pie, scrambled eggs, lasagne)
- Microwaving food or ready meals, whether fresh, frozen or canned, can save time and effort
- Eating small meals/snacks more frequently may be easier to face than 3 large meals. It can be useful to have meals served on small tea plates so that you do not feel overwhelmed by a large amount of food
- Try to drink plenty of liquids. Milk, glucose drinks or liquid nutritional supplements can also provide you with extra nutrients. Please ask your healthcare professional about more specific advice.

FINANCIAL SUPPORT: GRANTS AND BENEFITS

Having a cancer diagnosis can be expensive in ways you may not have realised. Costs such as travelling to and from hospital can soon mount up. There is a large range of benefits available to people undergoing treatment for cancer, which you may be able to claim, but the benefits system is complicated so you may choose to get advice from an experienced Benefits Adviser.

There is a Macmillan Benefits Advisor based at **Cheltenham** General Hospital and they offer advice sessions in the Information Centre, Oncology Outpatients (call the centre on 08454 224414 to find out more). You can also contact the adviser directly by phone on 08454 223053. If you are an in-patient the staff on your ward can help arrange a meeting with the benefits adviser.

A Macmillan Welfare Benefits Advisor is available for the Forest of Dean District. The advisor is employed on a full-time basis by - and based within - the Forest of Dean Citizens Advice Bureau in Cinderford. The advisor can see people on home visits and by appointment in the locality. If you would like to refer yourself or someone you know who is affected by cancer, please contact 01594 823937 extension 203 or by e-mailing macmillan@fod.cabnet.org.uk

There is a benefits advice clinic held at **Gloucestershire Royal Hospital** from 1.30 – 4 pm on certain dates. The Benefits Clinic is part of the 'Department for Work and Pensions' and is working in partnership with Gloucester City Council Welfare Benefit Team to deliver this service. They can give advice and assist in claims for:

- Disability Living Allowance
- Attendance allowance
- Housing and Council Tax Benefits
- Working Tax Credits
- Child Tax Credits
- Information for claiming benefits
- And much more ...

Please see the next page for how to book an appointment.

The Benefits Clinic is for planned appointments only so please telephone 08454 225735 to make an appointment. They will need to know your name, postcode, date of birth plus a little more about what information you require so that the advisor can prepare some information in advance.

The Health Information Room is located within the Atrium of the new outpatients building at Gloucestershire Royal Hospital, Great Western Road, GL1 3NN. The contact telephone number for information is 08454 225735.

The centre is open from 10 am until 4 pm Monday to Friday.

In **Herefordshire** Macmillan's Welfare Benefits Advisors are based at the Citizens Advice Bureau at 8 St Owen Street, Hereford, HR1 2PJ. They are hoping to make use of other outreach centres in Herefordshire as well as visiting people in their own homes, or hospital, wherever is most convenient for the client.

To contact the team, e-mail macmillan@herefordshirecab.org.uk or telephone 01432 377 587.

Macmillan/Citizen's Advice Case Officer:
Monday – Wednesday 9 am – 3 pm and Thursday 9 am - 1.30 pm
Administration work, taking referrals and booking appointments.

Macmillan Welfare Benefits Advisor:
Monday – Wednesday 9 am – 3 pm.

The service hopes to cover Monday – Friday ultimately.

In **Powys** a Macmillan Benefits Advisor will be based at the Social Services in Llandrindod Wells, Powys, LD1 6AA. Tel: 01597 827102.

In **Worcestershire** a Benefits Advisor from the Disability Information and Advice Line visits the Worcestershire Royal Hospital and is based in the Information Centre. They give benefits advice to carers and disabled people. They are available every Wednesday 9.30 am - 12.30 pm and visit people on the ward if needed. The service is also offered in the community. Their telephone number is 01905 27790 or for the North of the county 0800 970 7202. They will also provide help completing forms.

The Citizens advice bureau also advises on benefits. Contact details as follows:-

The Hopmarket, The Foregate, Worcester, WR1 1DL
Telephone: 01905 611371

Advice available by phone 10 am – 4 pm Monday, Tuesday, Wednesday and Friday

Opening Times:

Monday – 9.30 am – 4 pm

Tuesday – 9.30 am – 4 pm

Wednesday – 9.30 am – 4 pm

Friday – 9.30 am – 4 pm

There is also Worcester Housing and Benefits Advice Centre in the community 01905 612774.

Monday 9.30 am - 1.30 pm

Wednesday 9.30 am -1.30 pm

Friday 9.30 am -1.30 pm

No appointment necessary

Appointments are available Tuesday 9.30 am -1.30 pm

Worcester Housing and Benefits Advice Centre

13A Lowesmoor Road, Worcester, WR1 2RS

Telephone 01905 612774

enquiries@whabac.org.uk

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NUTRITION

GENERAL NUTRITIONAL ADVICE

Your illness or its treatment may cause loss of appetite, weight loss, taste changes, nausea or swallowing difficulties. A varied diet will provide you with nourishment and help to keep up your strength and energy levels.

Try to include foods from the following groups every day:

STARCHY FOOD

Bread, breakfast cereals, potatoes, rice & pasta.

PROTEIN FOODS

Meat, poultry, fish, eggs, nuts, peas, beans, soya & lentils.

DAIRY

Milk, cheese & yoghurt.

FRUIT & VEGETABLES

Fresh, frozen, tinned or dried fruit & vegetables & fruit juices. Aim to eat at least 5 of these a day.

FATS & SUGARS

The following are good in moderation: Butter, margarines, vegetable oils & cream, Sugar, jam, marmalade, honey, biscuits, cakes, sweets & chocolate.

IMPORTANT ADVICE

If you are thinking of taking vitamins, minerals or herbal remedies it is very important that you first discuss this with your oncologist to make sure they don't interact with your prescribed medications and cause adverse side effects.

If your appetite is poor, eating smaller meals more often may help. Try eating very small portions of three courses rather than a large portion of just one course. Keep nutritious snacks or supplements to hand to have between meals.

If you are losing weight, have any eating difficulties, or need advice about food, eating or drinking please ask your doctor or nurse to refer you to a dietitian. If you are taking any natural/food supplements, e.g. vitamins, it is important to check with your dietitian or oncologist since some supplements may have an impact on the treatments you are receiving.

A nutritional DVD produced by the Rarer Cancers Forum is available. The DVD is entitled: 'Turning it Around; Cancer and Nutrition'

It covers the following:

- Nutrition, eating problems and having cancer
- Nausea and sickness
- Changes in taste and smell
- Constipation
- Diarrhoea
- Sore mouth and difficulties in swallowing
- Pain
- Chinese medicines, herbal remedies & vitamin supplements
- Nutritional supplements (including sip-feed drinks)
- Ed Baines cooking demonstrations and recipes
- Further information

Copies can be obtained from:

Chief Executive
Rarer Cancers Forum
01227 738279

for a small charge (£5 as of May 2010), which includes post and packing and the monies go towards keeping the charity going.

http://www.rarercancers.org.uk/information/educational_resources/turning_it_around_cancer_and_nutrition

FOOD DIARY

You may lose weight as a result of your illness so it is important to keep yourself well nourished to help you cope with any treatments you may undergo. You may find it difficult to swallow or have lost your appetite. If this happens we can help you by giving appropriate advice and food supplements where necessary. Sip feed supplements can be mixed into various recipes to make them more palatable – you can ask your dietitian for recipe cards.

You can use the next pages to write down the foods that you can manage easily and those that are not as easy to take.

Date/Time	Food I can manage easily	Food that is difficult to eat

Date/Time	Food I can manage easily	Food that is difficult to eat

Version 5 June 2010

PRESCRIPTION CHARGES

You are entitled to free NHS prescriptions if you are:

- Undergoing treatment for cancer
 - Experiencing the effects of cancer
 - Experiencing the effects of treatment for cancer
- and**
- You are entitled to treatment on the NHS

You need to complete an application form (FP92A) – please see the next page which tells you where they are available. When you have completed the form, you will need to ask your GP to sign the form, or the surgery to add its stamp. The form then needs to be sent off to the address which is on the form. You will then receive an Exemption Certificate which is usually issued within 7-10 days of receipt. This should be shown to the Chemist when you collect your prescriptions. The card will last for 5 years and entitles you to all your NHS prescriptions for free and not just those relating to cancer. After 5 years, the card will need to be renewed.

If you have to pay for prescriptions prior to receiving your exemption certificate, ask for an NHS receipt (FP57). This receipt contains a refund claim form which you will need to complete and show (together with your exemption certificate when you receive it) at any Chemist and they will give you a refund. Refunds will be available from the date shown on your exemption certificate.

If you already receive free prescriptions, you will not need to apply for an exemption card.

If you have already paid for a pre-payment card for prescriptions, you are entitled to a refund for this. Write, enclosing your pre-payment card, to the address on the back of the card explaining that you are now exempt from paying and that you would like to claim a refund.

Adapted from a leaflet developed by Candy Stokes, Macmillan Information and Support Manager at Beechwood Cancer Centre, Stockport.

In the 3 Counties Cancer Network, forms are available from all doctors' surgeries, plus hospitals in the Network as follows:-

Cheltenham General Hospital

- Reception desk in the Oncology out patient department
- LINC clinic
- Pharmacy department
- West Block out patients
- The Cancer Information Centre.

Gloucestershire Royal Hospital

- Pharmacy

Hereford County Hospital

- Charles Renton Unit
- Oxford Suite.

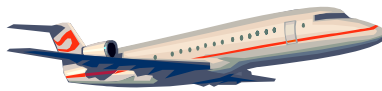
Worcestershire Royal Hospital

- Rowan Suite
- Pharmacy
- Forms are also given out routinely at pre-chemotherapy appointments.

Forms should be completed and sent off to:-

NHS Business Services Authority
Help with Health Costs
Medical Exemption
Newcastle upon Tyne
NE2 1ZL.

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TRAVEL INSURANCE FOR PATIENTS

If travelling on credit card insurance/annual insurance always confirm with them that you are covered for your condition.

When arranging travel insurance after a cancer diagnosis, undergoing treatment, or following completion of cancer treatment, always ask the following questions.

Don't forget that failure to disclose a previous cancer diagnosis, even as far away as 5 years, can result in the company refusing to pay for treatment or the cancellation of your holiday. **DON'T TAKE THE RISK OF NON-DISCLOSURE!**

1. What will my premium cost me?
2. What excess will I have to pay if I become ill while away?
3. What financial limit will your insurance company cover if I am ill on holiday?
4. If I am taken ill prior to travelling, does the premium also cover my family not being able to travel because of this?
5. Will the insurance cover costs of bringing me and my family home if we have to cut short our holiday due to my illness?

Please see the following for details of insurance companies.

PLEASE NOTE: We give this information to you in good faith. Responses from the companies may vary according to the type of cancer and where you are in your treatment regime. We are unable to recommend specific companies but trust one of these may be helpful to you. This does not mean they are in any way endorsed by the 3 Counties Cancer Network.

TRAVEL INSURANCE COMPANIES

Please see the note on the previous page.

All Clear Travel Insurance 08712 088579
www.allcleartravel.co.uk
e-mail: info@allcleartravel.co.uk

Freedom Travel Insurance 01223 454290
www.freedominsure.co.uk
e-mail: information@freedominsure.co.uk

Free Spirit Travel Insurance 08452 305000
www.leisurecare.co.uk
e-mail: freespirit@pjhayman.com

InsureCancer (Medi Travelcover Ltd) 01252
780190
www.insurecancer.com
e-mail: enquiries@insurecancer.com

Leisurecare Insurance Services 01285 640727
www.leisurecare.co.uk
e-mail: info@leisurecare.co.uk

Marrs Insurance Brokers Ltd 02089 201234
(Towergate Risk Solutions North London
www.marrs.co.uk
e-mail: northlondon@towergate.co.uk

PULSE 01280 850666
www.pulse-insurance.co.uk
e-mail: admin@pulse-on-line.com

White Star Insurance Brokers 01285 640003
www.whitestarinsurance.co.uk/
e-mail paul@cystrat.com

Some patients have found their own bank to be helpful – ask yours for details.

WIGS

Certain chemotherapy treatments can cause hair loss and your clinical team will explain this to you if this is the case. (Please note that not all chemotherapy treatments cause hair loss). If wigs are not mentioned then please ask the healthcare team about them if you wish to.

Despite free prescriptions for cancer patients from 1st April 2009, unfortunately this does not apply for the purchasing of wigs. However, if you are an in-patient and are expecting to lose your hair or have already lost it then there is no charge for a wig. Out patients need to pay the prescription charge (£60.00 as of April 2009).

Gloucestershire

The Cancer Information Centre at Cheltenham General Hospital deals with the provision of NHS wigs, whether to outpatients or inpatients, and issues NHS prescriptions. A wig consultant visits Cheltenham General Hospital every Wednesday afternoon (appointments made through the Cancer Information Centre – telephone 08454 224414) to visit the Oncology wards as a service to inpatients.

The Centre also has information and contacts for the provision of privately purchased wigs. If you decide to purchase a wig outside the NHS range (£89.00 + VAT) you will need to pay the full purchase price to the supplier and there is no financial reimbursement towards it. However the supplier will deduct the VAT from the purchase price as you are having medical treatment which causes hair loss.

Form WF10403 can either be collected from the information centre or requested by telephone (08454 224414) between 10.00 am and 5.00 pm. Complete the form (if you need assistance with this, please inform the staff in the Information Centre or ask your Key Worker) and return it to the Cancer Information Centre with a cheque payable to “Gloucestershire Hospitals NHS Foundation Trust” for the current amount (staff in the Information Centre will let you know what the current price is).

You will then receive a wig prescription form and a list of the local NHS approved wig suppliers (details on the following page). Please telephone your chosen supplier for an appointment and take the prescription form with you.

An NHS wig clinic is held every Tuesday from 10.30am - 4pm in the Information Centre. The Wig consultant provides a free consultation and will trim/alter wigs to suit individuals. The centre also deals with the NHS wig prescriptions and has a good stock of popular styles/colours. Ladies can take a wig away with them if they are suitable or they can be ordered for fast delivery from Wills Wigs in Bromsgrove.

Please also see the list of agents at the end of this section.

Herefordshire

In Hereford when a patient attends the pre-chemo therapy appointment for a talk about the treatment, they are given a letter stating Wills Wigs, as the hairdresser used, and includes contact details and a declaration of exemption form. Patients are asked to make an appointment with Wills Wigs for the wig and to take the exemption form along with them. A referral form is completed in the unit and sent off to the relevant department. The patient has the appointment, receives the wig and pays the prescription charge.

Wills Wigs are based in Bromsgrove and provide a service based in the Charles Renton Unit in Hereford County Hospital. This is held weekly on a Friday morning. This is an appointment only system.

Mrs Sue Newson
Wills Wigs
7/8 Holt Studios
49 Birmingham Road
Bromsgrove
Worcester B61 0DR

At the appointment, any prescription charges that may be payable by you will be explained. At the moment the current prescription charge is £59.20 per wig. This charge complies with NHS regulations and will change from April of each year. It is important that you take the exemption form and payment with

you to the appointment and if you have any documents regarding exemption from payment of any changes, it is important that you take these with you. You are entitled to one hair piece at 6 monthly intervals.

Please also see the list of agents on the next page.

Worcestershire

In Worcester when a patient attends their pre chemotherapy appointment they are given a letter and contact details to take to Wills Wigs in Bromsgrove (see contact details on the next page). The orthotic prescription form and the WF10403 are forwarded to the orthotic department by the nurse. The patient makes the appointment and attends Wills Wigs with the letter and receives the wig. At the present time the patient does not make a contribution to the cost of the wig.

Please also see the list of agents on the next page.

NHS APPROVED WIG CONSULTANTS

Main wig suppliers:

Banbury Postiche
Little Bourton House
Southam Road
Banbury
Oxon
OX16 1SR

Telephone 01295 757400
sales@banburypostiche.co.uk
www.banburypostiche.co.uk

Wills Wigs
The Studio
Holt House
49 Birmingham Road
B61 0DR

Telephone 01527 871709
info@willswigs.co.uk
Bromsgrove www.willswigs.co.uk/

Raoul Wigmakers
34 Craven Road
raoul@wigmakers.freeserve.co.uk
Paddington
London W2 3QA

Agents:

Lily de Beer
2-3 Berkeley Mews
Off High Street
Cheltenham
GL50 1DY

Telephone 01242 244288
www.lilydebeer.com

Laura of Appearances
15 Snowdrop Close
Abbeymead
Gloucester
GL4 4DZ

Telephone 01452 610389

Lush Salon
171a Hinton Road
Putson
Hereford
HR2 6BW

Telephone 01432 267467

Nick Pinnell
4 Merestone Road
Redhill
Hereford
HR2 7PS

Telephone 01432 278593
Home visits available

Nick Pinnell can also be contacted at:

CJ Styling
10 Bridge Street
Hereford
HR4 9DF

Telephone 01432 273908