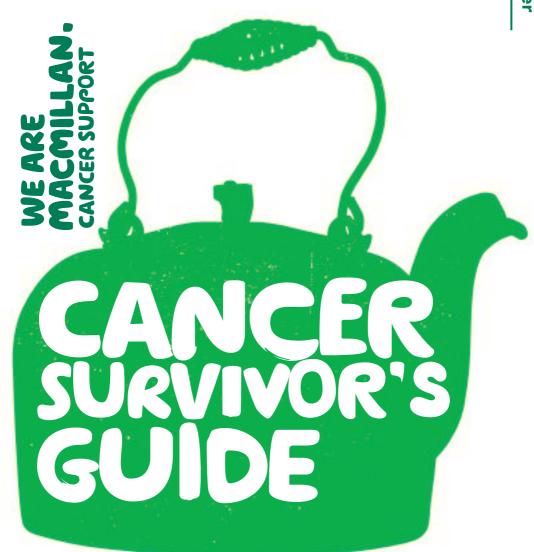
Because cancer doesn't end when your treatment is over





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The **Living with cancer** series is a range of booklets giving you the information you need if you are living with or affected by cancer. Other booklets available in the series:

- The cancer guide
- Men and cancer
- Talking to children when an adult has cancer
- I'm still me: a guide for young people living with cancer
- Cancer survivor's guide: because cancer doesn't end when your treatment is over
- Palliative care: practical help in advanced cancer
- Palliative care: emotional support in advanced cancer
- When someone with cancer is dying
- · Coping with shortness of breath
- Living with breathlessness
- · Managing breathlessness

To order any of this series call **0800 500 800** or to talk to someone about cancer call **0808 808 2020**

Introduction

Sixty years ago, most cancers were incurable. Today, thanks to better ways of spotting and treating the disease, more people are living with cancer than at any other time. Today, over one million people in the UK have been diagnosed with cancer and will need to adjust to the challenges and lifechanges that lie ahead.

There are 1.2 million people with cancer in the UK. Over 400,000 have been living with cancer for more than 10 years.

Sometimes, cancer doesn't end when the treatment stops. Many people who have been through treatment will experience some of its after effects. These might take some time to get better or, in some cases, stay for good. Cancer and its treatment can also affect your emotions. You may also have many practical needs and be unsure where to turn.

Macmillan Cancer Support's guide to cancer survivorship provides information about some of the emotional and practical issues you may face; it tells you about some of the after effects of cancer, and provides you with advice and contact details of individuals and organisations that can help. Against each topic, we have listed some of the publications* and websites you might want to read.

^{*} Publications marked with an asterisk (*) are either more than 5 years old or do not have a publication date. They may contain useful information but always check what is up to date.



1 Emotional effects of cancer

This section describes some of the emotions and feelings you may have, and some of the ways Macmillan Cancer Support and other organisations can help.

Feelings

From time to time, you may have lots of different feelings. These may be both positive and negative. There is no right or wrong way to feel. Remember, whatever feelings you have, you are not on your own.

Talking to others can help. This might be someone who is close to you, a counsellor, or someone from your support group. Many people find it helpful to express their day-to-day feelings in a diary.

Your doctor, members of your hospital healthcare team and organisations such as Macmillan Cancer Support are there to help.

You can discuss your feelings or practical and financial issues with trained professionals by calling one of the many cancer helplines. There are many useful publications, websites and online forums that may help.

The Macmillan CancerLine on 0808 808 2020 is a good place to start. They can talk to you about any needs you may have, and put you in contact with the people and organisations that can help.

Booklets and fact sheets

The cancer guide (2007)
Macmillan Cancer Support

Adjusting to life after cancer treatment

Cancerbackup

After treatment. A guide for cancer patients (2002)

The Royal Marsden Foundation Trust

The emotional effects of cancer (2006)

Cancerbackup

Websites

Macmillan Cancer Support www.macmillan.org.uk

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Royal Marsden NHS Foundation Trust

www.royalmarsden.nhs.uk

Relationships

When you are speaking to people close to you about your diagnosis it may not be easy to find the right words or share your feelings.

Sometimes you might want to protect them by not saying much.

They may also be protective, and might think they are doing the right thing by not discussing anything that could make you upset.

If you have a partner, your relationship may change. They may need to take on new or different roles. Problems, that may have been difficult before your cancer, might also resurface.

Your healthcare team understands the emotions you may have, and are there to listen and talk to you about any worries and concerns. There are also many organisations, helplines, websites, online forums and publications that can help.

Booklets and fact sheets

Talking to children when an adult has cancer (2007)

Macmillan Cancer Support

Lost for words - how to talk to someone with cancer (2006) Cancerbackup

Relationships, sex and fertility for young people affected by cancer (2007)

Cancerbackup

Talking about your cancer (2006)

Cancerbackup

Talking to children about cancer. A guide for parents and carers (2005)

Cancerbackup

Website

Relate

www.relate.org.uk

Your body, your sexuality and sexual relationships

Sexuality is about the feelings you have about yourself and how you express them to others. You can express your sexuality in many ways including your body language or how you dress. Your sexuality can be affected by cancer.

Some operations may change how your body looks and works, while other treatments may make you less interested in sex, or make sex more difficult. Your sexuality might be affected by depression, sadness, stress or fatigue.

In addition to any physical effects you might have, you may feel differently about yourself and how you look. This may affect the relationships you have.

There are many organisations that can help. Your family doctor may be able to organise a counsellor who is an expert in listening and talking to people about sexual problems. There are also many useful publications, websites, online forums and helplines.

Booklets and fact sheets

Female sexual matters (2005) Urostomy Association

Lack of sex drive (2007)

The Sexual Dysfunction Association

Male sexual matters (2005)

Urostomy Association

Relationships, sex and fertility for young people affected by cancer (2007)

Cancerbackup

Sex and breathlessness (2005)

British Lung Foundation

Sexuality and Cancer (2006)

Cancerbackup

Sexuality, intimacy and breast cancer (2004)

Breast Cancer Care

Sexuality and prostate cancer (2005)

The Prostate Cancer Charity

A guide to intimacy and relationships *

Changing Faces

Websites

Macmillan Cancer Support www.macmillan.org.uk

British Association for Sexual and Relationship Therapy www.basrt.org.uk

British Heart Foundation www.bhf.org.uk

British Lung Foundation www.lunguk.org

Cancerbackup

www.cancerbackup.org.uk

Changing Faces

www.changingfaces.org.uk

Orchid Cancer Appeal

www.orchid-cancer.org.uk

Relate

www.relate.org.uk

Sexual Dysfunction Association www.sda.uk.net

Body image

Body image is the perception you have about your body. It's unique to you. Some cancers and treatments can change how your body works and appears to you and those around you. While an operation can make this change less obvious, you might still feel different about how your body appears.

Whatever the physical change and challenges to your body, its emotional impact can be just as hard. There are many organisations and individuals that can help you overcome these changes.

For women, programmes organised by Look Good Feel Better help restore self-esteem by running make-up and hair care workshops around the UK. The Look Good Feel Better website also provides useful information for men.

Remember, while your body may have changed, you are still the same person inside.

Booklets and fact sheets

Breast cancer and hair loss (2004)

Breast Cancer Care

A confident choice. Breast prostheses, bras and clothes after surgery (2006)

Breast Cancer Care

Living with a colostomy (2007)Colostomy Association

When cancer affects the way you look. Managing the change in your appearance (2005)
Changing Faces

Handling other people's reactions*

Changing Faces

Swimwear*

Colostomy Association

Self Image*

The Ileostomy and Internal Pouch Support Group

Websites

British Red Cross

www.redcross.org.uk

Look Good Feel Better UK www.lookgoodfeelbetter.co.uk

Look Good Feel Better for Men www.lookgoodfeelbetterformen. org

Orchid Cancer Appeal (Men's cancers)

www.orchid-cancer.org.uk

The Limbless Association www.limbless-association.org

Sources of support

Your healthcare team and people who are close to you are likely to be some of the most important sources of support. Your healthcare team will also know what support services are available in your local area.

Support groups

Support groups are groups of people affected by cancer, who meet regularly to socialise and help each other. They are for people who have cancer and for friends and family who are caring for someone with cancer.

They provide the opportunity to talk and learn about each other's experiences. Many people find support groups can help them adjust to their life after cancer. Many support groups provide

counselling, and complementary therapies.

Attending support groups can also help you find out about other local services that may be able to make life easier for you, like help around the home and transport to hospital.

Contact the Macmillan
CancerLine on 0808 808 2020
or visit www.macmillan.org.uk
to find a support group near you.

Online support

If you have a computer, you can be part of an online forum, where you can read about other people's cancer experiences and the feelings they have. It's up to you whether you want to write anything or not; if you prefer, you can just read what others have written.

Forums also help you find out how other people are living with similar problems. Many have members from all over the world.

Macmillan Cancer Support runs several forums on the Share section of our website. Visit www.macmillan.org.uk/share

Online forums

All cancers

www.macmillan.org.uk/share www.cancerbackup.org.uk

Breast cancer

www.breastcancercare.org.uk

Cancer of the testicle, prostate, or penis

www.orchid-cancer.org.uk

For 12-16 year olds with a parent with cancer

www.riprap.org.uk

Kidney cancer

www.kcuk.org

Laryngectomee

www.webwhispers.org

Lung cancer

www.roycastle.org

Patient experience website

www.dipex.org.uk

Prostate cancer

www.prostate-cancer.org.uk

Pancreatic cancer

www.pancreaticcancer.org.uk

Sarcoma

www.sarcoma-uk.org

Young person with lymphoma

www.lifesite.info

Cancer helplines

These are telephone numbers where you can talk to specially trained people who understand the problems people with cancer face. They can give advice on any emotional, practical, and financial difficulties you may have. Some helplines are staffed by cancer nurses who can help you understand your cancer and answer any questions you, or your carers may have.

Numbers that begin with 0808 or 0800 are free.

Macmillan CancerLine – 0808

808 2020

Macmillan South Asian

CancerLines

Hindi – 0808 808 0100

Punjabi - 0808 808 0101

Urdu - 0808 808 0102

Youth Line

Macmillan YouthLine on - 0808 808 0800

All types of cancers

Cancerbackup – 0808 800 1234 **CancerHelp UK** – 0808 800

4040

1 Emotional effects of cancer

Other helplines

Breast Cancer Care - 0808 800 6000

Bowel Cancer UK - 0870 850 6050

Beating Bowel Cancer – 020 8892 5256

Brain Tumour UK - 0845 450 0386

Brain and Spine Foundation - 0808 808 1000

British Heart Foundation - 0845 070 8070

British Lung Foundation - 0845 850 5020

Cancer Black Care - 020 8961 4151

Changing Faces - 0845 450 0275

Colostomy Association - 0800 587 6744

Disabled Living Foundation - 0845 130 9177

James Whale Fund for Kidney Cancer - 01799 585033

Jo's Trust (cervical cancer support) - 01327 341965

Lymphoedema Support Network - 020 7351 4480

Lymphoma Association - 0808 808 5555

Myeloma UK - 0800 980 3332

National Association of Laryngectomee Clubs – 020 7730 8585

Oesophageal Patients Association - 01217 049860

Ovacome - 020 7380 9589

Prostate Cancer Charity - 0800 074 8383

Prostate Cancer Support - 0845 601 0766

Quit (Quit Smoking) - 0800 002 200

Rarer Cancers Forum - 01227 738279

Relate - 0845 130 4016

Roy Castle Lung Cancer Foundation - 0800 358 7200

Sex and Disability Helpline - 0707 499 3527

Sexual Dysfuntion Association - 0870 774 3571

Urostomy Association - 01889 563191

Support groups by phone

This is when you talk to lots of people linked by a phone. You can express your feelings and learn from each other. A cancer nurse is sometimes on the telephone line and can help with any questions you may have.

The Macmillan CancerLine on 0808 808 2020 will be able to tell you more.

Live chat programmes

Primary and secondary breast cancer

www.breastcancercare.org.uk

Counsellors

A counsellor is someone you can talk to, and share any feelings you have. Counsellors can help you make sense of your feelings.

Many GP practices have a counsellor or can put you in contact with one. Your hospital healthcare team can also make contact with a counsellor on your behalf. Some support groups and cancer information and support centres offer counselling services.

The British Association for Counselling and Psychotherapy can help you find a counsellor or therapist near to where you live. Contact 0870 443 5252 or visit www.bacp.co.uk

Clinical psychologists

Clinical psychologists can help to enhance your overall psychological wellbeing by relieving any distress you may have. This might involve treatments and counselling. Your healthcare team or GP will be able to tell you more.

Spiritual help

Some people find their religious faith or spiritual beliefs give them extra strength to face cancer.

Others find their faith is shaken by a cancer diagnosis.

You can talk to your religious or spiritual leader about your worries and fears. They are used to talking to people in your situation. You might find that your faith community is a good source of practical and emotional support.

The hospital chaplain is willing to help people of any religion – or

even people who don't have a faith. You can ask to talk to the chaplain any time.

Courses and other programmes

There are many courses for people who have had cancer. Macmillan Cancer Support runs the Living with cancer programme. It aims to help people find ways of managing their symptoms and side effects, regain confidence and enjoy a better quality of life.

The Expert Patients Programme helps people understand their illness, look after themselves, and be more in control of their lives.

The Odyssey charity helps people with cancer to regain self confidence through a programme of outdoor activities.

Contact the Macmillan CancerLine 0808 808 2020 for more details.

Websites

Macmillan Cancer Support www.macmillan.org.uk

Expert Patients Programme www.expertpatients.nhs.uk

Odyssey

www.odyssey.org.uk

Sources of information

While your healthcare team is there to explain and answer any questions you might have, it's easy to forget what was said or forget what some of the words mean. Some people might prefer it to stay that way, but some people want to know all the facts about what is happening to them and feel a sense of control when they do.

Publications

Many cancer charities provide information about cancer, its treatment, the emotional effect of the disease, relationships and much more.

Information about cancer is also available on the internet.

Finding websites that contain accurate and up-to-date information is not always easy.

Macmillan Cancer Support's A directory of information materials for people affected by cancer contains details of booklets, leaflets, books, audiovisual materials and websites on all aspects of cancer.

It's updated every year and there's a searchable version on the Macmillan website. To order a copy call Macmillan on 0800 500 800.

Cancer information and support centres

Many hospitals, some GP practices and libraries have their own cancer information and support centres. These are places where you can get free information on all aspects of cancer. Cancer information and support centres provide a relaxing environment where you can find information and talk to specially trained staff.

Cancer information and support centres provide a range of support services. Some offer free counselling, benefit advice, complementary therapies, coffee mornings and other social meetings, where you can meet people with a similar experience to your own, learn about living with cancer or attend 'look good feel better' programmes.

Call the Macmillan CancerLine on 0808 808 2020 to find your nearest cancer information and support centre.

Complementary therapies

Always consult with your healthcare team before using any complementary therapy.

Complementary therapies are kinds of treatment you can take, or something you can do to help with the emotional, and physical symptoms of cancer. Unlike cancer treatments, such as radiotherapy, chemotherapy, surgery and hormone therapy, they don't treat your cancer, but can help you relax.

If you want to find out more about complementary therapies, your local cancer support group, cancer information centre, hospice, or cancer treatment centre should be able to help. Some complementary therapies are available on the NHS.

Booklets and fact sheets

Cancer and complementary therapies (2005)

Cancerbackup

Complementary therapies (2007)

Breast Cancer Care

Complementary therapies (2007)

British Lung Foundation

Websites

The Prince's Foundation for Integrated Health

www.fih.org.uk

Penny Brohn Cancer Care

www.pennybrohncancercare.org

The Research Council for Complementary Medicine

www.rccm.org.uk

Tips about finding the right complementary therapy

- Find a good practitioner. Seek advice from cancer organisations or your local support group.
- Check whether there is an organisation that sets standards in the therapy you want to use, and if they have a list of qualified practitioners.
- Try and find a practitioner who has worked with people with cancer.
- Choose someone you can get on with.
- Ask for references to find out what other people have thought.
- Don't be misled by miracle cures.
- Don't be taken in by people who say you should abandon your doctor's treatment.
- Ask your GP or cancer treatment centre whether you can get complementary therapies on the NHS, or through a local cancer charity.
- Check the number of sessions you might need before the benefits are felt, and how long each session will take.
- Check the cost. Many therapies are not available on the NHS
 and can be expensive. It is worth checking, with a recognised
 organisation, what the cost of treatments should be for the
 therapy you choose.

Enjoying life and looking after yourself

When you are living with cancer, it's important to look after yourself:

- eat well every day
- if you feel unwell, get some extra rest and don't put off seeing your doctor
- accept offers of help or turn to others for help
- keep to a regular sleeping pattern
- try to keep fit with regular exercise, for it can help you relax and boost your energy
- try to share your feelings
- try to keep your social life alive by staying in contact with your friends
- recognise when you are 'run down' and stressed (headaches, trouble sleeping, tummy upsets, and colds that don't go away) and see your doctor for advice.

Ask your doctor or nurse about seeing a dietitian if you have eating problems. You can find your nearest nutritionist by contacting The British Nutrition Foundation.

The Oesophageal Patients
Association can provide a
restaurant card which you can use
in restaurants to ask for smaller
helpings of food.

The charity Odyssey can help you regain self confidence and a zest for life through a programme of outdoor activities.

Your library is also a good source of information about local events and activities.

The Cancer Laryngectomee Trust has developed a Laryngectomee Travel Guide to the British Isles. It provides a list of all hospitals that are able to respond to laryngectomee emergencies.

Booklets and fact sheets

Advice about soft and liquidised food: A guide for patients and their families (2007)
Christie Hospital NHS Trust

After treatment: A guide for cancer patients (2002)

The Royal Marsden NHS Foundation Trust

Cancerbackup recipes (2006) Cancerbackup Coping with eating difficulties when you have cancer: A guide for African and Caribbean patients (2007)

Cancer Equality

Diet and cancer (2006)

Cancerbackup

Diet and nutrition (2007)

Myeloma UK

Dietary and nutritional advice for ostomists (2007)

Dansac

Eating after bowel surgery (2007)

Bowel Cancer UK

Eating well when you have cancer: A guide for cancer patients when eating may be difficult (2007)

The Royal Marsden NHS Foundation Trust

Restaurant card

Oesophageal Patients Association

Staying healthy after bowel cancer (2007)

Bowel Cancer UK

Bowel cancer diet and nutrition: your recipe for recovery*

Beating Bowel Cancer

Websites

Cancer Equality

www.cancerequality.org.uk

Cancer Laryngectomee Trust

www.cancerlt.org

Myeloma UK

www.myelomaonline.org.uk

Odyssey

www.odyssey.org.uk

Royal Marsden NHS
Foundation Trust

www.royalmarsden.nhs.uk

The British Nutrition Foundation

www.nutrition.org.uk

The Christie Hospital NHS Foundation Trust

www.christie.nhs.uk



2 Practical issues

This section describes some of the practicalities of living with cancer.

Work

Returning to work can restore a sense of control, routine, and stability in your life. It also brings with it a source of regular income and can reduce any feelings of isolation by providing contact with friends and colleagues.

Fatigue is a common problem faced by people returning to work. It can be a daily problem and may mean that you will have to change your pattern of work.

As someone who has been diagnosed with cancer you have a number of rights and are protected by the Disability Discrimination Act.

You have the right to:

- not tell your employers about any tests you are having
- carry on working
- if needed, expect your employer to make reasonable adjustments to your working environment
- challenge your dismissal, if you are sacked or made redundant because of your health, even if you work part-time.

Macmillan Cancer Support has developed the Working through cancer guide for employers and guide for employees. They provide facts and figures about cancer, details of relevant legislation, and advice on the reasonable adjustments employers can make, when employees affected by cancer return to work.

If your employer wants to know more, they can visit our website www.macmillan.org.uk/work

You may find that work becomes too much and that you need to reduce your working hours, or leave your job completely. Talk to your employer about whether it may be possible to reduce your working hours, work from home, or have flexible working arrangements. If you are considering early retirement or resignation, we recommend you seek advice about the best options for your situation.

Call the Macmillan's Benefits Line on 0808 801 0304

Booklets and fact sheets

Working through cancer: a guide for employees (2007)
Macmillan Cancer Support

Working through cancer: a guide for managers (2007)
Macmillan Cancer Support

Work and cancer (2006) Cancerbackup

Doing work differently* RADAR

Websites

ACAS

www.acas.org.uk

Citizens Advice Bureau www.citizensadvice.org.uk

Equality and Human Rights Commission

www.equalityhumanrights.com

Jobcentre Plus

www.jobcentreplus.gov.uk

Government online – money, tax and benefits

www.direct.gov.uk

Benefits and financial advice

If you are struggling with the financial costs of cancer, or your income has been affected by your diagnosis, you may be able to get some of the following state benefits:

- Disability Living Allowance
- Attendance Allowance
- Incapacity Benefit
- Carers' Allowance
- Housing and Council Tax Benefit
- Income Support, including disability and carer premiums
- Pension Credit
- Working Tax Credit and Child Tax Credit
- help from the Social Fund

Financial help may be available to cover the cost of prescriptions, travel to hospital, fabric supports and wigs, dental treatment, eye tests and glasses. People who cannot use public transport may be able to get travel vouchers for taxis and door-to-door services.

Macmillan Cancer Support's guide to benefits, Help with the cost of cancer, is available by calling 0800 500 800.

It's a good idea to get help from an experienced benefits adviser. Contact the Macmillan Benefits Line on 0808 801 0304. Your local Citizen's Advice Bureau can help with benefit advice.

Booklets and fact sheets

Help with the cost of cancer. A guide to benefits and financial help for people affected by cancer (April 2007)

Macmillan Cancer Support

Money worries? We can help (2006)

Macmillan Cancer Support

Breast cancer and benefits (2006)

Breast Cancer Care

Breast cancer and childcare (2007)

Breast Cancer Care

Useful telephone numbers

Macmillan Benefits line 0808 801 0304

Benefits Enquiry Line for Northern Ireland 0800 220 674

Department of Work and Pensions Benefits Enquiry Line 0800 882 200

Website

British Red Cross (finance section)

www.redcross.org.uk

Other financial assistance

There are many organisations and occupational benevolent funds which may be able to help. They include:

- Macmillan Cancer Support provide grants to people with cancer in financial difficulties.
 Applications are usually made by health and social services staff on your behalf.
- The Independent Living Fund (ILF) helps with the costs of help at home. Applications have to be made through your local social services department.
- If you have been in the armed forces, you may be able to apply for a grant from the Soldiers, Sailors, Airmen and Families' Association (SSAFA), Forces Help, the Earl Haig Fund or the RAF Benevolent Fund.

Organisations

Earl Haig Fund Scotland 0141 221 8141

Independent Living Funds 0845 601 8816

RAF Benevolent Fund 0800 169 2942

SSAFA Forces Help 0845 1300 975

The Royal British Legion 0845 772 5725

Website

Macmillan Cancer Support www.macmillan.org.uk

Travel and travel insurance

Getting travel insurance can be more difficult for someone who has had a cancer diagnosis. It can mean that travel insurance, when it is offered, might be expensive and carry a high excess (the amount you pay of any claim you make).

Your insurance company may need a letter from your doctor that says you are well enough to travel and may also exclude any claim that is related to the cancer you have.

As premiums (the amount you pay for the insurance cover) vary, it's a good idea to shop around. Some insurance brokers specialise in this kind of insurance.

If you are travelling within the European Union, the European Health Insurance Card (EHIC) entitles you to free, or reduced cost emergency treatment within the European Union. You may have to pay for the treatment and reclaim the cost when you return to the UK.

European Health Insurance Card (EHIC)

EHIC cards can be obtained by post (forms from the post office), by telephone 0845 606 2030, or online www.dh.gov.uk/travellers. The website also provides health advice for travellers.

Insurance brokers and insurance companies

For an up-to-date list of companies who specialise in providing travel insurance to people affected by cancer contact Cancerbackup on 0808 800 1234.

Booklets and leaflets

Getting travel insurance when you have been affected by cancer (2007)

Macmillan Cancer Support

A laryngectomee's travel guide to the British Isles (2007) Cancer Laryngectomee Trust

Breast cancer and travel insurance (2006)

Breast Cancer Care

Travel and cancer (2006)
Cancerbackup

Care in your home

If your day-to-day living is becoming a struggle, there are a number of organisations and services that can help.

Nurses in the community

Community and district nurses are nurses that work in the community where you live. They are usually based at a GP practice and visit your home or care home to provide you, and your carer, with care and support. Your GP can contact them on your behalf.

District nurses can help treat any symptoms you may have. They can help to show you and your carer(s) practical ways of looking after yourself. Many district nurses are trained to provide specialist help.

Social workers

Cancer can change the way you live and work and create other problems that you might find hard to fix. You might have to take time off work during and after your treatment, or stop work altogether; you may find it hard to look after yourself as well as you did before cancer, or be worried about how you are going to pay the bills.

Social workers can help with any practical and money issues you may have. This might include changes in your home, to make your day-to-day living easier. Your social worker will be able to contact any specialist staff or organisations you might need.

Occupational therapists

Occupational therapists (OT) can help you adapt to changes in your everyday life. They can help you overcome practical problems that have emerged and enable you to live as independently as possible, at home, at your place of work or education. Like your social worker, they can help with advice, assess whether you need help around your home, refer you to other services, such as speech and language therapy and help you with work-related issues.

Occupational therapists have specialist knowledge of the range of disability equipment, housing adaptations and adaptations to the workplace that may be available for you.

The social services department of your local council, your doctor or consultant can arrange for you to meet an occupational therapist.

Other specialist staff

There are many specialists who can provide support and care during, and after, your cancer diagnosis. These might include dietitians, home carers, physiotherapists, speech and language therapists. Your hospital team, GP or social worker will be able to contact any specialist staff you may need.

Websites

Government online – social care

www.direct.gov.uk

Disabled Living Foundation www.dlf.org.uk

The Royal Association for Disability and Rehabilitation (RADAR)

www.radar.org.uk

Organisations which can help

Apart from Social Services and the NHS, there are many other voluntary organisations or charities, which provide a wide range of care services. Some organisations for example, provide nurses who will sit with you all night, should you need round-the-clock care; others might take you to hospital or help with shopping. Your doctor, cancer nurse and community nurse can organise these services on your behalf.

Carers assessment

If someone is providing regular care for you, you can ask for a 'carers assessment'. This looks at your carers needs. Your hospital social worker, practice nurse, district nurse or GP will be able to arrange this assessment.

Before the assessment, your carer should think about the kind of help that would make it easier for them to care for you. It's a good idea for them to make a list of everything they do for you, whether they work or want to return to work.

Your Social Services department can also help carers in other ways including giving breaks from caring and any practical help they may need.

Meals on wheels

Meals on wheels are meals (either hot or delivered frozen) that are delivered to your door. The menu reflects a range of dietary needs and religious customs for example diabetics, vegetarians, gluten free, kosher or halal. There is a small charge for each meal.

You might be eligible if:

- you live on your own and are having difficulty cooking your own meals
- the person you live with (or your carer) is not able to cook for you during the day.

You may also be able to have meals delivered as a temporary service if you are recovering from an operation at home and are unable to cook. Your social worker will be able to help organise meals on wheels and any other needs you may have.

Website

Government online www.direct.gov.uk



3 Physical effects

Cancer and its treatments can cause many changes to your body. Different parts may no longer work in the same way as they once did. You might look and feel different, and may need to learn new ways to cope with the changes that have come into your life.

Common side and after effects

The side effects of cancer can vary from one person to another.

Sometimes your cancer doctor will not always know what side effects you may have, or whether they will be short-lived or last a long time.

There are also after effects that can emerge many months or years after your treatment stops.

This section describes some of the side effects you can have, what they might mean to you, and some of the practical steps you can take. As treatments continue to improve, some of the side effects we've listed are rare, and reflect treatments that are no longer used.

Booklets and fact sheets

Controlling the symptoms of cancer (2007)

Cancerbackup

Fatigue

Fatigue is a general feeling of weakness that sleep doesn't always seem to solve. It can make you tired, no matter how simple the task. Fatigue can also make thinking difficult and affect your sex drive. It's a common effect during chemotherapy and usually goes away once the treatment stops, but it can also linger and, for some people, last a long time.

There are other reasons why you might be experiencing fatigue. While it can be a long term effect of cancer, talk to your doctor if your fatigue continues or returns.

Booklets and fact sheets

Coping with fatigue (2005) Cancerbackup

Fatigue (2006)

International Myeloma Foundation UK

Some tips for coping with fatigue (2005)

Lymphoma Association

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Tips for when you have fatigue

- plan out your day and make lists to help you remember what you need to do
- choose a time of day when you have more energy (usually in the morning) to do the most strenuous things
- accept help from others
- try not to multi-task. Finish one task before starting another.
- recognise that what you once did without thinking has become harder to do
- try to exercise regularly. It might seem odd, but people who
 exercise experience less fatigue than those who don't. It can
 start with something simple, such as walking for a few minutes
 each day.
- talk to your doctor if you are depressed, have any pain, or find it hard to sleep. All of these can make your fatigue worse.

Memory, concentration and behavioural problems

From time to time we all have memory problems. Most of us find it easy to forget where we left the keys, or walk to one part of the house only to forget why we were going there in the first instance.

Forgetfulness, and your ability to think and carry out tasks, is more common when you are stressed, depressed, and as you age. On top of this, many different kinds of cancer treatments including surgery or radiotherapy to the head can affect your memory, your ability to think straight or to learn new things.

It might mean that some of the things you did without thinking have become harder to do. When this happens, it's easy to become annoyed and frustrated. Your cancer specialist and doctor may be able to help, but there are many things you can do to adjust to the change.

Tips for memory, concentration and behavioural problems

- use organisers or diaries
- make lists of what you have to do
- try to work to a daily or weekly routine
- try not to multi-task. Complete one job before you start another rather than doing lots of things at once
- chose a time in the day when you feel more alert to carry out more difficult tasks
- improve your memory by repeating any new things you are reading or trying to do
- keep mentally active by doing crosswords, puzzles, reading newspapers, books or magazines
- try to relax by listening to music or doing other things that can help you wind-down
- try to exercise regularly and sleep at regular times.

Talk to your doctor who may be able to help. Your GP may organise for you to see an occupational therapist.

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Teeth and mouth problems

People who have had chemotherapy can develop teeth and mouth problems that usually go away a few weeks after the treatment has stopped. However, if you have had a bone marrow transplant you are more likely to develop infections of the mouth, such as gum disease, thrush, ulcers and other problems may continue long after treatment ends.

Other treatments, like radiotherapy to your head or neck can damage your salivary glands and teeth. It can mean your mouth becomes dry because you are not making enough saliva. This makes chewing more difficult and, as

saliva is a mild antiseptic, can cause mouth problems to happen.

If you have been taking regular bisphosphonate injections (also called zometa, or aredia) it might mean that you develop healing problems in your mouth.

It is important to visit your dentist before starting any treatment so that any dental work that needs to be done can be carried out. It's also important to visit your dentist regularly after your treatment, to stop any small problems becoming bigger.

Radiotherapy to the head and neck region and chemotherapy can make your mouth become dry. This can affect your speech, taste and ability to swallow. It can also cause halitosis or bad breath, as food and bacteria find it easier to stick to your gums and teeth. Saliva protects your teeth from infections and other problems that might come along. If your mouth is dry, you are more likely to get tooth decay and gum problems.

Tips for keeping your mouth safe and clean

- Gently brush your teeth, your tongue and inside of your mouth with fluoride toothpaste after every meal and before going to bed. If your teeth are sensitive, use toothpaste for sensitive teeth.
- Use a small soft toothbrush and change your brush regularly, as frayed bristles can hurt your gums and don't clean as well as new brushes. Soft toothbrushes are made by several manufacturers. Electric toothbrushes with soft heads are also suitable.
- Clean between teeth daily with floss or an inter-dental brush (a brush that can clean the small gaps between your teeth)
 because bacteria, which cause tooth decay and gum disease, can stay between teeth where toothbrush bristles can't reach.
- If you notice bleeding when you brush or floss your teeth, it may be an early sign of preventable gum disease. Visit your dentist or hygienist for professional cleaning and advice.
- Use gentle mouthwashes which you can make yourself. For example, mix 1/4 of a teaspoon of sodium bicarbonate (baking soda) in a cup of warm water.

Tips if you have a dry or sore mouth

- sip water regularly during the day or try chewing sugarless chewing gum; this can help you make more saliva and protect your teeth
- avoid drinks with caffeine, alcohol and fizzy drinks which can make your mouth dry
- drink water while you are eating and coat foods with salad dressings and oils: this will make chewing and swallowing easier and may improve your taste
- avoid crunchy foods as theses can scratch the lining of your mouth
- avoid using mouthwashes that contain alcohol
- try using a water spray bottle to wet your mouth or your dentist or doctor can prescribe you a saliva substitute spray if you need it
- · keep a glass of water by your bed for sipping during the night
- ask your dentist for regular fluoride treatment to prevent decay
- because you may be more prone to mouth problems, it's
 important to have regular visits to your dentist, especially if you
 have any worries or infections (like a sore, swelling, bleeding or
 a sticky white film in your mouth).

Tips if you have false teeth

- False teeth can be a great place for bacteria to hide. Make sure food does not collect underneath your dentures, as this can lead to ulcers, soreness and infection, especially if your mouth is dry.
- Clean your natural teeth with a tooth brush, and brush your dentures with denture cream. Disinfect your dentures, at least once a week, to kill any germs.
- If you have any discomfort, see your dentist who may be able to adjust your dentures to a better fit.
- Make sure that you visit your dentist once a year to check your gums and tongue for problems and visit your dentist right away if you have any worries or infections like a sore, swelling, or bleeding or a sticky white film in your mouth.

Finding a dentist

If you do not have a dentist, NHS Direct can give you a list of NHS dentists willing to register patients in your area.

Useful telephone numbers

NHS Direct 0845 4647

NHS 24 Scotland 0845 424 2424

Websites

NHS Direct

NHS England www.nhs.uk/england

HSC Northern Ireland www.healthandcareni.co.uk

NHS Scotland www.show.scot.nhs.uk

NHS Wales

www.wales.nhs.uk

You should tell your dentist about your cancer history, your previous treatments and any that are planned. You can ask your dentist to be referred to a special care dentist or ask your doctor to refer you to a suitable specialist for dental care.

If you need to have further treatment for your cancer, see a dentist before your treatment begins. Fixing any underlying problems can help to stop new problems that might be more difficult to treat, after your cancer treatment ends.

Booklets and fact sheets

Dry mouth (or Xerostomia) (2007) Cancerbackup

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Sexual problems

Cancer and its treatment can cause many sexual problems. Some of these are physical and are described below.

Impotence

Impotence is when a man cannot get an erection. Some treatments such as surgery and hormone therapy for cancers of the prostate, bladder, bowel, penis and testes, can make it difficult to get an erection. While this may be shortlived and recover once your treatment stops, sometimes, for example after surgery your impotence can last a long time or never improve.

Impotence might be a delayed side-effect of treatment, happening some months or years after your treatment ends. This is because radiotherapy, like surgery, can damage some of the nerves needed for an erection to happen, but this damage can take some time to show.

You can also have erection problems because of the way you feel. Being depressed, anxious or stressed can all affect your ability to get an erection.

Doctors are used to talking about impotence and other sexual problems. There are specialist clinics, counsellors, sexual therapists, operations, treatments and devices that can help improve impotence.

Booklets and fact sheets

Impotence or erectile dysfunction (2007)

Sexual Dysfunction Association

Sexuality and cancer (2006) Cancerbackup

Sexuality and prostate cancer (2005)

The Prostate Cancer Charity

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Orchid Cancer Appeal www.orchid-cancer.ora.uk

Sexual Dysfuntion Association www.sda.uk.net

The Prostate Cancer Charity www.prostate-cancer.org.uk

Tips about your impotence

- talk to your doctor, if you are stressed or depressed
- talk to your doctor about the treatments that can help. These can work well, especially if you have partial erections.
- talk to your partner about your feelings and frustrations
- talk to a counsellor or therapist if you have sexual problems.

Vaginal dryness

Some treatments can make your vagina dry and shrink. It can also make you more prone to vaginal infections. Depending on the cancer you have had, you may be able to take hormone replacement therapy (HRT) or a local dose of oestrogen. Talk to your cancer doctor or clinical nurse specialist about the best treatment for you. Lubricants that you can use in your vagina before sex can also help.

Booklets and fact sheets

Lack of sex drive or libido (2007)

The Sexual Dysfuntion Association

Painful sex or dyspareunia (2007)

The Sexual Dysfuntion Association

Sexuality and cancer (2006)

Cancerbackup

Vaginal dryness (2007)

The Sexual Dysfuntion Association

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Sexual Dysfuntion Association

www.sda.uk.net

Fertility

This is the ability of a woman to have a child and for a man to father a child. Infertility can happen if your cancer treatment damages either your ovaries and uterus or testes in men. Although you may become fertile again once your treatment ends, you might be infertile for the rest of your life.

If you are treated for cancer again, it may be possible to remove some of your sperm or eggs before your treatment and store them for future use. You may also be able to use donated eggs or sperm.

If you want to have children, adoption may be an option open to you. Your social worker, Social Services Department, and other organisations listed below may be able to help.

Booklets and fact sheets

Breast cancer during pregnancy (2007)

Breast Cancer Care

Cancer and fertility (2007) Cancerbackup

Fertility issues and breast cancer treatment (2006)

Breast Cancer Care

Fertility issues for patients with lymphoma (2007)

Lymphoma Association

Relationships, sex and fertility for young people affected by cancer (2007)

Cancerbackup

Sex and the prostate (2005)

Sexual Dysfunction Association & Prostate UK

Websites

Adoption Information Line www.adoption.org.uk

British Association for Sexual and Relationship Therapy

www.basrt.org.uk

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Human Fertilisation and Embryology Authority

www.hfea.gov.uk

Infertility Network UK

www.infertilitynetworkuk.com

Menopausal symptoms

This is when women stop having periods. It usually happens between the age of 45-55 years. Some cancer treatments including chemotherapy, radiotherapy, hormone therapy and surgery that removes your ovaries, can damage your ovaries and stop your periods. The natural menopause tends to happen over many months or years, while cancer treatments can cause it to happen very suddenly, often with more intense side effects than if you were having a natural menopause. The Daisy Network provides information and support to people who have had an early menopause.

Booklets and fact sheets

Breast cancer and menopausal symptoms (2007)

Cancerbackup

Menopausal symptoms and breast cancer (2006)

Breast Cancer Care

Websites

Daisy Network

www.daisynetwork.org.uk

Early Menopause

www.earlymenopauseuk.co.uk

Menopause Matters

www.menopausematters.co.uk

Ovacome (Ovarian Cancer)

www.ovacome.org.uk

Women's Health Concern

www.womens-health-concern.org

Nerve problems (peripheral neuropathy)

Nerves carry messages between your brain and the rest of your body and are needed to help you move, keep your balance, see and hear, sense pain and temperature.

Some treatments, including chemotherapy and radiotherapy to the head or spine, can cause nerve problems. Our nerves can also be damaged during an operation. It means you might have pins and needles, find it hard to balance, or feel numbness (lose the sense of feeling) in part of your body.

The most common type of damage is called peripheral

neuropathy. It tends to affect the nerves in your feet and hands, and may mean you can no longer sense or feel the ground below your feet, or be able to feel things with your fingers and hands.

Although peripheral neuropathy tends to ease after your treatment finishes, in some cases it can linger or never go away.

The loss of feeling might mean you find it hard to feel the brake pedals in a car, or difficult to keep your balance. You might also struggle to fasten buttons or do other day-to-day activities with your hands.

If you need to be treated for cancer again, and have had peripheral neuropathy before, talk to your cancer specialist. There may be other kinds of chemotherapy you can take that are less likely to cause peripheral neuropathy.

Booklets and fact sheets

Choosing equipment to maintain safety and independence at home (2006)

Disabled Living Foundation

Making a difference (choosing equipment for everyday living) (2005)

Disabled Living Foundation

Peripheral neuropathyCancerbackup

Peripheral neuropathy Myeloma UK

Peripheral neuropathy & neuropathic pain (2005)

The Neuropathy Trust

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Disabled Living Foundation www.dlf.org.uk

The Neuropathy Trust

www.neurocentre.com

The Royal Association for Disability and Rehabilitation (RADAR)

www.radar.org.uk

Living with nerve problems (peripheral neuropathy)

- Use mirrors to help you dress, fasten buttons or jewellery, and to do things that have become difficult. Seeing what you are trying to do, when you can no longer feel, can help.
- If your balance is affected, some people avoid sloping pavements and find it easier to use steps instead.
- Use thermometers that allow you to sense how hot something is. Thin strip-thermometers are sometimes the best.
- Special kitchen utensils which give you better grip are available, from potato peelers to large-handled mugs.
- Replace small knobs on cupboard doors with large ones.
- Use key pads on phones that make a noise when the number has been pressed.
- Contact the Disability Living Foundation for information on the range of products available.

3 Physical effects

Joint and bone problems

Chemotherapy and other treatments such as steroids and hormone therapy can cause bone and joint problems. Radiotherapy to the pelvis region can also cause bone problems to emerge later.

One of the most common problems is osteoporosis. This is when your bones become porous and begin to lose their strength. As osteoporosis has few signs and symptoms, most people don't find out they have osteoporosis until they have a fracture or break to one of their bones. Eating well and exercise might be some of the best ways to keep your bones healthy.

Talk to your doctor about osteoporosis, as there are many treatments that can help. Some treatments may cause dental problems. See Teeth and Mouth Problems in this section.

Booklets and fact sheets

Bone health and breast cancer (2003)

Breast Cancer Care

Exercises for people with osteoporosis*

The National Osteoporosis Society

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

Early Menopause UK

www.earlymenopauseuk.co.uk

The National Osteoporosis Society

www.nos.org.uk

Tips for keeping your bones strong

- Calcium is needed for strong and healthy bones. Your body contains about 1 kilogram of Calcium, with 99% of it inside your bones and teeth.
- Vitamin D helps your body hold onto calcium, while too much salt, fizzy drinks, smoking, alcohol and being overweight, can all reduce the amount of calcium your body contains and, therefore, the strength of your bones.
- Eat foods rich in calcium like milk, cheeses and yoghurts. Low fat cheeses and yoghurts have similar amounts of calcium as higher fat alternatives. Compared to milk, cream contains about half the amount of calcium.
- A good way to start is to have cereals for breakfast, with plenty
 of milk. Many cereals contain added calcium. The levels of
 calcium are about the same in skimmed, semi-skimmed and
 whole milk.
- Eat more nuts and seeds especially sesame seeds, and dried fruits in particular figs and apricots as these are good sources of calcium.
- Include tinned fish such as salmon and sardines in your diet.
 Tinned fish often contains small amounts of fish bones, which are high in calcium, and can be mashed with the fish.
 Compared to salmon and sardines, tinned tuna does not contain high levels of calcium.
- Green vegetables are a good source of calcium. Kale, water cress, broccoli, and spinach have the highest levels. Tofu also contains high levels of calcium.
- Bottled mineral waters can be a good source of calcium.
- Exercise regularly, especially exercise that places weight on your bones. You don't have to become a weight lifter, but jumping up and down on the spot and lifting small weights, such as a tin of baked beans (also a good source of calcium), is a good start.

3 Physical effects

Vitamin D helps our body absorb calcium from the foods we
eat. Our skin cells make vitamin D when they are exposed to
the sun. In the UK, about 20 minutes of sunlight each day
provides you with all the vitamin D needed. Outside activities
like walking and gardening expose your body to the sun, and
allow you to both exercise and make vitamin D at the same
time. Always remember to wear appropriate sun protection.

Bowel and bladder problems

If you have had an operation that removes part of your bowel or bladder or other treatments that mean you can no longer control how your bowel or bladder works, you may be using bags to collect your urine or waste.

Some treatments can cause bowel and bladder problems. You may have diarrhoea that comes and goes, or need to pass urine more often. The good news is that there are many organisations and suppliers that can help. Your local Continence Advisory Service will also be able to help. Your GP, district nurse and hospital team will be able to contact them for you.

Booklets and fact sheets

Healthy bladder – what to do if things go wrong (2005)

Healthy bowels – what to do if things go wrong (2006)
InContact

Travelling with confidence*
InContact

Troubled nights*
InContact

Just can't wait* InContact

Websites

Bowel Control www.bowelcontrol.org.uk

Tips for travel

- map out your journey and know where the local toilets are
- remember, flights can sometimes be delayed and luggage lost, so take extra bags in your carry-on luggage
- take spare pants, pads and plastic bags when you are away from your home
- if you have bladder problems, avoid foods that can make you constipated as this may make things worse
- the RADAR key provides access to all UK public toilets
- the 'Just Can't Wait' card can allow you to use toilets in shops and restaurants.

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

CORE (the Digestive Disorders Foundation)

www.corecharity.org.uk

Disabled Living Foundation www.dlf.org.uk

InContact

www.incontact.org

Promoting Continence

www.promocon.co.uk

Royal Association for Disability and Rehabilitation (RADAR)

www.radar.org.uk

The Continence Foundation

www.continence-foundation.org.uk

Heart and lung problems

Some kinds of radiotherapy to the chest region, can cause heart and lung problems. Better ways of delivering radiotherapy has made this problem less likely to happen.

If your heart has been damaged, it might mean your heart does not work as well as it once did. Heart problems can have no symptoms and so, if you are worried, talk to your doctor about having your heart checked. If you have any chest pain, tell your doctor right away.

Some of the signs of lung problems include chest pain, a shortness of breath, or a niggling dry cough that doesn't go away. Sometimes the lung problem is short-lived but it can also last for a long time. As the risk of developing lung problems is greater if you smoke, it's another good reason to quit.

Talk to your doctor if you are feeling breathless, have pain when you breathe, or a cough that lingers. Inhalers can sometimes help to open up the airways in your lungs and make breathing easier.

Websites

British Heart Foundation

www.bhf.org.uk

British Lung Foundation

www.lunguk.org

Go Smokefree

www.gosmokefree.co.uk

Quit

www.quit.org.uk

Lymphoedema

This is a swelling, usually in your leg or arm and happens when your cancer treatment has affected the way your body drains fluid. It's more common in people who have had their lymph nodes removed. Once you have had lymphoedema, it's unlikely to go away completely and can return for no apparent reason.

There are many things you can do to treat lymphoedema and help prevent it happening again. Exercises, elastic bandages, and gentle massage can all help.

See your GP, specialist nurse straight away if you notice any swelling or see any redness or swelling around a cut.

The British Lymphology Society website allows you to search for your nearest lymphoedema service.

Tips to prevent lymphoedema

- Insect bites, grazes, cuts, sunburn and too much strain on your arms or legs can make lymphoedema worse. It's best to use high factor sun screens, insect repellent, and treat all cuts, grazes, and bites right away.
- Use gloves, if you are gardening or thimbles if you sew to avoid cutting or pricking yourself.
- If you shave under your arms, try an electric razor to avoid cuts.
- If you have a pet, be careful that it does not scratch you.
- Avoid very hot showers, saunas, and baths.
- Try to avoid using an arm that is prone to developing lymphoedema for lifting heavy things like shopping bags and other day to day tasks.
- Avoid crossing your legs if they have, or might develop, lymphoedema.
- Being over-weight can make lymphoedema worse.

Booklets and fact sheets

Coping with lymphoedema of the arm (2002)

Wessex Cancer Trust

Coping with lymphoedema of the leg (2003)

Wessex Cancer Trust

Living with lymphoedema after breast cancer (2007)

Breast Cancer Care

Reducing the risk of lymphoedema (2006)

Breast Cancer Care

Understanding lymphoedema (2006)

Cancerbackup

Websites

The British Lymphology Society www.thebls.com

Lymphoedema Support Network

www.lymphoedema.org/lsn

Another cancer happens

While your cancer treatment is designed to kill cancer cells, it can sometimes damage healthy cells. It's this damage that, over time, may cause them to change into cancer cells. Spotting cancer early

offers the best chance of treating any new cancers that emerge. Not all cancers have tell-tale signs that are easy to find. It might be that you just don't 'feel right' and can't pinpoint any one symptom.

If you think something doesn't feel right, or have a symptom that is new and unusual to you, talk to your family doctor, who can check out what might be wrong, organise tests, and talk about any concerns you might have.

Booklets and fact sheets

Are you worried about cancer? (2006)

Cancerbackup

Cancer – know the warning signs (2005)

Cancer Research UK

Lifestyle and cancer – reduce the risk (2005)

Cancer Research UK

Websites

Cancerbackup

www.cancerbackup.org.uk

CancerHelp UK

www.cancerhelp.org.uk

See your doctor if you have:

- an ache or pain that doesn't go away
- a sore that hasn't healed
- a mole that has changed shape, size or colour, or started to bleed
- a nagging cough or hoarseness
- an unusual lump or thickening under your skin
- a loss of weight that can't be explained
- difficulty in swallowing
- changes in your bowel motions and how often you go to the toilet
- bleeding between your periods or if you start to lose blood again long after your periods have ended
- a fever that doesn't seem to be getting any better or feeling tired for no obvious reason.

Care after cancer

Follow-up plans

Most people diagnosed with cancer today will have a 'follow-up plan'. This is a plan for your care after your treatment has finished. It's likely to mean regular check-ups to make sure your cancer is not coming back, and to check whether everything is going ok.

Your follow-up plan is about you and what emotional, practical and financial support you may need.

Follow-up appointments are a good time for you to talk to your specialist about any problems or worries you have. You should be given a contact telephone number to use if you have any problems between appointments.

If you were diagnosed with cancer many years ago, you may not have had a follow-up plan or no longer have follow-up appointments. You might have forgotten what type of cancer you had or the treatments you were given. Your GP can help find out the details from the hospital where you were treated.

Follow-up tests

There are a number of tests and scans that can help you and your doctor look for any problems that may be invisible to the eye. For example, bone-density scans can help see if you have osteoporosis, and blood tests measure some of the proteins that cancer cells sometimes make. Your GP or cancer specialist can organise these tests for you.

Questions to ask your doctor or cancer specialist

Asking questions can help you find out more about your cancer and help your doctor provide the best possible care and support.

Questions for your doctor

- Is there anything I can do to lower the chance of my cancer coming back?
- Are there any signs and symptoms I should look for?
- How often should I have a follow up appointment?
- What should I do if I am worried about my health?
- Are there any screening tests you think I should have?
- Are there any information resources you would recommend?



4 Useful organisations

Macmillan Cancer Support

Macmillan can offer you information, advice and support through a wide range of services.

Macmillan CancerLine

Our specialist advisers offer confidential advice and help you find the information you need.

Freephone 0808 808 2020
Textphone 0808 808 0121
Monday to Friday 9am-9pm
Calls are free
Email
cancerline@macmillan.org.uk

South Asian CancerLine

Hindi – 0808 808 0100 Punjabi – 0808 808 0101 Urdu – 0808 808 0102 Monday to Friday 9am-6pm Calls are free

Macmillan YouthLine

Macmillan's YouthLine is available for young people aged 12 to 21.

Freephone 0808 808 0800 Monday to Friday 9am-9pm Calls are free Email youthline@macmillan.org.uk

Macmillan Benefits Helpline

The Macmillan Benefits Helpline is a telephone advice service for people with cancer, their family and carers who need help to access benefits and other kinds of financial support.

Freephone 0808 801 0304 Monday, Tuesday, Friday 10am-5pm Wednesday 12pm-5pm Calls are free

Macmillan self help and support groups

We support over 750 independent cancer self help and support groups across the UK.

Contact Macmillan CancerLine or email cancerline@macmillan.org.uk

Macmillan cancer information and support centres and mobile centres

Visit one of our centres where you will find clear information and face-to-face support.

Contact Macmillan CancerLine or email cancerline@macmillan.org.uk

Macmillan publications

We produce publications about day to day practical and emotional issues. These are available free to anyone affected by cancer.

To order call 0800 500 800 or visit our website at www.macmillan.org.uk

Macmillan website

Our website provides detailed information on all our sources of support as well as a forum where you can share your experiences. www.macmillan.org.uk

Living with cancer course

This is a free six-week course for people living with cancer, run by trained tutors who have had cancer themselves.

To find out more, contact CancerLine on 0808 808 2020 or visit the website at www.macmillan.org.uk

Useful organisations

ACAS

Brandon House 180 Borough High Street London SE1 1LW Helpline 0845 747 4747 www.acas.org.uk

Age Concern

Astral House 1268 London Road London SW16 4ER Helpline 0800 009 966 www.ageconcern.org.uk

Beating Bowel Cancer

39 Crown Road
Twickenham
Middlesex TW1 3EJ
Tel 020 8892 5256
Email
info@beatingbowelcancer.org
www.beatingbowelcancer.org

Bowel Cancer UK

7 Rickett Street London SW6 1RU Tel 020 7381 9711 Advisory service 0870 850 6050 Email admin@bowelcanceruk.org.uk www.bowelcanceruk.org.uk

Breast Cancer Care

5-13 Great Suffolk Street London SE1 ONS Helpline 0808 800 6000 Email info@breastcancercare.org.uk www.breastcancercare.ora.uk

British Association for Counselling and Psychotherapy

15 St John's Business Park Lutterworth LE17 4HB Tel 0870 443 5252 Email bacp@bacp.co.uk www.bacp.co.uk

British Association for Sexual and Relationship Therapy

PO Box 13686 London SW20 9ZH Tel 020 8543 2707 Email info@basrt.org.uk www.basrt.org.uk

British Lung Foundation

73-75 Goswell Road London EC1V 7ER Tel 0845 850 5020 www.lunguk.org

British Lymphology Society

10 St Aidans Close Cheltenham Gloucestershire GL51 0HL Tel 01242 245200 Email info@thebls.com

British Nutrition Foundation

High Holborn House 52-54 High Holborn London WC1V 6RQ Tel 020 7404 6504 Email postbox@nutrition.org.uk www.nutrition.org.uk

Cancerbackup

3 Bath Place Rivington Street London EC2A 3JR Tel 0808 800 1234 www.cancerbackup.org.uk

Cancer Equality

27-29 Vauxhall Grove Vauxhall London SW8 1SY Tel 020 7735 7888 Email info@cancerequality.org.uk www.cancerequality.org.uk

4 Useful organisations

CancerHelp UK

PO Box 123 Lincoln's Inn Fields London WC2A 3PX Tel 0808 800 4040 www.cancerhelp.org.uk

Cancer Laryngectomee Trust

PO Box 618 Halifax West Yorkshire HX3 8WX Tel 01422 205522 Email info@cancerlt.org www.cancerlt.org

Changing Faces

The Squire Centre 33-37 University Street London WC1E 6JN Tel 0845 450 0275 Email info@changingfaces.org.uk www.changingfaces.org.uk

Citizens Advice Bureau

www.adviceguide.org.uk www.citizensadvice.org.uk

Colostomy Association

15 Station Road

Reading RG1 1LG
Helpline 0800 587 6744
Email

cass@colostomyassociation.org.uk www.colostomyassociation.org.uk

Continence Foundation

307 Hatton Square
16 Baldwins Gardens
London ECIN 7RJ
Helpline 0845 345 0165
Email
continence-help@dial.pipex.com
www.continence-foundation.org.uk

CORE (the Digestive Disorders Foundation)

3 St Andrews Place London NW1 4LB Tel 020 7486 0341 Email info@corecharity.org.uk www.corecharity.org.uk

Dansac Limited

(manufacturers of stoma care products) Victory House Vision Park Histon Cambridge CB4 9ZR Tel 0800 581117 Email dansac.ltd@dansac.com www.dansac.co.uk

Disabled Living Foundation

380-384 Harrow Road London W9 2HU Helpline 0845 130 9177 Email advice@dlf.org.uk www.dlf.org.uk

Early Menopause UK

www.earlymenopauseuk.co.uk

Equality and Human Rights Commission

www.equalityhumanrights.com

Expert Patients Programme

www.expertpatients.nhs.uk

Go Smokefree

Helpline 0800 169 0169 www.gosmokefree.co.uk

Government online

www.direct.gov.uk

Ileostomy and Internal Pouch Support Group

Peverill House 1-5 Mill Road Ballyclare County Antrim BT39 9DR Tel 0800 018 4724 Email info@iasupport.org www.the-ia.org.uk

Incontact

SATRA Innovation Park Rockingham Road Kettering Northants NN16 9JH Tel 0870 770 3246 Email info@incontact.org www.incontact.org

Kidney Cancer UK

PO Box 2473 Uttoxeter ST14 8WZ Tel 01889 565801 www.kcuk.org

Let's Face It

72 Victoria Avenue Westgate On Sea Kent CT8 8BH Tel 01843 833724 www.lets-face-it.org.uk

Limbless Association

Queen Mary's Hospital Roehampton Lane London SW15 5PN Tel 020 8788 1777 www.limbless-association.org

Look Good Feel Better UK

West Hill House 32 West Hill Epsom Surrey KT19 8JD Tel 01372 747500 Email info@lgfb.co.uk www.lookgoodfeelbetter.co.uk

4 Useful organisations

Lymphoma Association

PO Box 386
Aylesbury
Buckinghamshire HP20 2GA
Helpline 0808 808 5555
Email
information@lymphoma.org.uk
www.lymphoma.org.uk

Lymphoedema Support Network

St.Luke's Crypt Sydney Street London SW3 6NH Tel 020 7351 4480 www.lymphoedema.org/lsn

Myeloma UK

Broughton House 31 Dunedin Street Edinburgh EH7 4JG Infoline 0800 980 3332 Email myelomauk@myeloma.org.uk www.myelomaonline.org.uk

National Osteoporosis Society

Manor Farm
Skinners Hill
Camerton
Bath BA2 OPJ
Helpline 0845 450 0230
Email info@nos.org.uk
www.nos.org.uk

Neuropathy Trust

PO Box 26 Nantwich Cheshire CW5 5FP Tel 01270 611828 www.neurocentre.com

Oesophageal Patients Association

22 Vulcan House Vulcan Road, Solihull West Midlands B91 2JY Tel 0121 704 9860 Email opa@ukgateway.net www.opa.org.uk

Orchid Cancer Appeal

St Bartholomew's Hospital London EC1A 7BE Tel 020 7601 7167 www.orchid-cancer.org.uk

Ovacome

Elizabeth Garrett Anderson Hospital Huntley Street London WC1E 6DH Tel 020 7380 9589 Email ovacome@ovacome.org.uk www.ovacome.org.uk

Pancreatic Cancer UK

31 Brooklyn Drive
Emmer Green
Reading RG4 8SR
Tel 0118 947 2934
Email
enquiries@pancreaticcancer.org.uk
www.pancreaticcancer.org.uk

Penny Brohn Cancer Care

Chapel Pill Lane
Pill
Bristol BS20 OHH
Helpline 0845 123 2310
Email helpline@pennybrohn.org
www.pennybrohncancercare.org

Prince's Foundation for Integrated Health

33-41 Dallington Street London EC1V 0BB Tel 020 3119 3100 Email info@fih.org.uk www.fih.org.uk

Promoting Continence

Redbank House
4 St Chads Street
Cheetham
Manchester M8 8QA
Tel 0870 760 1580
Email
promocon@disabledliving.co.uk
www.promocon.co.uk

Prostate UK

10 Northfields Prospect Putney Bridge Road London SW18 1PE Tel 020 8877 5840 Email info@prostateuk.org www.prostateuk.org.uk

Prostate Cancer Charity

Helpline 0800 074 8383 Email info@prostate-cancer.org.uk www.prostate-cancer.org.uk

Quit

Tel 0800 002200 www.quit.org.uk

Relate

Tel 0845 456 1310 Email enquiries@relate.org.uk www.relate.org.uk

Roy Castle Lung Cancer Foundation

200 London Road Liverpool L3 9TA Helpline 0800 358 7200 www.roycastle.org

4 Useful organisations

Royal Association for Disability and Rehabilitation (RADAR)

12 City Forum 250 City Road London EC1V 8AF Tel 020 7250 3222 www.radar.org.uk

Royal Marsden NHS Foundation

www.royalmarsden.nhs.uk

Sarcoma

PO Box 128 Ludlow Shropshire SY8 1YL www.sarcoma-uk.org

Sexual Dysfunction Association

Suite 301 Emblem House London Bridge Hospital 27 Tooley Street London SE1 2PR Helpline 0870 774 3571 Email info@sda.uk.net www.sda.uk.net

The Stroke Association

240 City Road London EC1V 2PR Helpline 0845 3033 100 Email info@stroke.org.uk www.stroke.org.uk

Urostomy Association

Central Office
18 Foxglove Avenue
Uttoxeter
Staffs ST14 8UN
Tel 01889 563191
Email
secretary.ua@classmail.co.uk
www.uagbi.org



Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. One in three of us will get cancer. 1.2 million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

For further copies, call us on 0800 500 800 or visit www.be.macmillan.org.uk

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