



after

after



what does this mean for you?

will cancer
come back?



can I travel
abroad?



What about
smoking?



Cover pictures:

Main - Paul Malcolm Baxter, Johannesburg, South Africa

Left - Daniel De-Gale, Croydon

Middle - Sarah Gilmour, Essex and Friends

Right - Anthea Martin, London

Edited by Dr Annie Griffiths

Produced on behalf of the CCLG Late Effects Group
in conjunction with CCLG Publications Committee.

Contributors: Christine Eiser, Ruth Elson, Dr Annie Griffiths,
Jude Kenney, Rene Marston, Dr Anthony Penn, Dr Denise Williams

Production of this booklet was made possible by CLIC Sargent

© CCLG 2007

Designed and Published March 2005 reprinted November 2007

Translated by CLIC Sargent in 2006 to Punjabi, Bengali and Gujarati
(Download from www.aftercure.org)

We are grateful to those survivors who contributed their thoughts
and photos and especially those survivors who contributed at the
UK Survivors Group - July 2004.

Also to photographer, Dave Page, for the Joshua O'Mallery
photograph.

Registered Charity No: 286669



Children's Cancer and Leukaemia Group

3rd Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH

Tel: 0116 249 4460

Fax: 0116 254 9504

Email: info@cclg.org.uk

Website: www.cclg.org.uk

Contents



Introduction

4



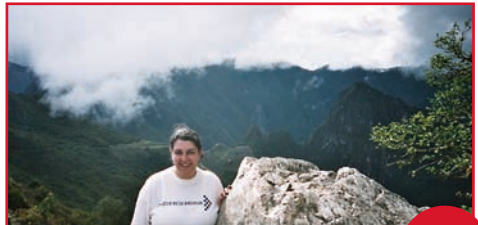
Life Insurance and
Mortgages

11



Follow up and
Future Care

6



Travel/Vaccinations

12



Education and Jobs

8



Fertility and Sexual
Function

14



Disability

10



Lifestyle - How to
keep healthy

15

INTRODUCTION

You have survived **cancer** or a **similar illness** and that means you are one of an increasing number of young adults who have been treated successfully. There are now over 20,000 adult survivors of childhood cancer in the UK alone. This package has been produced to help answer some questions you might have and explain why you may still need to be followed up.

It is important that survivors of childhood cancer are monitored to detect and manage any long-term problems caused by the disease or treatment to ensure the best possible quality of life. You may know a lot about your illness or you may know very little. We hope this booklet will help answer any questions and encourage you to ask about anything else that isn't covered. You may have been treated for a tumour or condition that was not cancerous but because of the treatment you had this booklet still applies to you. Your doctor will explain why.

The first part of the package is a booklet. It covers general topics. We have included several web sites and phone numbers for further information. One site is www.aftercure.org which includes more specific fact sheets about the effects of different treatments on different parts of your body depending on the treatment you had.



Above: Sisters Laura and Amy, both cancer survivors

Visit www.aftercure.org for information sheets and useful links

The second part is a brief treatment summary card. It is important to know what treatment you had so you can understand the problems that might occur. This card is small so it can be kept in a wallet or purse for easy access if you ever need to know the details of your treatment. For example, you will need it for an antenatal visit or employment medical.



Some survivors talk about experiencing job discrimination, or difficulties obtaining health or travel insurance. This may be because people know very little about cancer and are frightened about what is involved. Their reaction may be to avoid contact with people who had cancer. This is a good reason for you to know about your disease, its treatment and potential effects later in life. In this way you can talk to people about your cancer. The more people get to know about childhood cancer the easier it will be for you and for other children in the future.

The risk of a problem occurring later on is different for everyone, it depends on:

- Your type of cancer
- The age when you were treated
- The treatment you had.

Two thirds of survivors will have some problem related to their treatment. For some this will be very minor. For others it may be more major. In any case you are not alone if you have a problem. We have included quotes from survivors of childhood cancer. We hope that this booklet will help you knowing that other survivors often have similar feelings and worries.

It is important to remember that although your cancer experience will always be part of you it does not define the person you are.

“It was amazing singing for my country at Eurovision in front of an international audience - a really magical experience that I’ll never forget”

Survivor Chris Doran,
Waterford, Ireland (below)



FOLLOW UP and FUTURE CARE

Why come to clinic?

Cancer is treated in different ways and sometimes the treatments can cause long-term problems. Cancer treatment includes:

Chemotherapy – anti-cancer drugs
Radiotherapy – radiation treatment
Surgery

Sometimes only one of these treatments is used and sometimes two or even all three types of treatment are used in combination. Each of these treatments, apart from treating the cancer, can also have an effect on normal cells/tissues that may only become apparent many years after finishing treatment. These long-term problems caused by treatment are called “late effects” as they occur after all the curative treatment has finished. Research on late effects may help with planning new treatment regimes to try and limit the problems for future patients.

When you were treated most information will have been given to your parents. Now as an adult the information is given to you and coming to clinic gives you the chance to ask questions. Many people will look on these visits as reassuring, a way of checking that everything is all right and if there are any problems they will be found early and treated.

Will I always have to come?

That depends on the treatment you had. It is sometimes difficult to know who is likely to get late effects.

Will cancer come back?

Everyone is at risk of developing cancer and this risk increases with age. Survivors and their parents naturally worry that cancer may come back again. A small number of people who are cured of cancer when young develop another cancer later on. There are two main reasons for this:

1. Some cancer treatments can themselves increase the risk of other cancers.
2. Although rare, some families have a higher risk than others because family members share some inherited risk factor.

You can help yourself by not doing things that we know are linked with cancer. This includes smoking and sunbathing.

If I feel ill what shall I do?

You should go and see your GP. They will decide if you need referral to the hospital. If you are very worried you could call the hospital contact number on your treatment summary card, but usually it is better to go through your GP. There is a very useful website with general information called www.cancerbackup.org.uk. They also have a helpline for information.

Will I have to take medicines for ever?

Some survivors may have to take medication for life. This is usually because you are not producing enough hormones naturally, for example if your thyroid is underactive or if you are not producing enough sex hormones. If you are at risk of any hormone imbalance this will be checked with a blood test at your clinic visit.

When can I put it all behind me? I don't want to think about cancer any more.

This is understandable but unfortunately you cannot ignore your past medical history. The doctors will only continue to see you if you need regular check ups and there are tests that are occasionally necessary. Please discuss any anxieties you have about coming to the clinic rather than just not turning up. Cancer is part of you but it's not who you are.

Can/should I bring my parents or partner to clinic?

Yes, if you feel more comfortable coming with someone, you can bring your parent, partner or close friend to clinic. However it's your health and well-being that's most important to us so you may prefer to come on your own.

"I am now 16 years old and for the last 4 years I've spent a lot of my time studying hard at school and just having fun. Despite some setbacks along the way I am slowly but surely determined to try and live my life as normal as possible.

Daniel De-Gale, Croydon
(below with his mother)



EDUCATION & JOBS

All young adults are entitled to continue into higher education after leaving school, regardless of previous ill health, provided of course you can satisfy the qualification standards.

If you are applying to University or college an excellent place to start looking for information is via the UCAS website www.ucas.com.

There are sections for students, parents, colleges, schools and educators. It explains which courses are available at which universities, how to apply, qualifications needed as well as Access courses for those over 19 years.

It has a direct link to 'Skill' www.skill.org.uk. This is the National Bureau for students with disabilities, promoting opportunities for young people, and adults with any kind of disability in post 16 education, training and employment across the UK. It also has links to DSA (Disabled Student Allowance), which is designed to pay for extra costs, which disabled students may incur. Usually colleges and universities try to be helpful to students with disabilities or chronic health problems. Difficulties are most likely to result from practical problems such as physical access to buildings but this is improving as a result of legislation. A letter from your doctor can be helpful.

"I was diagnosed with Leukaemia when I was 3 years old, now I'm fully cured and working as an Assistant Shop Manager and enjoying life to the full!"

Sarah Bowmen, Leics (below)



Visit www.ucas.com
for educational
opportunities for
young people
over 16



I missed a lot of school work when I was ill. Who can help?

Cancer treatment can be very disruptive to education, particularly in teenage years. Schools should be supportive and careers advisors can be a very good source of information if you have to change direction because of your treatment. They may be able to suggest other ways you can be involved in the area you had chosen.

What job can I do?

You can do most jobs providing you can offer the relevant qualifications and ability. Employers have to act fairly in their selection of applicants for jobs. If you are unsuccessful with an application you can ask the employer to explain why you were not selected for the job.

The Department of Trade and Industry has produced a wide range of booklets, fact sheets and leaflets providing practical guidance on employment regulations and procedures. (www.dti.gov.uk)

Can I join the Armed Forces?

The Armed Forces have strict guidelines about people joining up. In the past it has been very difficult for people who have been treated for cancer to be accepted in the Forces. They state clearly that anyone who joins needs to be medically fit and able to serve worldwide, that training will be physically demanding and mentally taxing and new recruits will be able to



Above: Joshua O'Malley, Hemel Hempstead

Visit www.mod.uk for information about armed forces recruitment



meet the challenge. Each application is assessed individually but you will be asked to declare information about your past medical history and have a medical examination with one of the Forces doctors and it will be their decision as to whether you can join. The same procedure applies to the Territorial services. Their website is www.mod.uk and there are links through to navy, air force and army.

Should I tell my employer I had cancer?

Answer questions honestly, you only have to give the medical information if you are specifically asked. It may be helpful to emphasise how long ago you received treatment. Your treatment summary will be helpful here. Again, it may be useful to ask a potential employer to contact your doctor if they need more information.

DISABILITY

If I have a disability what are my rights?

The Disability Discrimination Act (DDA) 1995 gives disabled people rights in the areas of:

- Employment
- Access to goods, facilities and services
- Buying or renting land or property

Amendments currently being proposed aim to extend civil rights and opportunities for disabled people. An excellent source of information on the DDA and current legislation can be found on the disability website www.disability.gov.uk. The Consumer's Association in conjunction with the Disability Rights Commission has produced a booklet entitled Rights for People with Disabilities. To order a copy tel: 0845 3000343 or download it from the Legal Services Commission website at www.legalservices.gov.uk

You may also be able to get advice from the following agencies, particularly if you feel you are being discriminated against because you are a disabled person:

- A Trade Union
- Your local Law Centre
- A Citizens Advice Centre
- A solicitor



“Although cancer has left me with a weak arm that has limited mobility I can still hold my son, and I managed to fit this kitchen - with a little help from my dad!”

William Hawkins, London (below)

LIFE INSURANCE and MORTGAGES

Will I be able to own my own house?

Personal insurance is usually needed when you take out a mortgage on a house. Survivors are sometimes refused insurance cover, or are only offered cover under special conditions. This may involve paying a higher premium. The type of treatment you had and how long ago it was may affect the decisions. Every case is looked at individually. There are no absolute bars to any type of insurance, including critical illness cover, and no survivor should ever be declined without a full medical report. This is often more helpful if it is provided by the doctor you see at the hospital. It may be beneficial to include your hospital doctor's details with your application, as well as those of your GP.

You should approach large insurance companies because they are more likely to have dealt with cases like yours in the past or you may wish to contact an Independent Financial Advisor (IFA). IFA's can contact several life insurance or mortgage lenders on your behalf and offer independent advice on which companies offer the best terms for your situation. However, they may charge a fee or take commission when a policy or mortgage is arranged.

On a positive note one insurance underwriter stated clearly that they start from the position "How can we offer insurance?" not "Are they eligible?"

Legal and General wrote to St James's to check the information I'd given them, but it must have been OK - my premium was less than my husband's who had listed caving as one of his hobbies!

Vanessa Moss, Leeds



Above: Jon Fredrickson, Bristol

TRAVEL/ VACCINATIONS

Can I travel abroad?

Yes. If you have had a bone marrow transplant you may need to be selective as to where you visit. North Western Europe, the northern Mediterranean, North America or Australasia are all acceptable places, after a transplant. If you want to visit other countries you should seek advice as to which vaccinations are required as there are some live vaccines that you shouldn't have.

If you are taking medicines abroad, especially if you are taking needles and syringes, a letter from your doctor may be required explaining what they are for. This can reduce the problems at customs and airports.

Will I be able to get travel insurance?

You will be able to get insurance but the premium may be higher. There are some companies that specialise in offering insurance to people who have a medical condition. It is worth shopping around for the best policy. Cancerbackup, the cancer information charity, has a fact sheet about travel insurance and list of companies that may be helpful. You can call for a free copy (see number on page 13). It is important to be honest even though your treatment may have been



Above: Sarah Gilmour in Africa, with World Challenge Expeditions

Useful travel websites:
www.fitfortravel.scot.nhs.uk
www.travelhealth.co.uk
www.nasta.org

years ago. If you did become unwell and you had not declared your past illness you may find your insurance will not cover you.

Can I have travel vaccinations?

This depends on the treatment you had. If you had a bone marrow transplant you will need to be more cautious, discuss this with your doctor.

Non live vaccines, like hepatitis A, cholera, rabies and typhoid are safe and should be used as indicated. There are some vaccines that you can't have after a transplant. These tend to be live vaccines such as yellow fever, typhoid and live oral polio.

If you visit an area where malaria is endemic then you are advised to take full anti-malarial precautions. For those who have had their spleen removed or had a transplant and total body irradiation, malaria is particularly dangerous. Careful thought should be given before travelling to an area where there is malaria.

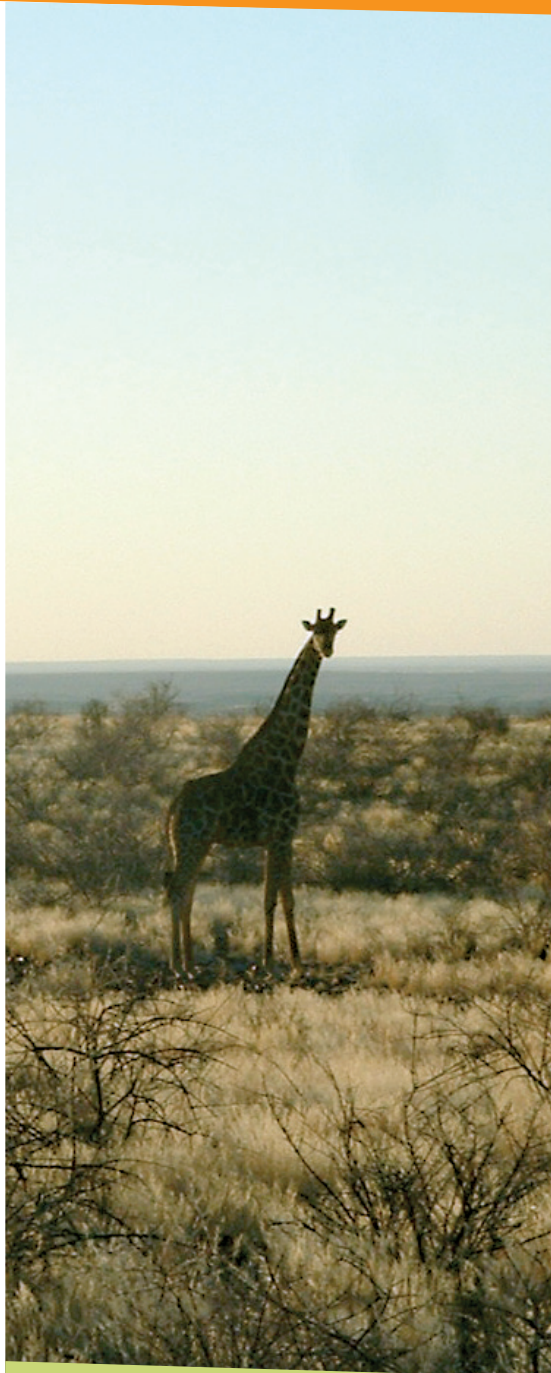
Useful websites are:

www.fitfortravel.scot.nhs.uk

www.travelhealth.co.uk

www.masta.org

Cancerbackup is a useful source of information on travel related queries though it does deal more with people still having treatment rather than those off treatment for some time. You can telephone on 0808 800 1234 or visit www.cancerbackup.org.uk.



Above: Picture taken in Namibia by Sarah Gilmour, Essex

FERTILITY and SEXUAL FUNCTION

Can I have a baby?

Some people think that any treatment for cancer leads to infertility, this is not true.

For girls, if you are having regular periods naturally, not withdrawal bleeds because of the pill or HRT, it usually means you can also become pregnant. For boys, it is more difficult to know. You need to ask at the clinic if any of your treatment could make it difficult to have a baby. You may be advised to have a sperm count to check. No test is 100% reliable so you do need to take precautions if you don't want your partner to become pregnant.

Should I use contraceptives?

Yes, if as a girl you do not want to become pregnant, or if as a boy do not want to father a child you need to use contraception. It is important to use condoms to protect yourself against sexually transmitted diseases (STD).

Will my sex life be affected?

This is very unlikely. Most men and women treated for cancer have normal sexual function.



Above: Cancer survivor Sarah Talbot-Ponsonby, with daughter Ankaret

Some people think that any treatment for cancer leads to infertility, this is not true.

Will my baby have cancer?

Apart from some very rare types of cancer which are known to be inherited (for example an eye tumour called retinoblastoma) there isn't any evidence that the children of people treated for cancer have any higher risk of developing cancer than other people.

Will my pregnancy be normal/will I need special care?

If you become pregnant you should let your antenatal clinic know your past treatment so they can decide if you need any special care. Take your treatment summary card with you. If you have been having regular heart scans (echocardiograms) because of the chemotherapy you had, you will need to have a heart scan during your pregnancy. This is because pregnancy puts an extra strain on your heart. If you had radiotherapy to any area of your abdomen you may be at risk of having a premature baby. However for the majority of women who had cancer their pregnancy is normal and uncomplicated.

LIFESTYLE - How to keep healthy

Can I sunbathe?

We know that sun causes skin cancer. In very hot places such as Australia, children are required to wear hats and tee-shirts, even in the school playground, to prevent skin cancer. Some survivors of childhood cancer may be at risk of second cancers, this includes skin cancer. In order to minimise the risk of skin cancer it is a good idea to wear sunscreen. This should be a high factor. After your holiday don't be tempted to keep up your tan on a sun bed! The very intense rays are especially damaging.

If a mole changes shape, size or colour, bleeds or itches, you need to see a doctor.

Finally check your skin for moles. If a mole changes shape, size or colour, bleeds or itches, you need to see a doctor.

Does having had cancer mean you get more tired?

Not usually. If you feel you get more tired than your friends, doing the same activities, you should mention it at your clinic visit. Your doctor may suggest you need a blood test to check if you have a hormone imbalance. This is not very common.

What shall I do if someone offers me a cigarette?

Sometimes people are in a situation where they feel pressurised to have a cigarette, maybe at a party. Smoking has been clearly linked with cancer. It has been known since the 1950's that it causes lung cancer, as well as cancer of the mouth, throat and bladder. It is not a good idea for anyone to smoke. Some cancer treatments can increase the risk of a second cancer. You may be even more at risk if you smoke. The risk is especially high if you had radiotherapy to your chest and lungs.

My friend has cancer and lots of problems with her memory. Will the same happen to me?

Some people do have problems with their memory after treatment but this is not common. Late effects are very dependent on the type of cancer you had and how you were treated. As always, if you have particular concerns discuss them with your doctor at the clinic. Attending the follow up clinic will help to ensure that any problems are detected early as well as giving you the opportunity to raise any worries you have about your health.

Can I go to the gym/diving?

For many people who had cancer, there is no problem at all about taking strenuous exercise. In fact, most people are encouraged to take exercise. It helps to keep you trim and can be fun, especially if you exercise with friends.



Above: Daniel De-Gale, Croydon

It is not a good idea for anyone to smoke. Some cancer treatments can increase the risk of a second cancer. You may be even more at risk if you smoke.

Some people need to be careful, if they were treated with certain drugs. These drugs (anthracyclines) are very good at treating cancer cells but they can occasionally damage healthy heart muscle. If you routinely have heart scans (echocardiograms) you should ask your doctor about doing strenuous exercise, such as weight lifting.

If you want to take up sports such as diving, you will need to undergo a medical. There are certain situations where diving would be considered unsafe e.g. following some chest surgery but there is a medical panel to consult about specific medical issues available through the British Sub Aqua Club (BSAC). Their website gives lots of information about being medically fit to dive www.bsac.com

Why do I feel different from my friends?

After treatment, you may be dealing with late effects of treatment as well as struggling to find a new “normal” in your life. Surviving cancer can bring on a range of feelings including relief and happiness as well as fears of recurrence, anxiety, or guilt. We hope this booklet will help you, knowing that other survivors often have similar feelings.

The way I look reminds me of my treatment

You may have been left with some scars after your treatment, you may feel your



Above: Anthea Martin, London

hair is thinner or different from before. Sometimes scars can be removed by plastic surgery; you can discuss this at the clinic. If your hair is thinner it is very important to check you are eating a good balanced diet and make sure you have enough B vitamins and are not anaemic. It is also important to check your hormone levels as both your thyroid and sex hormone levels have an effect on your hair growth.

Should I worry about getting ill again?

Most young adults don't worry about things like cancer or heart problems. It is natural for survivors to be fearful about the possibility of a relapse or fear of late effects. These worries can make you feel different from your friends. However the chance of getting a second cancer is still very small.

Can my experience of cancer help others - there seem so many unanswered questions?

It is important to find out as much as possible about cancer and its treatment and so doctors must do research both with those children who are newly diagnosed and those that have been treated. For this reason you may be asked to take part in a study looking at the effects of some aspect of your disease and treatment at any time. Your clinic doctor will be able to tell you if there are any long-term follow up studies relevant

to you being carried out at the moment. Your doctor will explain the study to you and you will need to sign a consent form to participate. Certain studies provide essential information on a variety of problems that may arise, the risk factors for developing problems and in some cases the effects of different treatments. This enables us to help current and future generations of patients.

What can I give back? Can I give blood/donate organs?

Many people feel they would like to give blood or donate organs. The rules about this following treatment for cancer are constantly changing.

For blood donation, currently, you are able to donate (and are encouraged to!) if you were treated for a solid tumour, finished treatment over 5 years ago and did not receive blood yourself after 1980. There is a very helpful website, with information, registration on line and with a telephone number for you to discuss anything with a medical advisor. (www.blooddonor.org.uk)

Similarly, organ donation is possible for people treated for cancer and the UK transplant programme would encourage you to register. Like blood donation, you can discuss organ donation with a doctor involved either by phone or email. (www.uktransplant.org.uk)

CHILDHOOD CANCER SURVIVOR GROUPS

In this booklet we have tried to provide useful information on some of the more important late effects, and issues associated with treatment of cancer as a child. We hope that it will help answer most of the questions you have on surviving childhood cancer. Survivors groups and meetings offer an opportunity to meet other survivors and gain more detailed information for those who want it.

In 2001 the first international survivors meeting took place in Luxembourg, and has been part of the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) conference ever since. The annual Childhood Cancer Survivor Network meetings, run by survivors, for survivors, provide an opportunity for people from all over the world to meet and learn about issues related to their disease and its treatment. It is a good place to hear about how survivor groups work in different countries, and get ideas about how to start a survivor group in your area. CLIC Sargent has kindly sponsored these meetings financially.

The UK Childhood Cancer Survivors' Group is a national group established by several adult survivors of childhood cancer. Supported by CLIC Sargent, an annual meeting is held where experts in their respective fields discuss issues more relevant to survivorship in the UK, and

cover in more detail some of the subjects raised in this booklet. Besides being informative, these conferences provide the opportunity to meet people who have had similar experiences to you. UK survivors were also given the chance to say what information they would like to have included in this booklet. For further information about the UK Childhood Cancer Survivors' Group, please contact the CLIC Sargent Helpline on 0800 197 0068 or email helpline@clicsargent.org.uk.



Above: Nicole, vice chairperson of the ICCCPO survivors group

For information on
childhood cancer
survivor groups visit
www.icccpo.org

This booklet is available in English, Punjabi, Bengali and Gujarati from www.aftercure.org along with factsheets and useful links.



For further copies telephone the CLIC Sargent Helpline on 0800 197 0068, email helpline@clicsargent.org.uk or visit www.clicsargent.org.uk.



supported by

CANCER RESEARCH UK



Children's Cancer and Leukaemia Group

3rd Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH

Tel: 0116 249 4460

Fax: 0116 254 9504

Email: info@cclg.org.uk

Website: www.cclg.org.uk

Registered Charity No: 286669

CCLG leaflets are available to download from www.childcancer.org.uk.