After Treatment

a guide for cancer patients

Patient Information Series

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A guide for cancer patients

Previously funded by
The Diana, Princess of Wales Memorial Fund Project
based at the Royal Marsden NHS Trust

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THE WORK CONTINUES

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This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

Published by

The Royal Marsden NHS
NHS Foundation Trust

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Revised December 2009
Planned review December 2012

The Royal Marsden NHS Foundation Trust
Fulham Road
London SW3 6JJ

www.royalmarsden.nhs.uk

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No conflicts of interest were declared in the production of this booklet.

ISBN 0-949015-39-3

Designed & Printed by
Lundie Brothers Ltd.
Croydon, Surrey

PI-0030-04

Foreword

This is one of a series of booklets written to provide information for patients and their relatives. It‘s impossible to include everything you may want to know. Everyone will have specific questions about what they can and can‘t do, and when. Your doctor, nurse, radiographer or therapists will be able to answer specific questions. However, many questions or concerns are common to all people and this booklet tries to answer them.

This booklet has been prepared with input from Royal Marsden Hospital health professionals who are experts in their field, patients and carers.

We hope you find it helpful and would welcome your comments so that the next edition can be improved further.

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When treatment has finished...

You have finished, or are about to finish, your cancer treatment programme. This may have been an operation, radiotherapy or chemotherapy or a combination of these. Treatment may have taken weeks or months.

After your diagnosis, you may have felt a range of emotions, such as fear, anger, sadness and guilt. Treatment may have been physically and emotionally demanding. You may have overcome many challenges and learnt new ways of coping with physical changes and stressful situations.

Now you may be starting to look forward to the future, a return to your usual lifestyle and only having to visit the hospital for follow-up checks at regular intervals.

Perhaps one of the ways you coped was by thinking of all the things you would like to do when treatment was over. People often imagine that the end of treatment will be a positive moment and a reason to celebrate. It may be confusing and surprising to find that your previous feelings don't disappear straight away. Many people continue to feel anxious or sad. There may also be feelings of insecurity and loneliness as you have fewer links with staff and fellow patients. You may experience a conflict of emotions, fear before follow-up appointments but confidence that your progress is being checked. These are common feelings.

One common effect of treatment and its demands on you is fatigue – extreme tiredness – which can affect all aspects of your lifestyle and emotional well-being.

You may have fears that you are not getting over treatment as quickly as you thought you would. Remember everyone is an individual and recovers in their own time, both physically and emotionally.

Everyone will have specific questions about what they can and can't do, and when. You should ask your doctor, nurse, radiographer or therapists. However, many questions or concerns are common to all people and this booklet tries to answer them. It provides information on physical changes and lifestyle advice as well as coping with emotions and ways of dealing with stress.

> “You want reassurance from somebody who you think knows what they’re talking about”

Physical and emotional well-being are closely linked so some information may be repeated in different sections. The order in which the information is presented does not reflect any one persons priorities – we hope you will take what you need from each bit. The most important thing is to ask if you have concerns and talk to the people you feel most comfortable with.

Physical adjustment

Many people want to try to get back to their usual activities as soon as they can after cancer treatment. This may not always be possible. There may be some things you are no longer able to do or it may take more time to regain your energy levels or physical abilities.

You may need practical help with everyday activities for weeks or months after treatment has finished. This isn’t unusual. While you were having treatment family and friends may have helped with shopping, childcare or tasks around the home. They may assume you are feeling well now your treatment is over, especially if other, more obvious side effects are improving. Let them know how you are feeling and perhaps you can suggest ways in which they can continue to help.

> “I used to go to yoga before but I found I just couldn’t cope”

You may need to think about how you cope with other activities, day-to-day or planning social events. Some people find that it helps to keep a diary of how they are feeling. This way you can monitor your energy levels and plan activities around the times you have most energy and not overtire yourself.

Day-to-day activities

Some common problems which you may experience include:

- Fatigue – extreme tiredness and loss of stamina
- Peripheral neuropathies – tingling or numbness due to some treatments
- Pain and loss of flexibility
- Shortness of breath
- Unsteadiness
- Anxiety
- Weakness
- Having to do things differently or rely on others to help (a change in functional independence)
- Feeling overwhelmed by all that has happened

These problems, and many others, can be helped by an occupational therapist and/or physiotherapist. They can work with you and advise on equipment or adaptations to your home to increase your independence. They can also look at how you can plan your daily routine to prevent becoming overtired or suggest ways of coping with stress.

> “What I wasn’t prepared for when I finished my treatment was feeling a different person and not knowing how to cope with the changes, the change that I had to make from the person I was to being a person with cancer”

Most people do find that their energy levels pick up, although this may take several months. However, it is important to check that there isn’t a physical cause for your tiredness such as anaemia. Your GP (family doctor) will be able to arrange a blood test and, if necessary, treatment.

Work or study

Returning to work after a long break can be tiring when you are well, let alone after you have been ill. Perhaps you did not need to take much time off work during your treatment. If you do find that you are tired, you may want to consider taking a break from work. It may be better in the long term to allow time for your body to recover rather than continuing to struggle with tiredness. Sometimes, working part-time can be useful. Talk to your employer.

> "I decided I needed to be honest and open and tell my boss what treatment I had had and what time off I would be likely to need in the future. He was brilliant, very supportive and understanding. He said it was much easier knowing so that he could plan the needs of the rest of the department around that. We decided that the rest of the office didn't need to know all the gory details and so he agreed not to divulge any personal information unless at my request."

You may have been studying at the time your cancer was diagnosed or you may be thinking of starting a course now. If you are tired, you may want to delay starting, or returning to, your studies. Many people find that they lack the ability even to concentrate on a newspaper or a novel or a TV programme. If a course is very demanding, you may want to wait for a while. Your college tutors may be able to help you to make a decision. An occupational therapist may be able to help you to manage your fatigue.

Leisure activities

People have many different ways of enjoying their leisure time. You may be, or have been, involved in sports or gentler pursuits. All of these help you to relax and enrich your life. They may include walking, swimming, reading a book, listening to music, going to films or theatre or relaxing with friends – or something more energetic. If you took part in sports, you may wonder when you can start again. Even a small amount of regular activity such as walking can be beneficial to both your physical and mental well being. Be sure to build up your

> I play golf and it was my aim, I wanted to be back playing golf three months after my operation. After the operation I had chemo but I played through my chemo and I played through my radiotherapy. It was only half way through my radiotherapy that I was too sore to swing the club for a few weeks. I think it's very important to have something that you try very hard to keep going. I didn't play 18 holes, I might have played 6 holes. I didn't play it 2 days after I'd had the chemo but I played it a week or 10 days after I'd had chemo.

level of activity slowly and balance this with periods of rest. A physiotherapist can help you plan a realistic and progressive exercise programme. This will depend on how you feel and the type of treatment you have had.

You may have had to accept that, due to your illness or treatment, there are certain activities you can no longer take part in. You may have to find something new.

Whatever physical activity you want to take part in, start slowly and build up exercise gradually. If you have difficulties, stop. You may have already seen a physiotherapist during your treatment and have asked them for advice about this. If not, ask your doctor or another member of the team to refer you to a physiotherapist now. It can be arranged for you to see a physiotherapist at the hospital or nearer to your home via your GP. Everyone is an individual and it is impossible to give general advice on what you can and can't do and when.

> What kept me going was music. I discovered a band that I fell in love with and I just danced my way through the whole thing and it certainly lifts your spirits.

There may be other reasons why your activities are restricted, such as a low blood count following chemotherapy. You may be told to avoid crowds for a while meaning you can't go to social events. This may be very frustrating if you are someone who enjoys going out. Your doctor, nurse or another member of the team looking after you will be able to advise you when you can start socialising again.

It may also be frustrating if you can't concentrate on reading or watching TV. Your ability will gradually return as you begin to recover. You may need to set aside time to read a book or choose your favourite programmes rather than watching TV all evening.

Exercise

You may have been given specific exercises to improve your muscle strength, range of movement or posture by your physiotherapist after your operation or radiotherapy. You will have been advised how long to continue these exercises. If you notice changes in your ability to follow these exercises, speak to your doctor or the person who taught them to you initially.

Physiotherapists can also advise you about how to maintain and improve your physical fitness, and control symptoms such as breathlessness, balance problems or reduced stamina.

There is increasing evidence that keeping fit and taking part in regular exercise can be of benefit following cancer treatment. If you are having specific problems you can discuss a referral to a physiotherapist with your doctor.

Sex

You may have concerns about when and if you can start, or resume, sexual activity. All sorts of things will affect this, such as your illness, treatment, side effects and how you feel about yourself. Talking to your partner may be helpful so that they understand how you feel about this.

It's impossible to give general advice. Discuss your concerns with your doctor, nurse or another member of the team caring for you. They may be able to advise you about physical aspects of sex, suggest ways of showing love and affection or refer you for more help.

Sleeping well

Your sleep patterns may have been disturbed since diagnosis and during treatment due to stress and worry. Once disturbed you may find you have to work hard to get back to a normal pattern. There are no rules about what is a good nights sleep. Some people manage well on five hours while others need eight or nine hours to feel rested.

The main cause of sleep disturbance is not being able to relax physically and mentally. An occupational therapist may be able to teach you breathing and relaxation exercises to help with poor sleep. The following suggestions may also help:

- Don't try to catch up on lost sleep by napping in the day. This disturbs the night/day pattern further.
- Avoid eating meals too late in the evening.
- Avoid drinking alcohol or smoking in the hours before you go to bed.
- Avoid drinking tea, coffee, hot chocolate or other drinks which contain caffeine, like cola, late in the evening. A warm milky drink is better if you need a drink before going to bed.
- Make sure your bedroom is warm and free from draughts.
- Make sure your bed is comfortable, re-arranging the pillows, and so on.
- Find ways of relaxing before and around bedtime, reading, listening to calming music or having a warm bath.
- Try learning a relaxation technique (see page 37).
- Go to bed when you feel tired, not just because you have always gone to bed at a certain time.

If, once you go to bed, you toss and turn it may be better to get up for a while. Read a book or watch TV until you feel tired and sleepy.

Some people find waking in the night on several occasions is a problem. Waking for a few minutes will not lead to sleep deprivation but may be annoying. If you wake then toss and turn for an hour or more, it may help if you get up for a while. Sit in a warm place with a warm drink and read until you become sleepy again, then return to bed.

Sometimes you may need medication – sleeping pills – in order to get enough sleep and avoid sleep deprivation. Talk to your doctor about this. S/he will be able to advise you, prescribe tablets and discuss how long you should take them for. There are also natural or herbal alternatives which are available from chemists and health food stores. Check with your doctor before you take these.

Looking after your skin, hair and nails

Following cancer treatment, your skin may appear generally dry. It may have become discoloured, or it may have become more sensitive to sunlight. You will need to wash your skin daily, using warm water and a mild, unperfumed or baby soap. This helps to prevent the build up of normal flora (bacteria) on the surface of the skin and reduces the risk of infection. Take care to dry thoroughly. Regular use of plain moisturiser, such as aqueous cream, will help to restore the skin to it's previous condition. In time you will be able to return to using your preferred products.

> “I didn't really get much about my own hygiene or maybe I did. There was ever so much stuff said to me that never ever sunk in, that maybe they did.”

If you have had some lymph glands removed, or treated with radiotherapy, then you may be at risk of getting lymphoedema. This is tissue swelling when there is a failure in the lymph drainage system. You can find more information about lymphoedema in a leaflet in this series, *Lymphoedema – your questions answered.*

Many people plan a holiday for the end of their treatment. If you are going to a sunny climate, following your treatment, then you should use a sun block **and** cover up with light clothing. This includes skiing holidays when the sun can be very strong. Be careful to check that any area treated with radiotherapy is completely covered as, for example, a v-neck top may expose the corner of a treated area.

> "It was very hot but I just stayed in the shade an awful lot. I took very high factor creams and things like this. Something that I have done before but not to the extent that I did it….I was just more aware because I love the sun, I just felt that if I got burnt that I'd be more prone to getting skin cancer because I'd had breast cancer. A lot of things don't bother me this year that would have done last year (6 months after treatment)."

White cotton will reflect harmful ultraviolet rays and help to keep you cool. Wear a wide-brimmed hat and try to stay in the shade. In the years to follow you need not be quite so careful, although remember that exposure to intense sunlight can be harmful to anyone. You should always use a high factor sun cream (15+) and avoid the sun altogether between the hours of 11am and 3pm.

If you like to swim, remember to shower and moisturise afterwards as both chlorine and salt will dry your skin. If your groin area has been treated, avoid walking with bare feet and always make sure that you have dried thoroughly between your toes. This may help to reduce the risk of infection and lymphoedema. If your toenails are difficult to cut, it may be helpful to see a chiropodist (or podiatrist).

After surgery

Once your stitches or clips have been removed and your surgical scar is well healed you should be able to wash and dry the area as normal. Deodorants and perfumes can be used at the site of surgery, if needed, once the scar is completely healed. Advice may change if you go on to receive radiotherapy. Moisturiser will also help to restore the skin to it's previous condition. Regular gentle massage of the skin over the underlying muscle can help to reduce the risk of the skin attaching itself to the tissues below it. Some surgical scars can be raised and bumpy (keloid). Speak to a member of your surgical team as there may be ways of improving keloid scars.

After radiotherapy

During radiotherapy you probably experienced changes to your skin at the site of the treatment. This may have been irritating, mild, pinkish discolouration or blistered and broken skin. You may have needed creams or dressings as advised by the radiographer, specialist nurse or doctor. The armpit, groin or under the breast are areas that, if treated, are more likely to have been sore due to friction from skin and clothes.

Your skin may be back to normal four to six weeks after you have finished treatment. It can take longer if you have had a severe reaction to treatment. If a skin cancer has been treated you may have a dark patch in that area. If the area treated was below skin level then any colour change will fade with time.

During the early weeks, following treatment, you should continue to use a mild, unperfumed or baby soap and a plain moisturiser, such as aqueous cream, daily on the area that has been treated. You can use deodorant on the treated area once the skin is back to normal. You can also start to use your preferred moisturiser but be wary of developing allergies to new products. Use a moisturiser on your whole body so it becomes part of your personal care routine. Massaging moisturiser into the treated area may help to prevent long term formation of soft tissue fibrosis (scarring from radiotherapy). For example, a breast treated with radiotherapy may feel firmer to the touch than an untreated breast.

> “I had eczema as a kid, I had asthma and eczema and it brought the eczema back again, I thought I had skin cancer around my breast because it flared up. After I'd had radiotherapy it flared up. But nobody said anything to me. I decided myself that I wasn't going to put things, harsh things on my skin.”

Later you may notice tiny blood vessels appearing under the surface of your skin in the treated area. These are called telangectasia. It may be possible to treat these with laser therapy. You can discuss this with your hospital doctor. If laser treatment is not possible, you may like to use cosmetic camouflage if the area is particularly obvious.

Hair loss can be a side-effect of radiotherapy, depending on the area of the body that was treated. This is usually temporary although it may take several months for your hair to regrow. Your doctor should have told you before treatment if your hair loss was likely to be permanent.

After chemotherapy

Chemotherapy is treatment with anti-cancer drugs. It destroys cancer cells, which divide rapidly. Other cells that divide rapidly such as skin, hair and nail cells may also be affected.

If you have lost your hair during chemotherapy, it could take six months or longer to re-grow. During this time you should wash your hair twice a week using a shampoo, with neutral pH, and a conditioner. Your hairdresser will be able to advise you if you wish to colour your hair or consider a perm. Ammonia and peroxide can damage new hair. You should wait at least six months before using a chemical dye. Vegetable dyes can be used sooner. If you are considering have a perm, talk to your hairdresser who will be able to assess the condition of your hair. In the months and years to come you will be able to go back to your usual products and style.

During chemotherapy treatment your nails may have become discoloured, split or brittle. Fingernails grow more quickly than toenails and are more likely to be damaged by the treatment. All nails should be kept clean to reduce the risk of fungal infections. If they are trimmed regularly and filed to prevent catching them on clothes, this can help to limit damage. False nails should be avoided, as the adhesive would further damage the natural nails. Nail polish may be used to disguise the appearance of the nails. Nails generally grow at the rate of 0.05 – 1.2millimeters per week, so damaged nails may take six months to grow through.

If you received your cancer treatment in the haematology department, your platelet count may remain low for some time. Check with your specialist nurse as you may need to see a chiropodist. If you are immunosuppressed, you are at risk from viral infections which include verruccas. These can be painful to walk on and, although the chiropodist can’t treatment them completely until your blood count has returned to normal, they can be made to feel more comfortable.

Hormone therapy

Hormone therapy is given as a maintenance treatment for some types of cancer. Some people have this type of treatment for several months or years. Hormone therapy may affect the texture of your hair and the condition of your skin. You may wish to change from your usual hair and skin care products, and your usual routine to suit the altered textures of your hair and skin.

Teeth and gums

Oral hygiene is very important. If you have had chemotherapy, or radiotherapy in the area of the mouth or neck, you will have been taught about careful mouth care. While you are receiving treatment this is for your comfort and to reduce the likelihood of a mouth infection. If you are immunosuppressed, you will need to continue with good mouth care until your blood count returns to normal. You should discuss this with your specialist nurse as you may have individual needs. If you have been treated in the head and neck unit, you may also have very specific mouth care needs and should talk to your specialist nurse.

One rare affect of chemotherapy may be discolouration of the teeth. It’s not clear which drugs can cause this or if it is a lasting effect.

In the months to come you can probably return to your usual teeth-cleaning routine. If you are unsure, speak to your specialist nurse or hospital doctor.

Make sure you are registered with a dentist and resume your six-monthly routine checks. If your dentist has questions about your treatment or special needs, s/he should contact your hospital doctor.

Healthy eating

When you have finished cancer treatment eating well is important to ensure your body receives all the nutrients it requires to work

> I think everyone should have dietary advice… ….People feel they are doing something for themselves. Everything else gets done to you.

properly. The advice in this booklet is for people who have finished their cancer treatment, have a good appetite and are able to eat well. You may have had trouble with eating during your treatment and occasionally this can continue after treatment. If you are still experiencing problems, have lost weight or are underweight then the advice in this booklet is not for you. You should ask to see a dietitian. Another booklet in this series, *Eating well when you have cancer* may be useful.

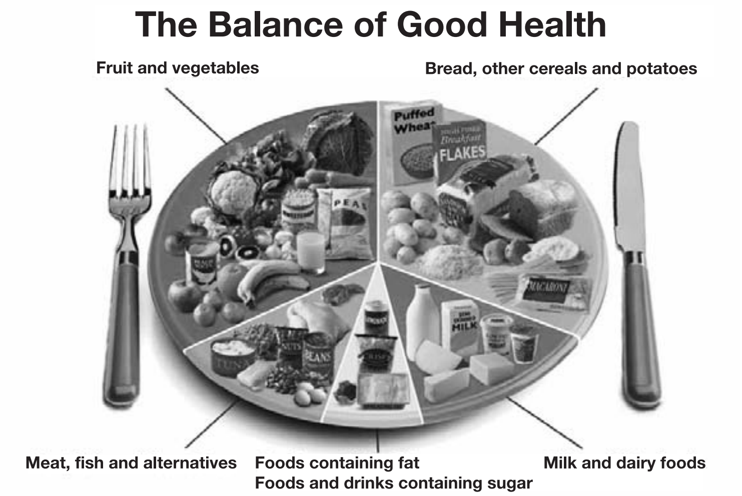
What is healthy eating

Healthy eating doesn't mean trying to lose weight or worrying about what to eat. Often it will just mean making minor changes to the foods you already eat, eating more of some foods and less of others. It's mainly about getting the right balance between the types of foods.

The World Cancer Research Fund (2007) has also published its diet and lifestyle recommendations. These recommendations are aimed at people with or without cancer and are summarised below:

- Maintain your weight within the normal BMI range (see page 20 to calculate your BMI).
- Be physically active for at least 30 minutes every day.
- Reduce your intake of high calorie foods and avoid sugary drinks.
- Eat at least five portions of fruit/vegetables every day.
- Eat a portion of pulses or wholegrain foods with every meal.
- Reduce your intake of red meat to no more than 500g (18oz) a week and eat minimal amounts of processed meats.
- Limit your alcohol intake to two drinks a day for men and one drink a day for women.

- Lower your salt intake. This can be helped by reducing the amount of salty and processed foods you may consume.
- Do not use dietary supplements for the prevention of cancer.



There are five main groups of valuable foods

Courtesy of the Food Standards Agency

If you are interested in reading more about changing the balance of your diet, there are a number of leaflets, websites and cookery books you may find useful (see page 43).

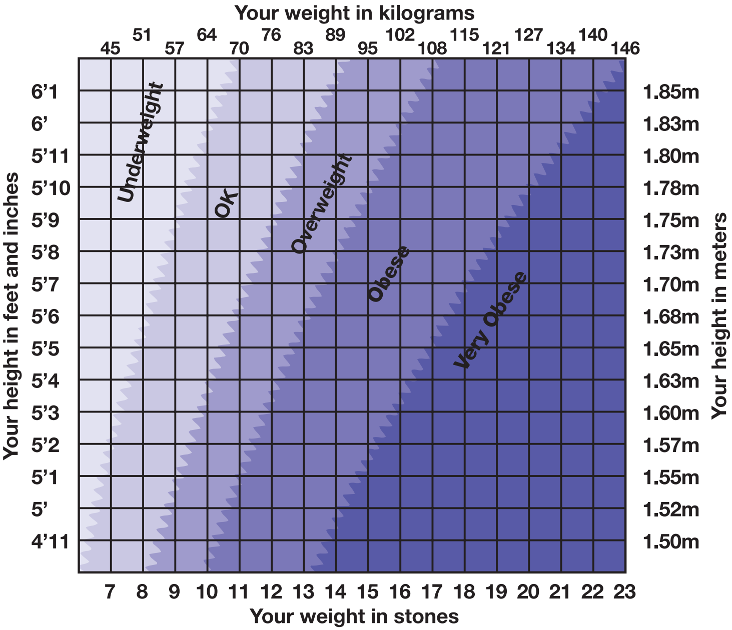
What is my ideal weight?

You can use the chart opposite to find best weight range for you. Find your height and see which range your weight is in.

Underweight: You may need to eat more or choose higher energy foods. You may find the advice in *Eating well when you have cancer* will help you reach an 'OK' weight.

OK: Your weight is good, but make sure you are getting the right balance of foods in your diet.

Overweight: You should try to lose some weight and get the right balance of foods in your diet.



Take a straight line across from your height (without shoes) and a line up from your weight (without clothes). Put a mark where the two lines meet.

Obese: You need to lose weight and get the right balance of foods in your diet.

Very obese: You need to lose weight as soon as it is safe for you to do so. Speak to your GP and ask to see a dietitian.

If you need to lose weight then wait until you have recovered from your treatment. Check with your doctor that it is an appropriate time to try to lose weight.

Some common questions answered

Do I need to take vitamin and mineral supplements?

By following healthy eating advice you will get a wide variety of vitamins and minerals from your food. If you have a good appetite and are eating well, it's unlikely that you need extra – in fact getting vitamins and minerals from food is by far the best way of taking

> I think a thing on vitamins would be good because I know you're supposed to take vitamins and stuff. I never really know which ones to take and why. I know it says on the bottle but there are so many different types. And when, should you be taking them forever and can you OD on them? Can you be taking too many of them? Does one counteract another, stuff life that.

them. At certain times, if you're not eating well, you may need to take a one-a-day multivitamin tablet. During these periods you may wish to see a dietitian who can check whether you are eating a balanced diet.

At present there is no evidence that taking extra vitamins as supplements will reduce the chance of cancer recurring (returning). Exceptionally high doses, well above the recommended daily intake, may be harmful and have unpleasant side effects eg. headaches, skin discolouration.

Never take large doses of vitamins or minerals without first speaking to your dietitian or doctor, who can check how much you are getting from your diet. Also be careful if you take more than one vitamin and mineral preparation – you may be taking the same vitamin in different supplements, making it easy to take too much.

It is easier now to buy vitamin and mineral supplements from abroad, via the internet. Some of these may contain trace elements that are voluntarily banned in the United Kingdom as they are known to be harmful so be careful when buying anything in this way. Ask to see a dietitian if you want to check any of your vitamin and mineral supplements.

There is often interest in the possible benefit of particular vitamins or minerals. Recently there's been some interest in the subject of calcium intake and bone density, particularly for women. An adequate calcium intake is important in trying to reduce the risk of osteoporosis. The debate is whether adding calcium to the diet will actually improve bone density in women over the age of 40. While there is uncertainty about this, it is sensible to try and take an adequate amount.

Calcium is present in milk, milk products (low fat varieties are still a good source of calcium), fish which contains bones such as sardines, pilchards, tinned salmon and, to a lesser extent, vegetables and flour. Hard water is also a source of calcium. If your diet is low in these foods, you may need to take extra calcium. If you are unsure, ask the dietitian for advice.

Should I buy organic fruit and vegetables?

Organic is the term given to food grown in a way to avoid the use of chemicals as much as possible. There are strict guidelines about the use of pesticides and herbicides on fruit and vegetables. The organic licensing bodies have their own approved list of compounds organic farmers may use. As a result organic foods are likely to be considerably lower in pesticide residues than conventionally produced food although organically produced food will not necessarily be residue free. Organic foods may be more expensive. There has also been some discussion as to whether organic food is more likely to cause food poisoning because of the use of organic waste in its production but there is no evidence to support this.

> “I think that's one of the things I found after I was going through my chemotherapy, there was nowhere, information on what to eat and eat well. I had to research it all myself, books whatever. Nobody was there to actually to tell you what sort of diet to follow.”

Organic fruit and vegetables contain the same nutrients, vitamins and minerals as fruit and vegetables grown in the conventional way. You should eat at least five portions of fruit and/or vegetables daily, whether these are organic or not.

Are food additives safe?

Additives must undergo rigorous testing before they are considered safe and allowed to be used in food. When an additive is accepted as safe to be used in the European Community it is given an ‘E’ number. Any food additives are listed on the ingredients by the full name, the E number or both. Other additives which haven't yet been accepted in Europe are listed in full on the food label. The regulations apply to all food additives, whether they are manmade or ‘natural’.

Food additives may be used to help preserve food, such as preservatives and antioxidants. They may also be added to colour, sweeten or flavour foods.

There have been concerns about whether food additives are a risk to health. Safety levels set are at an acceptable daily intake for each additive. This is the amount we can eat every day for a lifetime without risk to our health. As new evidence becomes available these levels may be changed, or additives added to or taken off the approved list.

In terms of your overall health, the quality of your diet is the most important thing – don’t worry unduly about additives. If you are concerned, or know that you react to certain additives, food labelling helps you to avoid them.

Should I drink coffee?

Over the past few years, people have been interested in whether or not coffee drinking is harmful to health. Coffee contains **caffeine**, which may cause an increase in alertness, heart rate and blood pressure when taken in excess.

Tolerance of coffee varies quite considerably – so it’s a case of finding a level that suits you. Concerns about how coffee drinking may relate to long term health problems, such as cancer and heart disease, haven’t been confirmed – so enjoy drinking coffee in moderation.

Other drinks such as tea, chocolate, cola and energy-boosting drinks also contain caffeine so they should be drunk in moderation.

Should I look for foods labelled ‘low fat’?

Foods labelled as ‘low fat’, or ‘reduced fat’ and ‘diet’ are a common feature on the supermarket shelves. In fact, such terms are often used to attract us to that particular brand or product. However, what do they actually mean and should we be buying them?

If you are trying to lose weight or reduce your fat intake, it’s a good idea to go for the ‘low fat’ or ‘diet’ options. They will contain less fat and/or sugar and provide less energy (calories) than their counterparts. For example, a full fat yoghurt can contain four times more fat than a low fat variety and double the energy of a ‘diet’ yoghurt. As the name suggests ‘reduced fat’ products contain less fat than the full fat alternative but aren’t necessarily low in fat, for example, reduced calorie mayonnaise or reduced fat crisps. Some of these foods may also be high in sugar so take care to read the label.

> “That is, I think, one of the most important things, it’s what you eat.”

Should I eat red meat?

Many people are confused as to whether they should be eating red meat or not. Meat is a valuable source of a number of nutrients, including iron, but try to choose lean meat.

In the United Kingdom on average we eat 3oz (90g) of meat, eight to 10 times each week. Healthy eating guidelines state that we shouldn’t eat more than this.

Should I be eating soya foods?

Some plant foods, particularly soya, contain small amounts of phyto-oestrogens. Larger amounts of phyto-oestrogens are also present in supplements, such as those made from red clover. These substances are known to act like very mild oestrogens in the body. It is unclear what action such substances may have for patients who have breast cancer. Small quantities in food may be unlikely to have a detrimental effect but always check with your doctor or dietitian before taking more concentrated supplements.

Are convenience foods bad for me?

Canned and frozen foods have been available for a long time. However, there’s recently been an increase in the amount of chilled and frozen foods in shops and supermarket. There’s a greater variety of convenience foods available, including pre-prepared meals, sauces, puddings and desserts and people are buying more.

These foods are usually very quick and easy to prepare, often only requiring reheating in the microwave or oven. So, where time or energy is a limiting factor, convenience foods are useful. However, they can be low in fibre and vitamins and high in salt so don't rely on them all the time. Have a portion of vegetables or salad with the meal to increase the nutritional value. If you're trying to cut down on your fat intake, go for the healthy options or 'low fat' varieties.

Should I avoid take-aways and 'fast-food'?

Many different fast food outlets offer pizzas, burgers, fish and chips and Indian or Chinese food. Their appeal is not only the flavour but their convenience – no preparation, cooking or washing up required! However, take-aways and 'fast food' tend to be high in fat, so if you're trying to reduce your fat intake, limit your number of take-aways. If you know you are immunosuppressed, you may need to avoid take-aways.

What about alcohol – what is a sensible amount to drink?

For many people drinking is a pleasant social activity and it doesn't cause any problems if we don't drink too much. Drinking large amounts of alcohol has been linked to certain cancers and other health problems.

If you do drink alcohol then limit alcoholic drinks to 2 drinks for men and 1 for women a day.

A unit of alcohol equals

- ½ pint ordinary strength beer, lager or cider
- ¼ pint of strong beer, lager or cider
- a single pub measure of spirits
- a small glass of wine
- a small glass of sherry or other fortified wine

If you are taking any medication, check with your doctor or pharmacist that you can drink alcohol.

How can I avoid food poisoning?

Food poisoning is caused by harmful bacteria such as salmonella, clostridium, campylobacter, and E.coli. They cause unpleasant symptoms such as diarrhoea, vomiting and stomach pains.

Poor food hygiene is the main contributing factor in food poisoning outbreaks and so, with good hygiene standards, food poisoning can be avoided. The government has introduced stricter laws to keep food safer and cleaner, but once we buy food, it’s up to us to store it and prepare it safely. So follow these simple rules:

- Follow good personal hygiene, always wash your hands before preparing any food
- Cook food thoroughly
- Keep food at the right temperature ie. keep chilled foods in the fridge
- Prevent cross contamination eg. avoid food touching or dripping onto other food when being stored, wash chopping boards thoroughly and don’t use them if they are chipped or damaged
- Keep the kitchen clean

The following websites have more information on food safety:
www.food.gov.uk/multimedia/pdfs/cateringfromhomesafely.pdf
www.eatwell.gov.uk/keepingfoodsafe

Is there any special diet I should follow?

In recent years, there has been a lot of interest in diet and cancer, and, in particular, about ‘complementary’ and ‘alternative’ diets. Some people have claimed to cure or control cancer using a diet and people are often confused as to whether or not they should follow one of these.

The term **‘complementary diet’** refers to any unusual or unorthodox change to a normal diet which claims to benefit people with cancer. The authors of such diets often advise that they are followed in **association with** accepted cancer treatments like radiotherapy and chemotherapy. The diet recommended by the Bristol Cancer Help Centre is an example (see page 29).

The term **'alternative diet'** refers to a change to a normal diet which claims to treat or cure cancer and is often followed **instead of** conventional medical treatment. Gerson Therapy is an example of an alternative diet (see page 29).

Should I be on one of these diets?

There have been few clinical trials or research studies in this area. To date there is no scientific evidence to support claims made by complementary or alternative diets. It is unlikely that any change in diet has any great medical benefit in cancer treatment.

If you're considering one of these diets, discuss it with your doctor or a dietitian. The dietitian will help you to make a choice by discussing the advantages and disadvantages of different diets.

What are the problems with them?

Many people experience eating difficulties or lose weight as a result of their cancer or their treatment. These diets are low in energy (calories) and protein and tend to be bulky and therefore very filling. They can cause weight loss and malnutrition in people who have problems eating.

Meal preparation may be time consuming and difficult for people who are feeling tired. The diet may also be expensive as it may include large quantities of organic fruit and vegetables.

Many complementary and alternative diets recommend exceptionally large doses of vitamins and minerals such as Vitamin C, beta-carotene, zinc and selenium. Very high doses of some vitamins and minerals may be toxic to your body and bad for your health, for example vitamin A and B6. They are not recommended. If your diet is limited and you think a multivitamin and mineral supplement may be useful, discuss this with the dietitian.

If you are concerned about vitamin or mineral supplements you are already taking, always check with the dietitian.

Should I eat dairy products?

A number of complementary and alternative diets recommend that dairy products are excluded from the diet, often in addition to other foods, as it is suggested that these may promote cancer growth. These recommendations are based on individual case studies rather than clinical trials and have no scientific evidence to support them. Therefore it isn't necessary to avoid these foods. Dairy products can be a good source of vitamins and minerals, particularly calcium. If you are concerned about your fat intake, choose low fat versions.

Examples of complementary diets

We will update and change the advice we give on these diets if research in the future shows them to be of benefit.

The Bristol Approach to Healthy Eating

This guidance has been developed by Penny Brohn Cancer Care and is based on the 2007 World Cancer Research Fund report: Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective. It follows the guidance as outlined on page 19 of this booklet and in addition the Bristol Approach encourages the use of organic foods where possible.

Macrobiotics

Macrobiotics is a philosophy of life which has been used in natural healing for centuries. Foods are classified as Yin foods, representing feminine, dark and negative principles and Yang foods, representing masculine, light and positive principles. The aim of the diet is to balance these for each individual in order to obtain a healthy mind and body.

Aspects of our personality and illness are also classified as Yin and Yang so the diet needs to be individually planned for each person. The basic principles of the diet used for cancer patients are:

- It is mainly vegan
- 50% of each meal consists of wholegrain cereals
- It contains a large quantity of raw vegetables

- It is low in salt
- It is low in fat

If you are interested in any of these diets, **please ask** to see a dietitian who can give you further advice and information. The dietitian will help you to explore all the advantages and disadvantages of the diets before you choose whether or not to adopt one. Certain aspects of these diets may be able to be brought into a sound, well balanced nutritional plan, providing it does you no harm and doesn't affect your health.

Example of an alternative diet

Gerson Therapy

This is an extremely strict regime which includes coffee enemas and other unusual medications.

- It is vegan
- It contains the juice of raw fruits and vegetables
- It is low in salt
- It is low in fat

Alternative diets, such as Gerson, cannot be recommended under any circumstances because they have been seen to seriously affect the health and treatment of patients.

What about other supplements?

Some people may choose to try other supplements, herbs or preparations that claim to benefit health or influence cancer. Many of these are not nutrients but may be taken for a medicine-like effect. Check with your doctor or pharmacist that they are suitable for you to take. If you are advised to avoid any foods when taking such supplements, you may wish to contact the dietitian to check that your diet is still adequate.

You may be able to get more information about these supplements from your hospital's drug information service, Macmillan or the Food Standards Authority.

Complementing your cancer care

What are complementary therapies?

Complementary therapies is the term given to a collection of approaches which may be used to support you during and after your cancer treatment. They may be used for self help, symptomatic relief and wellbeing. Such therapies include acupuncture, aromatherapy, art therapy, Chi kung, hands on healing, herbal medicine, homoeopathy, massage, meditation, reflexology, relaxation, shiatsu, visualisation and yoga.

What do complementary therapies do?

They offer ways for people to help themselves and cope with cancer. There is no evidence to suggest that any of these complementary therapies alone cure cancer. However, many people find them supportive and that they help with some of the issues facing the person as a whole.

Many of the self help approaches offer relaxation and focusing techniques while other therapies can provide symptomatic relief. The therapies may promote feelings of increased wellbeing.

Where to go for complementary therapies

National Health Service

There may be some complementary therapy services provided on the NHS like those at your cancer hospital as well as national services, such as those provided at the five homeopathic hospitals in the UK located in London, Glasgow, Tunbridge Wells, Bristol and Liverpool. Some of these homoeopathic hospitals run special clinics for people affected by cancer. You can ask your GP for a referral to one of these NHS hospitals.

Cancer support centres

Some cancer support centres also offer complementary therapies. Check which local and national centres may offer this kind of support. It may be that such centres offer one or more complementary therapies for patients affected by cancer.

Private complementary therapy services

Complementary therapies are often provided privately. If you choose to see a private therapist, it is important that you see someone who is not only competent at the therapy, but will understand enough about what you are going through with your cancer treatment at the hospital.

It is wise to check that the therapist belongs to a recognised professional organisation, and that the therapist has knowledge and experience of working with people with cancer. You may find that your GP has some complementary therapists working in the practice.

What are alternative therapies?

These are therapies which people choose instead of their regular medical cancer treatments, they are not complementary. Alternative therapies may make claims to cure cancer. If you are thinking about one of these, discuss it with your doctor first. There is no evidence to suggest any one alternative therapy cures cancer. Some of them are very expensive, may be difficult to follow and should be approached with caution.

Emotional and psychological adjustment

> I think that when you finish your treatment you also get other moods and they swing and you're treading very soft ground and you need to get your confidence back. Because often when you are diagnosed with cancer you feel perfectly well.

A diagnosis of cancer, treatment and the physical effects of this inevitably affect you emotionally and psychologically. You have had to cope with a life-changing experience and, although the first shock may have worn off, new emotions and concerns may arise at the end of treatment.

Some common concerns and suggestions to help you through difficult situations are covered in this section.

Fear of your cancer coming back

For many people, coping with the fear of the cancer coming back and uncertainty about the future is the hardest part of finishing treatment. During treatment you may feel that something is being 'done' against the cancer. It is also often a very busy period. All your concentration and energy on a day-to-day basis may be focused on coping with various appointments, treatments and side effects. When treatment ends, it is natural to have feelings of insecurity and anxiety. You will have more time to think about the possibility of recurrence and it may feel as though there is nothing now 'fighting' your disease.

> I don't want to be taking up their valuable time (the hospital) if there's nothing wrong, yet there was a fear, it was a genuine fear this could be 'it' again, yet I still didn't bypass the doctor and go straight to the hospital, I still went to the doctor and he told me to go to the hospital.

You may find it very difficult to cope with anxiety about symptoms. Many people worry that every ache or pain they experience is a sign that the cancer has returned or is progressing. They sometimes hold back from contacting their doctors or nurses due to fear of bothering them or appearing stupid. If a symptom does persist and you are concerned, talk to your medical or nursing team. They are very used to dealing with such queries.

Isolation

People can often experience isolation when treatment ends. This may be because you have less contact with nurses, doctors and fellow patients. You may also find that family and friends don't realise that you are struggling with fears and anxieties. Partners, relatives and friends may stop talking about the cancer and treat it as past history. They may offer reassurance that there is nothing to worry about now. Sometimes, they simply have no idea about your own feelings because you have not talked about them. Alternatively, their reactions may be to do with their own embarrassment when talking about cancer. They may just feel glad and relieved that they can have a break from the subject of cancer for a while in order to recover themselves.

> "People are really (embarrassed) when you tell them, they don't know what to say to you"

Your family and friends will have their own emotional reactions to your illness. They too may be struggling with their own anger, fear and guilt. They may hide this in order to protect you, or you may feel that you have to protect them from how you are feeling. Open communication is needed to find out how both parties feel they are coping with the end of your treatment. People will have limitations on what support they can offer you. One way to explore this is to spend some time identifying who can provide what (practical, emotional, financial, social and spiritual support) within your network of friends and family. Some people prefer to attend a support group to meet others with similar experiences and to hear how they have coped.

Bad days

Some people expect to feel positive 100% of the time. They are afraid that having any negative thoughts or feelings may affect the outcome of their illness. Family and friends may say "You must keep in a positive frame of mind to stay well". Although a positive attitude may enable you to get more out of life, you can't expect to be happy and positive all the time.

> I wish I'd known earlier about it (the support centre), I wish they'd told me about it at the end of my treatment or even when I was diagnosed that there were places to go.

Don't be surprised if you have a bad day. It's a normal part of life whether you're well or ill. Everyone has bad days occasionally. Not allowing yourself to feel sadness, guilt, fear or anger puts more pressure on you. Talking about negative feelings can be a huge relief.

Think about what you have achieved in spite of everything that has happened.

Stressful times

People often find that there are certain events that may set off their worries and anxiety all over again. You may read something in the paper or have an outpatient appointment. Perhaps it is the anniversary of the day of your diagnosis or you hear that someone else you know has cancer. You may find it easier to reassure yourself if you know in advance what may raise your anxiety levels. You can then prepare how you are going to cope with it. All your hard work learning how to distract yourself, how to use relaxation exercises and how to challenge your negative thoughts can come in useful (see page 38).

> They're asking how you are and they really want to hear you're all right. You say fine, you might be feeling lousy but you say fine.

Gathering information

People often talk about how they feel less in control since their diagnosis and having to face uncertainty about their future. They say they have sometimes lost confidence about dealing with issues that wouldn't previously have caused concern. One subject that often comes up related to control is looking for information about their illness or treatment.

> "I didn't ask as many questions as I should have done at the time, I found out a lot more things about my particular case afterwards."

People have different information needs. Some find that they don't want to know any more than the most basic information. Others find that finding out as much as they can and being involved in any decision-making can help them feel more in control. Usually doctors wait for people to ask questions before telling them everything that may happen now or in the future.

Some people find that the information becomes a burden to them as, once given, it can't be taken back and may create more anxiety.

It may help if you think about what sort of information you might find useful and to tell the staff what you need.

Some suggestions which may help you

You may have times when you are anxious, stressed and suffer from a low mood which may be made worse in certain situations and by fatigue. Think about what has worked for you in the past when you have felt like this. You may also want to consider some new ideas.

"Tool kit"

You may find it helpful to develop a "tool kit" to help you manage your feelings and maintain control of your lifestyle. These could include:

- Recognising your needs
- Identifying sources of stress

- Talking about your problems
- Setting aside time for relaxation and leisure
- Planning ahead
- Deciding what is important to you
- Using local resources such as support groups
- Exploring complementary therapies
- Giving yourself rewards or treats
- Avoiding words like “must” and “should”

Relaxation

Some people find that learning relaxation exercises is a very effective and enjoyable way of dealing with stress and anxiety. Including relaxation exercises into your day may help you to release tension, and reduce muscle aches and pains. They can give you time to focus on your own needs for a while. Other benefits include improving the quality of sleep and reduction of the side effects of stress, such as pain and fatigue. Relaxation can also restore a sense of well-being and may help you to feel more in control of your life.

People often say that they find it difficult to relax. However, there are many different types of relaxation exercises that you can learn via therapist-led sessions, tapes or books. You may need to try several types before discovering which one works best for you. Ask your local hospital if they offer a relaxation programme. Local cancer support centres may also offer relaxation groups as part of their programme.

Counselling

Counselling takes place when a counsellor meets a client in a private and confidential setting to explore a difficulty the client is experiencing. It may be coping with major life changes, dissatisfaction with life or loss of a sense of direction and purpose. It is always at the request of the client and no one can properly be ‘sent’ for counselling. A counsellor is not there to tell you what to do, but will listen and help you reach your own understanding and decisions.

Counselling may be available through the NHS, sometimes in GP surgeries or through the hospital where you have been treated. Some voluntary organisations also offer counselling free of charge or at a cost related to income. Many counsellors work in private practice offering individual or group sessions. Group sessions can often work out cheaper. To find out more about what might be available to you, ask around. You could start with your GP, practice nurse, specialist nurse or contact some of the organisations listed at the end of this booklet (see page 42).

Challenging negative thoughts

Step 1

If you are anxious, the sort of automatic thoughts you may experience will make you see everything as a threat. If you are feeling low, you will see yourself, and the world around you in a negative way. You may think 'I'm just a failure now that I can't work anymore,' or 'Whatever they say I know the cancer will kill me'. When you feel low, anxious or hopeless, write down what you are thinking and feeling, and what was going on when you first started feeling this way. For example:

Emotion	Situation	Automatic thoughts
Anxiety (80%)	Watching TV programme about cancer	What if the cancer comes back? I won't be able to cope. Everyone is coping better than me, I'm useless.

Step 2

When you can identify your automatic thoughts, the next step is to challenge them and replace them with more realistic thoughts. Then go back and re-rate the emotion that you felt. For example:

Rational response

I've coped with it so far, there's no reason I can't do the same in the future. As for everyone else, I only see the outside. Inside they may be as scared as I am. (Anxiety now 30%).

Step 3

Ask yourself if you have any evidence for thinking this way, or are you just assuming the worst? You may be thinking about the most pessimistic aspects and ignoring the positives. For example:

Automatic thought	**Rational response**
Perhaps the doctors are just being nice to me when they tell me there's no sign of cancer now.	From what I know of the staff here, they wouldn't lie to me. All the evidence from the tests shows the treatment has been effective.

Step 4

Is there an alternative way of looking at it? Try to find out if you are taking a blinkered view of your situation or are there other, more constructive ways of thinking that you're not using?

Automatic thought	**Rational response**
What's the point of doing anything if I can't be cured? I might as well give up.	There are still things I can do and enjoy. If I plan for the next few months I'm likely to be able to do most of the things I need to do but if I give up now I'll just get more depressed.

Step 5

Is what I'm fearing so bad? Sometimes if you face up to the thing you are scared of, you realise it's not as bad as it seems. Many people find they cope much better than they thought they would.

Automatic thought	**Rational response**
I couldn't stand it if I had to have chemotherapy.	I've handled other treatments. Chemotherapy would be unpleasant but if other people can cope with it, there's no reason why I can't.

Step 6

What are the consequences of thinking this way? Even if your thoughts are accurate, they may not be helpful to you. It is realistic to be sad about some of the consequences of having cancer but if you find yourself thinking of nothing else your life becomes limited and it gets harder to enjoy the good things that are still going on.

Automatic thought	**Rational response**
Will I ever get better? I felt a pain in my foot yesterday, could it be the cancer coming back?	By concentrating on all these pains I'm making myself worse because I know they're only minor aches I've always had.

Planning for action – When you have identified and tested your negative automatic thoughts and replaced them with more constructive ones, think of what action you can take. You might decide to get more information about a treatment, or you might decide to test out the belief that you can't get pleasure anymore by trying some new activities. Another plan of action would be to devise a coping method that you could use every time you get particular negative thoughts.

If you find that constant negative thoughts about recurrence are increasing or not going away, you might decide that you want to seek some help. Perhaps there are particular concerns that you would like to deal with such as a change in how you see yourself or loss of fertility. You may find it helpful to join a support group where you can meet other people in a similar situation and share experiences and information. Group support may not suit everyone and you may want to look for other help to learn how to cope with your feelings of uncertainty. This can take many forms, one of which is counselling. (see page 37).

Facing the future

Adjusting to life after treatment means adapting to a new routine and a new sense of normal. Many people want to return to their previous way of life as quickly as possible and resume their old roles, activities and responsibilities. However, others describe feeling that cancer has given them a push to reassess their lives and find out who or what is important to them.

Your priorities may have changed and some things may no longer seem so important or even rather trivial. Some people have said that their experience has helped them to become more assertive and they have started to say what they want and need for the first time in their lives! Sharing experiences, even if they are negative ones, can bring people closer together and many people say that their relationships with partners and families are better since their cancer experience.

All in all, your life may have changed forever but it is never too late to make the most of your potential to enjoy an excellent quality of life.

Sources of information and support

British Association for Counselling and Psychotherapy
BACP House
15 St. John's Business Park
Lutterworth LE 17 4HB
Tel: 0870 443 5252
Fax: 0870 443 5161
Website: www.bacp.co.uk

Provides a list of counsellors divided into counties, giving counsellors' qualifications, type of problems counselled and probable cost; and an information sheet with counselling guidelines.

Macmillan Cancer Support
89 Albert Embankment, London, SE1 7UQ
Tel: 020 7840 7840
Macmillan Cancerline: 0808 808 0000
Website: www.macmillan.org.uk
Provides a range of free information and support on all aspects of cancer including:

- diagnosis and treatments
- secondary cancer
- advanced cancer
- palliative care
- advice on benefits and other kinds of financial support
- information on local cancer support groups and organisations near you

Macmillan Youth Line
Website: www.macmillan.org.uk/whybother
Online information for young people affected by cancer

Carers UK
32-36 Loman Street
Southwark
London SE1 0EE
Tel: 020 7922 8000
CarersLine: 0808 808 7777 (freephone)
Website: www.carersuk.org

Provides information and support to people who are caring at home. Publishes a range of free leaflets. Branches and local offices throughout the country – contact the national office for details.

Chartered Society of Physiotherapy
14 Bedford Row
London WC1R 4ED
Tel: 020 7306 6666
Fax: 020 7306 6611
Website: www.csp.org.uk

Can provide information on NHS and private physiotherapists with a special interest in cancer care. Produce public information leaflets.

Food Standards Agency
Aviation House
125 Kingsway
London WC2B 6NH
Tel: 0845 606 0667 (publications only)
Tel: 020 7276 8829 (enquiries)
Website: www.food.gov.uk

Publishes various booklets including *Catering from home safely, and Men and Food*

The Prince's Foundation for Integrated Health
33-41 Dallington Street
London EC1V 0BB
Tel: 020 3119 3100
Fax: 020 3119 3101
Website: www.fih.org.uk

Provides information on orthodox, complementary and alternative methods of healthcare including information about the integration of complementary and conventional healthcare.

Further reading

There are now many books available about cancer and its treatment and more on complementary therapies or ways of reducing stress and increasing well-being. A browse through the health section of a large bookshop or your local library will help you to select a book that suits you. Always check the qualifications of the authors and the publication date to make sure the information is from a reputable source and is up-to-date. One reference guide to treatments for mind and body is:

Encyclopedia of Natural Healing
Anne Woodham & Dr David Peters
Dorling Kindersley (2000)
ISBN 07513 1207X

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:
The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

Titles available in this series

A number of Patient Information Series of booklets are available on the Internet at www.royalmarsden.nhs.uk

After treatment – A guide for cancer patients
Benign breast conditions – A guide for women (pocket booklet)
Breast health – A guide for women (pocket booklet)
Breast reconstruction
Central venous access devices – A guide for patients receiving intravenous therapies
Chemotherapy
Clinical trials
Coping with nausea and vomiting – A guide for cancer patients
CT scan (leaflet)
Eating well when you have cancer – A guide for cancer patients when eating may be difficult
Lymphoedema – A guide for cancer patients
Lymphoedema (leaflet)
MR scan (leaflet)
Radionuclide therapy
Radiotherapy
Ultrasound scan (leaflet)
Your operation and anaesthetic

Further information about the Patient Information Series and other booklets is available from:

The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

P1-0030-01