

Bouncing back

Living life after cancer

Peterborough & Stamford Locality
Cancer Patient & Carer Involvement Group





Introduction

This booklet has been produced by the Peterborough Cancer Patient and Carer Involvement Group (**CPIG**). The aim of the booklet is to provide answers to commonly asked questions and direct you to useful websites and contacts to help you as you move away from treatment and back into living with a diagnosis of cancer.

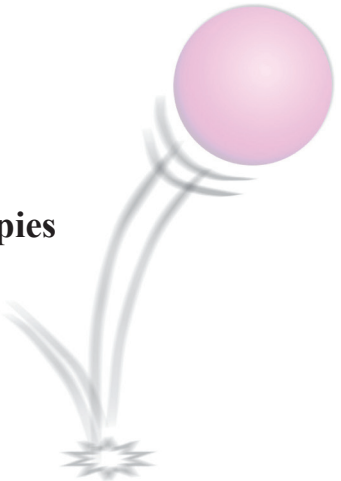
To find out more about CPIG please ring 01733 874000 ext 8911

CPIG wish to thank all those who contributed to the booklet particularly Jill, whose vision it was in the first place & Carol whose enthusiasm & dedication was inspirational.

Our thanks also go to the West Anglia Cancer Network for providing the funding to print this booklet.

Content:

	Page
After Treatment	4
Healthy Living	7
Complementary Therapies	17
Financial Information	21
Returning to Work	24
Travelling Abroad	29

A decorative graphic consisting of a pink sphere at the top, connected by a grey, curved stem to a starburst-like base at the bottom. The stem has several smaller, curved lines branching off it, giving it a dynamic, upward-reaching appearance.

After Treatment

How long after treatment ends can you expect to continue experiencing fatigue, that bad taste in your mouth, 'chemo-brain', and other chemotherapy or radiotherapy side effects to last? When will your hair grow back again?

As a general rule of thumb it can take anything from 6 months to a year for you to return to your 'old self' and this is a gradual process. When treatment stops it doesn't mean that the side effects disappear overnight. As everyone is different in the treatments received, recovery time will vary.

The period following chemotherapy/radiotherapy is sometimes quite difficult to cope with as you and everyone else see this as a time to start moving forward.

Make sure your friends and family understand that just because treatment is over that doesn't mean that you are going to be able to jump right back into working full time, laying a new patio and decorating the spare room!!

Manage your expectations; decrease the stress and the pressure on yourself in whatever ways you can. There are a lot of decisions you can make to take charge of how your life goes whilst you are in this recovery process. Ideally you will have had the opportunity to discuss long term side effects of your treatment with the professionals caring for you as your treatment comes to an end.

After your chemotherapy/radiotherapy has finished you will have regular follow up appointments with your hospital doctor, and sometimes these appointments will involve scans or x-rays.

Initially appointments may be every month or three months, decreasing to every six months and eventually decreasing to only once a year.

Follow up appointments are an important part of your ongoing care, and they will give you an opportunity to talk over anything that you may be worried about. If you have any problems or have any health concerns between these appointments let us know as soon as possible, so that we can arrange to bring you to the hospital to discuss these problems, and minimise your worry time.

You can now resume your normal dental care and also discuss the feasibility (depending on the time of year) of having a 'flu or pneumonia injection with your GP.

Healthy Living

Diet:

Your taste will return to normal gradually once your treatment has finished. Also, once you are past your risk period (i.e. when your blood count has returned to normal levels), then you can resume a normal diet.

You may however like to change the way you cook, i.e.:

- Eat a variety of foods that include at least five portions of fruit and vegetables per day
- Change the way you cook food – try grilling instead of frying and steaming instead of boiling
- Reduce the amount of fat and sugar in your diet. The bulk of most meals should be starch-based foods such as cereals, wholegrain bread, potatoes, rice and pasta.

Further information is available at:

- www.healthyliving.gov.uk/
- www.nutrition.org.uk (contains information on healthy eating)
- www.cancer.gov/cancerinfo/eatinghints (eating hints for cancer patients: before, during and after treatment)

Alcohol:

Don't drink too much alcohol. A small amount of alcohol is usually fine, but too much can be harmful. The upper limit for "low risk drinking" recommended by UK medical bodies is up to three units per day for men and up to two units per day for women. Obviously the advice is not to consume a week's limit in one or two nights!

Women have a lower limit than men mainly because women's bodies tend to be smaller, and have more fat and less water.

This means that the alcohol is less diluted and stays in the body for longer. Units can be confusing to a lot of people so a quick guide to what **one unit** represents is as follows:

- Half a pint of 3.5% beer/lager/cider
- 1 small glass (125ml) of wine at 9% but many pubs and restaurants use bigger glasses and most wines are now about 11-13%
- A 25ml pub measure of spirits at 40% although some pubs now serve 35ml as standard

For further information see www.healthyliving.gov.uk/ or contact their helpline on 0845 278 8878

Smoking:

If you smoke, stopping smoking is often the single most effective thing that you can do to reduce your risk of future illness.

The risk to health falls rapidly as soon as you stop smoking (but takes a few years before the increased risk reduces completely). If you need help to stop smoking please see your GP/Practice Nurse for help as there are various treatments available that may help you.

Exercise:

It is fine to exercise if you feel like it! Check with your doctor to ensure that there are no specific things that you should not do, but for most people gradually getting into a sensible routine of exercise is fine.

Try simple things like swimming, exercising in water as water supports your body or try walking. Setting yourself small targets and gradually increasing over a period of days and weeks to a level you feel comfortable with is the most sensible way of increasing your energy levels.

Fatigue:

Tiredness and fatigue can be extremely distressing as you may not always have the energy to complete things you want to do. This is a very common side effect of cancer and its treatments and can take some time to improve after completion of treatment.

To some extent age can have an effect as well. People under 40 tend to recover quicker from the effects of some treatments than perhaps older people.

Hair care:

After chemotherapy/radiotherapy your hair will start to grow within a few weeks of the treatment ending. You will notice wispy, baby hair to begin with, and then stronger “normal” hair will grow through.

Please note that your hair may grow back a different colour or texture. A number of people also comment that their hair grows back curly initially.

After approximately 6 months of completing your chemotherapy/radiotherapy your hair will be strong enough for you to colour or perm it. There are also natural products available if you are thinking of colouring your hair.

Skin Care:

Whilst undergoing treatment you may have been advised on special skin care, continue with this regime for up to 4 weeks after treatment has finished. When there is no visible skin reaction you can go back to your normal washing routine.

Sun Care:

When out in the sun always use a high skin protection factor sunscreen (SPF 15 to 30 or above) on any skin exposed to the sun. Follow the instructions on the bottle and reapply as recommended, particularly after swimming.

Wear clothing made of cotton or natural fibres as these have a closer weave and offer more protection against the sun. Never allow your skin to burn.

Stay out of the sun during the hottest part of the day – usually between 11 a.m. and 3 p.m. Try to sit in the shade, even at other times of the day.

If you have had radiotherapy, keep the treated area completely covered.

Use fake tanning lotions or sprays to give yourself a tan instead of sunbathing or using a sun bed.

Sexuality

Sexuality is a very personal matter and means different things to different people. Your feelings can change at different times in different places and in different situations.

Your treatment may have affected your physical ability to give and receive sexual pleasure; it may have altered how you feel about your body; you may feel scared or sad about having an intimate relationship, and you might be finding it difficult to discuss this with your partner.

Our sex lives are usually private and not openly discussed with strangers but you may feel that you need to talk to someone for support and advice if you are not sure of how to deal with your feelings.

Your nurse or doctor will discuss these issues with you but if you want further advice and support contact the British Association for Sexual and Relationship Therapy via their website on www.basrt.org.uk or telephone/fax on 020 8543 2707

You now no longer need to use condoms as an additional precaution if you were advised to during your treatment.

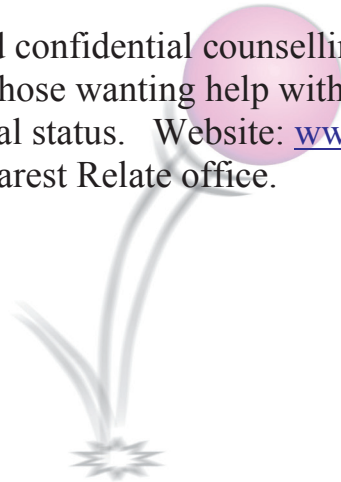
Infertility Network

Provides information to all those suffering from infertility, from finding out they may have a problem conceiving through to investigations treatments and alternative parenting options.

Website: www.infertilitynetworkuk.com/ or telephone 08701 188088

Relate

Relate offers private and confidential counselling psychosexual therapy and educational services to those wanting help with adult couple relationships, regardless of your marital status. Website: www.relate.org.uk/ or look in the Yellow Pages for the nearest Relate office.



Complementary Therapies

There are many complementary therapies on offer such as acupuncture, Alexander Technique, aromatherapy, Reiki, reflexology, etc. as some people like to use these therapies alongside conventional medicine. Always use a reputable therapist who observes a code of conduct.

However, it is always advisable that you inform either your GP or oncologist that you are considering complementary therapies as some therapies are not advisable depending upon the type of cancer you have had.

These are contacts for obtaining more information on complementary therapies:

Macmillan Support	A directory of services can be ordered by telephone: 01344 350310 or on www.macmillan.org.uk/cancerinformation .
The Prince of Wales's Foundation for Integrated Health	They provide information about the integration of complementary and conventional healthcare. The National Guidelines for the Use of Complementary Therapies in supportive and palliative care is also a good source of information. Website: www.fihealth.org.uk

<p>The Institute for Complementary Medicine</p>	<p>This charity provides the public with information on all aspects of safe and best practice of complementary medicine. The ICM has a register of professional practitioners who have all individually proved their competence to practice. Telephone: 020 7237 5165 Website: www.i-c-m.org.uk</p>
<p>Cancerbackup</p>	<p>They produce a booklet 'Cancer and Complementary Therapies' which explains what complementary therapies are and how they may help. It gives a brief description on the most used therapies, and includes useful addresses and a reading list. You can view this booklet online or by contacting</p>

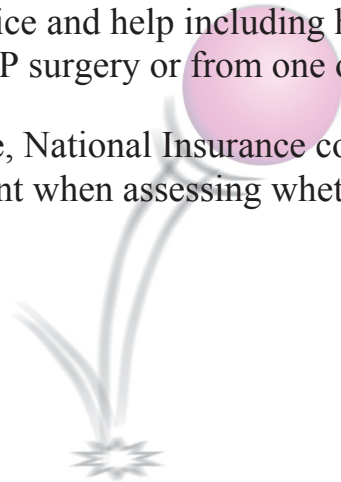
	<p>Cancerbackup for a printed copy (free to patients). Telephone: 0808 800 1234 Website: www.cancerbackup.org.uk</p>
--	---



Financial information

The benefit system can be confusing to a lot of people. There are many places where you can seek advice and help including hospital social worker, Macmillan nurse, and GP surgery or from one of the links below.

Factors such as your age, National Insurance contributions, and length of illness will be taken into account when assessing whether or not you are eligible for benefits.



These contacts may be of use to you:

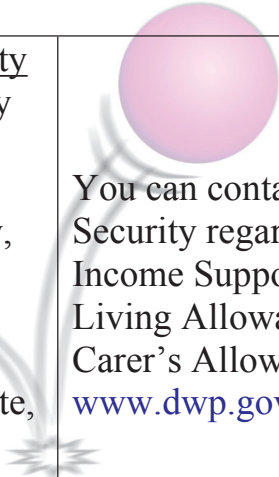
Jobcentre Plus/Social Security
Peterborough Social Security
Office:

Telephone: 01733 297600
Clifton House, 84 Broadway,
Peterborough, PE1 1QZ

Peterborough Jobcentre:
Telephone: 01733 415500
Frobisher House, 72 Westgate,
Peterborough PE1 1RR

or visit

www.jobcentreplus.gov.uk



You can contact Jobcentre Plus or Social
Security regarding information on:
Income Support, Incapacity Benefit, Disability
Living Allowance, Attendance Allowance and
Carer's Allowance (you can also visit
www.dwp.gov.uk)

<p><u>The Pension Service</u> Telephone: 0800 99 1234 or visit www.thepensionservice.gov.uk</p>	<p>You can contact The Pension Service to apply for Pension Credit.</p>
<p><u>Benefit Enquiry Line (BEL)</u> Telephone: 0800 882 200 Or visit www.dwp.gov.uk</p>	<p>The Benefit Enquiry Line can advise you on the benefits you may be entitled to. They also have two booklets (IB1 and SD1) outlining these benefits. You can also get a copy from your local Citizens Advice Bureau (www.peterboroughcab.org.uk) Telephone: 0870 126 4024 or 01733 558 383. They can also arrange to give their information through interpreters and information in other languages is also available on their website.</p>

Returning to Work

You can go back to work when you feel ready. Please remember the recovery process may be slow, so choose to go back when you feel able and consider a phased return to work.

It's daunting for anyone going back to work after a lengthy period of time off sick, let alone someone who has had a diagnosis of cancer. Some employers don't realise that the effects of treatment can last after the treatment has finished, one of the most common being tiredness.

The symptoms or side effects of treatment for cancer vary from person to person depending on the type of cancer and treatment received. It can be temporary for some but for others they may need longer to adjust and some may need to make changes to their work situation.

There is also the psychological impact on you (which can vary from each individual) with an acknowledgement that this may take time to come to terms with.

Meeting with your employer

When you feel you are ready to return to work it is important that you meet your employer beforehand to discuss how this will be managed. If you are still experiencing some of the side effects of treatment your employer will need to know to enable them to consider a gradual return to work and possibly discuss any changes they need to make before your return. Employers however are only obliged, by law, to make 'reasonable' adjustments.

The following points may be of help to you:

- Discuss with your employer about having an action plan (this will provide clarity for both you and your employer)
- Agree set dates when the action plan will be reviewed (set by mutual agreement)
- Discuss the possibility of a phased return to work within a fixed timescale if you feel that you cannot go back straight away to the hours you originally worked
- Explore the change of working hours or reduced working hours
- Discuss possible changes to your role, temporary or otherwise
- Ensure you have a return to work interview so that both you and your employer are happy that you are ready to return to work

If you and your employer agree to a permanent change of hours or role then your Contract of Employment and Job Description may need to be amended to reflect this.

Disability Discrimination Act (DDA)

People with HIV, cancer and multiple sclerosis are now covered by the Disability Discrimination Act effectively from the point of diagnosis, rather than from the point when the condition has some adverse effect on your ability to carry out normal day-to-day activities and it is unlawful for an employer to discriminate against a person because of their disability. Visit www.pointofdiagnosis.org.uk for more information.

This Act also protects an employee in the recruitment process, terms and conditions of employment, opportunities for promotion, training and benefits, unfair dismissal, unfair treatment compared to other workers and harassment and victimisation.

If your cancer causes disability that affects the type of work you do, you may be eligible for help from 'Access to Work' Scheme at your local Jobcentre Plus Office, telephone: 0845 6060 234 or visit www.jobcentreplus.gov.uk

If you have had a diagnosis of cancer and you feel that you are being discriminated against by your employer, you can get advice and support from the Disability Rights Commission. They will inform you of your rights and support you through any legal action against your employer. Their telephone number is 08457 622633 or visit www.drc-gb.org

Travelling abroad

If you are considering travelling abroad there are several things you may want to consider.

- Are you fit to travel? You can go on holiday after your chemotherapy treatment has finished. Discuss your plans with your doctor prior to your last treatment
- Do you need to take particular equipment with you?
- Are you allowed to take particular medications abroad with you?
- Can you get travel insurance? Be prepared that revealing a pre-existing condition of cancer increases the cost of insurance.
- Do you have a European Health Insurance Card? (This replaces the E111 form) It entitles you to reduced costs, sometimes free, medical treatment within the European Union.

You should however still consider purchasing independent travel insurance in addition to this card. You can apply online at www.ehic.org.uk, telephone 0845 606 2030 or go to your Post Office

- The information you receive may vary dependant upon the source. A reliable up- to-date place for information is Cancerbackup. Call them free on 0808 800 1234 or visit their website on www.cancerbackup.org.uk

