



Children's
Cancer and
Leukaemia
Group

Aftercure

A guide for teenage and young adult survivors of childhood cancer



www.cclg.org.uk



Children's
Cancer and
Leukaemia
Group

Working together to
beat childhood cancer

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on behalf of the CCLG Late Effects
Group in conjunction with the CCLG
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multiprofessional experts in the field
of children's cancer.

We are grateful to those survivors whose
comments and ideas have shaped the
development of this booklet.

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ChildrensCLG



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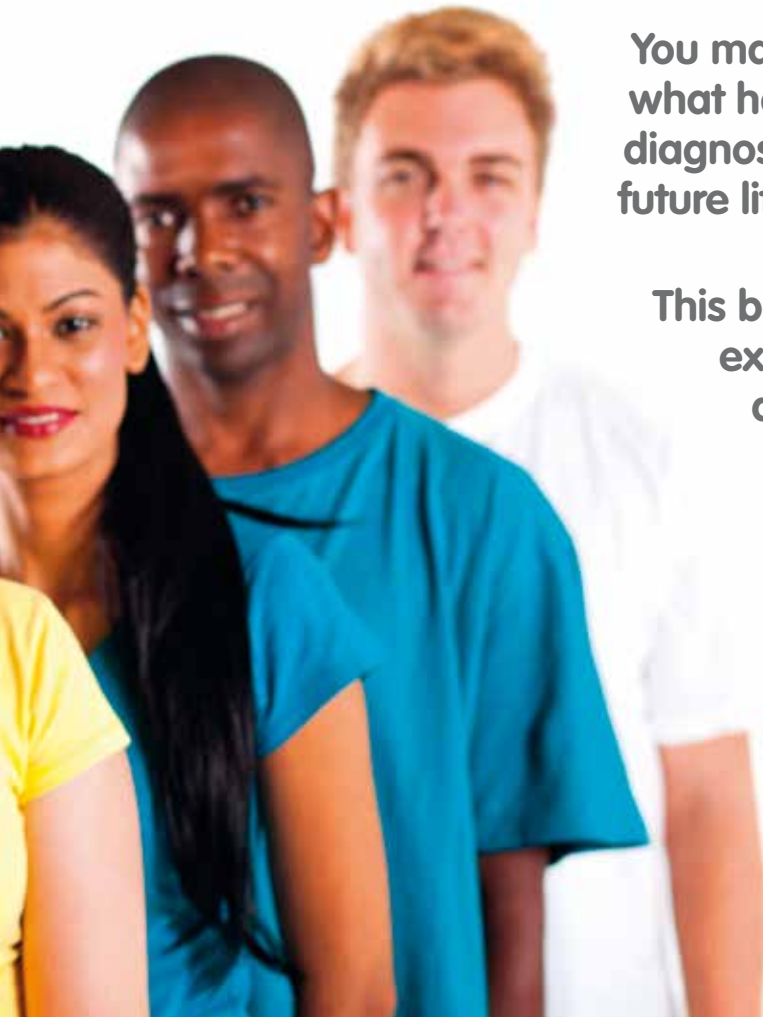
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BMA Patient Information Awards
Highly Commended 2014



You are one of an increasing number of teenagers and young adults who have been treated successfully for childhood cancer. Nowadays, there are over 35,000 survivors of childhood cancer in the UK so you are not alone.

A photograph of three young adults, two men and one woman, smiling and looking towards the camera. The woman is in the foreground on the left, wearing a yellow top. Behind her are two men, one in a blue t-shirt and one in a white t-shirt.

You may have many questions as to what happens next and how your diagnosis and treatment may affect your future life.

This booklet has been written by cancer experts and helps answer some questions you might have and explain why you may still need follow-up care.



I love my wrinkles
and grey hairs.

Well, okay maybe I don't love
them, but I love the fact that I'm
old enough to get them. When I
was a teenager diagnosed with
Ewing's sarcoma, I wasn't sure I'd
reach my 16th birthday let alone
my late 30s. They are little signs of
normality that, during treatment, it
feels like you'll never regain.
But you do - and normality feels
really amazing.

Anthea

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What happens next?

As a survivor of childhood cancer it is important you are offered the opportunity to review your previous treatment in a specialist long-term follow-up clinic. You may know a lot about your illness or you may know very little.

Long-term follow-up clinics provide you with an opportunity to learn about and plan, together with your follow-up team, the follow up you will require. Follow up at this stage in your journey aims to detect and manage any problems caused by your cancer or its treatment to ensure you have the best possible quality of life.

Approximately 60% of survivors will have a problem or 'late effect' related to their treatment. For some this will be very minor, for others it may be more major. 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 received.

We hope this booklet will help answer some questions and encourage you to ask your key worker or follow-up team about anything that they have not 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. If this is the case, your doctor will explain why.

This booklet is the first part of a package which also includes a dedicated website for childhood cancer survivors - www.aftercure.org.

**IT IS IMPORTANT TO
REMEMBER THAT
ALTHOUGH YOUR CANCER
EXPERIENCE WILL ALWAYS
BE A PART OF YOU, IT
DOESN'T NEED TO DEFINE
THE PERSON YOU ARE.**

The website offers the latest specific fact sheets about the effects of different treatments on different parts of your body (e.g. your heart) depending on the treatment you had.

Your long term follow-up team should provide you with an end of treatment summary. Keep this somewhere safe for easy access if you ever need to know the details of your treatment. For example, you may need it for an antenatal visit or pre-employment health check when starting a new job.

Long-term follow up is not just to support you with medical problems. Some survivors talk about experiencing job discrimination or difficulties obtaining health or travel insurance. This is a good reason for you to know about your illness, its treatment and potential effects later in life. In this way you can talk to people about your cancer.

The feeling of being a survivor is not daily but the gratitude for being able to continue never fades. One element I have relished in my life has been as a surprising ambassador for survival and I will always reach out to people as an example of a hopeful outcome.



Andrea

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;
- biological therapies – newer therapies used to stimulate the immune system such as monoclonal antibodies or vaccines;
- stem cell or bone marrow transplant

Sometimes only one of these treatments is used and sometimes two or even three types of treatment are used in combination. Each of these treatments, in addition to treating the cancer, can also affect normal cells/tissues and this 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 treatment has finished (see page 25 for more details).

When you were treated as a child, most information will have been given to your parents or carers. Now, as a young adult, the information should be 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 alright and if there are any problems these can be addressed.

Will I always have to come?

This is an individual decision between you and your follow-up team. It will depend on both the treatment you had and other factors such as your general health and social circumstances.

However, with information, education and access back to your long term follow-up team if required, it is hoped that eventually you will no longer need to attend regular hospital follow up but instead manage your own health needs with the support of your GP.

Will the cancer come back?

Everyone is at risk of developing cancer and this risk increases with age. Survivors and their families naturally worry that cancer may come back again but most people in long term follow-up are considered cured. 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 reduce your chances of cancer recurring by eating a healthy diet, taking regular exercise and not doing things that we know are linked with cancer, such as smoking and sunbathing.

What shall I do if I feel ill?

You should go and see your GP or out-of-hours healthcare service. They will decide if you need referral to the hospital. If you are very worried you could call the hospital's contact number on your treatment summary card, but usually it is better to go through your GP or similar local service.

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

It's understandable to feel this way; however, you cannot change the fact that you had cancer and it's important to attend follow-up care. The healthcare team will only continue to see you if you need regular check-ups and if there are tests that are occasionally necessary. Please discuss any anxieties or difficulties you have about coming to the clinic rather than just not turning up. Your diagnosis of cancer will always be part of you, but it's not the whole you. You may find your experience of having cancer has given you new strengths or views on life. You need to think about how you want to move forward in life.

Can I bring my parents or partner to clinic?

Yes, if you feel more comfortable coming with someone, you can bring your parent(s), partner or close friend to clinic. Or you may prefer to come on your own; the choice is yours.

Am I entitled to free prescriptions?

Patients who are receiving medication for the late effects of cancer can apply for a medical exemption certificate in order to receive free prescriptions. To find out more visit

www.nhs.uk/nhsengland/healthcosts/pages/prescriptioncosts.aspx.



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.

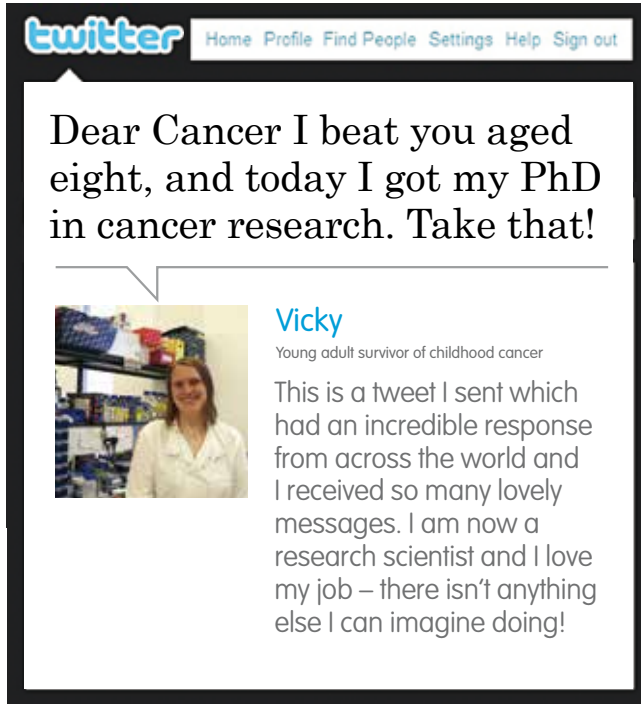
If you are applying to university or college an excellent place to start looking for information is via the UCAS website: wwwucas.com. There are sections for students, parents, colleges, schools and educators. It explains which courses are available at which universities, how to apply, the qualifications needed, as well as the availability of Access to HE courses.

Disability Rights UK (www.disabilityrightsuk.org) offers a wealth of information for young people and adults with any kind of disability in post-16 education, training and employment across the UK. The DSA (Disabled Student Allowance) is designed to pay for extra costs which disabled students may incur (see www.dsa-qag.org.uk, GOV.UK – www.gov.uk and nidirect.gov.uk for Northern Ireland).



Since my treatment finished 10 years ago, I have been to university, graduated with a first and trained as a teacher – all the goals I wanted to reach! I wouldn't take back having cancer. I've learned how strong I am and have become even more determined to succeed!

Kelly



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 follow-up doctor can be helpful.

I missed a lot of school work when I was ill.

Who can help?

Your cancer treatment may have disrupted your education, particularly if you were a teenager when you were treated. 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 UK government website GOV.UK has a wide range of practical guidance on employment regulations and procedures (www.GOV.UK) as does the Northern Ireland government website (nidirect.gov.uk)

Can I join the Armed Forces?

The Armed Forces have strict guidelines about people joining up, particularly those wishing to join the RAF as aircrew. In the past it has been very difficult for people who have been treated for cancer to be accepted into the Forces. They state clearly that anyone who joins needs to be medically fit and able to serve worldwide. Training will be physically demanding and mentally taxing and new recruits must be able to 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. It will be their decision as to whether you can join. Their website is www.mod.uk and there are links through to the Royal Navy, Royal Air Force and the British Army. The same procedure applies to the Territorial Services. Your clinical team will support your application.

Should I tell my employer I had cancer?

Answer questions honestly, you only have to give 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 follow-up doctor if they need more information.

Equal opportunities

Everyone in the UK has rights to protect against discrimination.

If I have a disability, what are my rights?

You have rights to protect you from discrimination. These rights covers areas including:

- employment
- education
- dealing with the police

The Equality Act 2010 and the United Nations (UN) Convention on the Rights of Persons with Disabilities (2006) help to enforce, protect and promote your rights. An excellent source of information on current legislation can be found at GOV.UK.

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

- a trade union
- your local law centre
- a citizen's advice centre
- a solicitor

Despite having my right leg amputated during treatment, I now travel the world playing wheelchair basketball. I fell in love with the sport when I went along to a roadshow and haven't looked back since! I felt so proud to play for Team GB in the London 2012 Paralympics. Amazing!

Gaz



Life insurance and mortgages

Buying a house is one of the most important decisions you will make in your life.

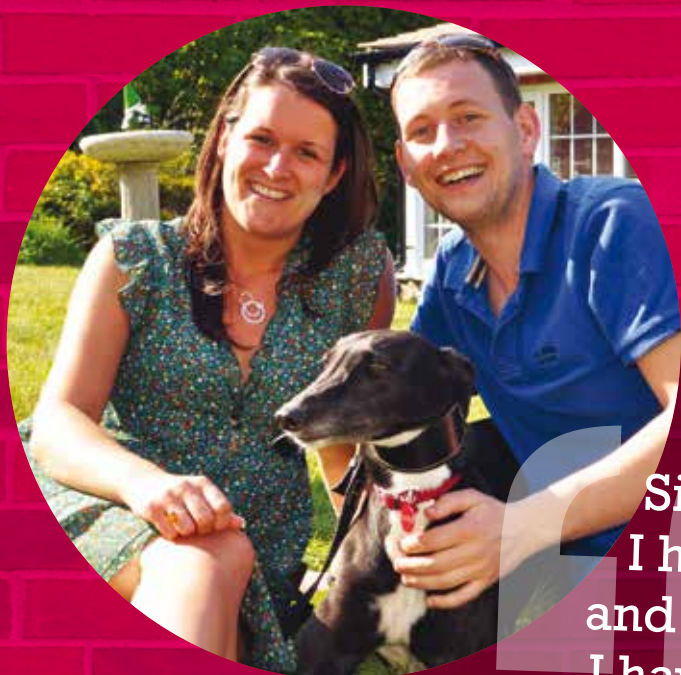
Will I be able to own my own house?

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). IFAs 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.

Discuss with an insurance underwriter and ask them for advice on how they might be able to offer and arrange insurance, rather than focusing on whether you will be eligible for insurance.





Since beating cancer
I have felt empowered
and energized by life and
I have had some amazing
opportunities come my way.
I have recently bought
my first house with my
boyfriend and our gorgeous
pet greyhound. Life has
never been better!

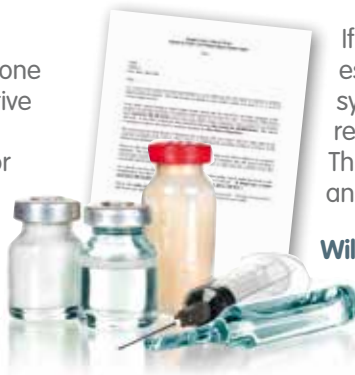
Lizzie

Travel & vaccinations

While travelling is fine for most people, there may be some issues to think about beforehand.

Can I travel abroad?

Yes, although if you have had a stem cell or 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 will 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

REMEMBER
If travelling
abroad, plan well
in advance

USEFUL WEBSITES FOR TRAVEL INFORMATION

www.fitfortravel.scot.nhs.uk
(this is the Scottish NHS website, but the information is suitable for everyone)

www.travelhealth.co.uk

www.masta.org

www.macmillan.org.uk or
telephone **0808 808 0000**
Macmillan Cancer Support is
a useful source of
travel information
for people who
have been affected
by cancer.



some companies that specialise in offering insurance to people who have a medical condition. It is worth shopping around for the best policy. It is important to be honest even though your treatment may have been years ago. If you did become unwell while on holiday and you had not declared your past illness you may find your insurance will not cover you. Your medical team may be able to advise.

Can I have travel vaccinations?

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

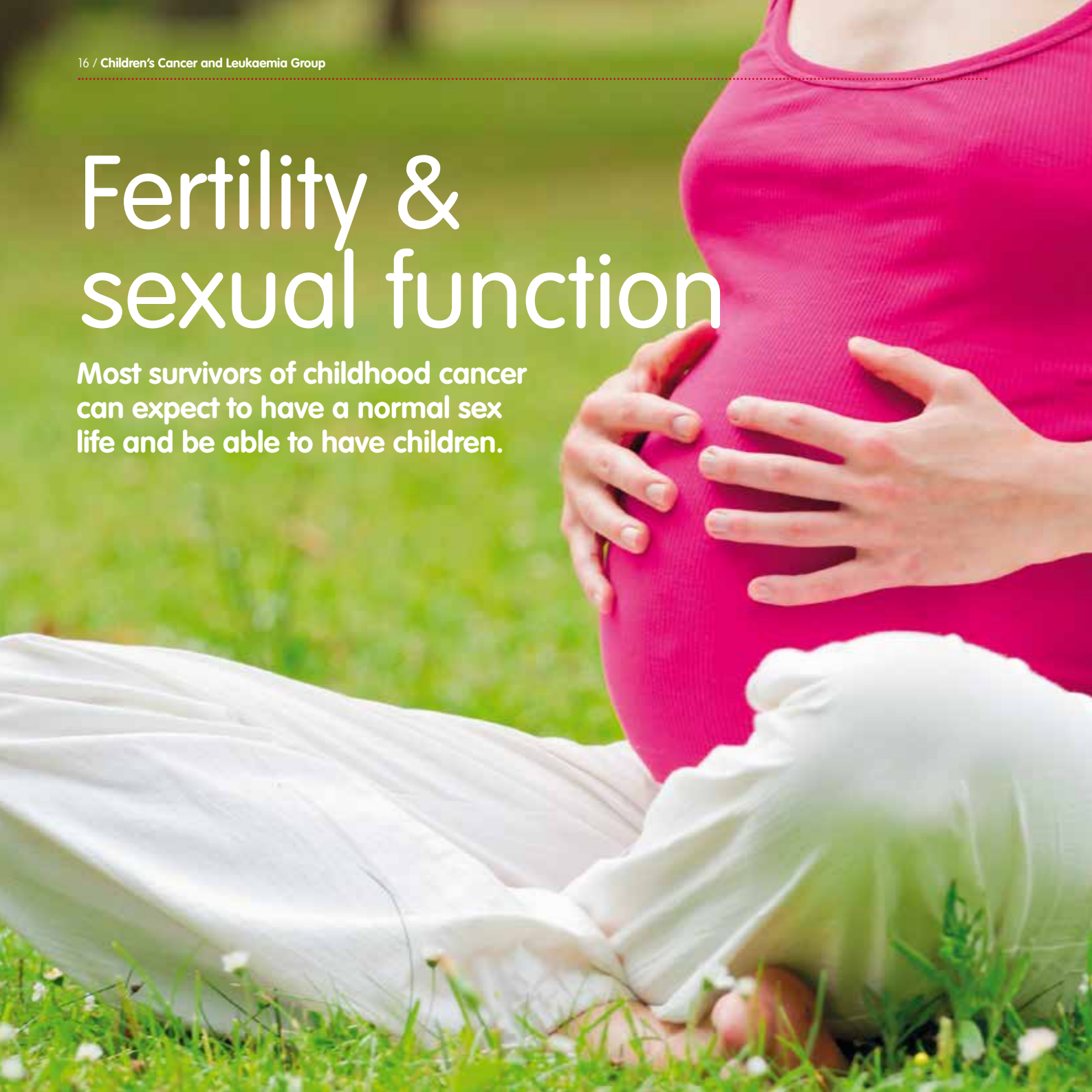
Non-live vaccines, like hepatitis A, cholera, rabies and certain typhoid vaccines are safe and should be used as indicated. There are some vaccines that you cannot have after a transplant. These tend to be live vaccines such as yellow fever, live oral polio and typhoid.

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.



Fertility & sexual function

Most survivors of childhood cancer can expect to have a normal sex life and be able to have children.



What about pregnancy?

Most people can expect to be able to have children after treatment for childhood cancer. For girls, if you are having regular periods naturally (not withdrawal bleeds because of the pill or HRT); it is a good sign that pregnancy may be possible. For some women, the menopause may occur earlier than normal and this can influence the timing of future pregnancies. For boys, it is more difficult to know. 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. Speak to your long term follow-up team about your individual circumstances and the effect your treatment will have had on you.

Should I use contraceptives?

Unless you want to start a family, you should always use contraception. It is also important to protect yourself against sexually transmitted diseases (STD) by using condoms.

Will my sexual function be affected?

This is very unlikely. Most men and women treated for cancer can have sex without problems. Sometimes there may be issues if you have had surgery or radiotherapy to the pelvis, or if you have had radiotherapy to the head affecting hormone levels. If you have concerns discuss these with your clinical team.

Will my baby have cancer?

This is extremely unlikely. 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?

For the majority of women who have had cancer, their pregnancy will be normal and uncomplicated. If you become pregnant you should let your antenatal clinic know about your previous treatment. You should also let your long-term follow up team know so they can decide if you need any special care. 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.

Despite being told that the chemotherapy drugs used to treat my cancer may affect my fertility, 20 years later I fell pregnant naturally and had a healthy, happy pregnancy. Our daughter Ella is even more special than any other baby because we were never sure if she would be possible!

Katherine

Feelings and emotions

Diagnosis and treatment for cancer is a difficult and stressful time for children, teenagers and young adults and their families.

During your treatment, you and your family were focused on getting through day-to-day life and juggling hospital, school, work and siblings. New feelings can emerge after treatment has finished as you begin to come to terms with your experience. Whatever you are feeling now is normal and right for you.

You may feel some of the following emotions:

- Relief and happiness
- Fear of the cancer returning
- Frustration about how your life has changed
- Sadness about the loss of a regular childhood
- Guilt that you have survived when others didn't
- Feeling different from peers
- Vulnerable because of your cancer experience and you may have worries about your health
- Invincible because you have survived and can therefore do anything (this can possibly lead to unhealthy or risky behaviour)
- Resentful as parents may become over-protective
- Unexpected triggers and emotions caused by anniversaries of cancer events
- Distress and anxiety due to the diagnosis of a late effect related to your cancer treatment or a new health problem

Most childhood cancer survivors and their families cope very well with moving onto the next chapter in their lives. Years later, some survivors find that they have undergone positive, meaningful and beneficial changes in themselves and their values as a result of surviving their experience.

Sometimes, however, coping with physical problems or other stresses related to your cancer experience can make you feel down or distressed. These can be triggered by reminders of the upsetting aspects of treatment.

If you feel depressed or anxious, and the feelings last more than a couple of weeks or interfere with your day-to-day life, it's important to seek medical help. Please talk to your follow-up team or GP if this is the case. It can also be helpful to talk through your worries with others such as friends and family.

Survivor groups (including online and local meetings) can offer opportunities for you to meet other survivors to share experiences and to talk about ongoing issues. You may also like to visit www.jimmyteens.tv to view short films by other survivors.



I feel so much stronger
about my personality.
I firmly believe that nothing
is impossible. No matter what
happens in my life in future,
I know that the secret for
me is to find the good
reasons why I should
fight, and to simply ignore
the disadvantages.

Megi

Lifestyle

how to keep healthy

By being aware of potential health risks, you have the chance to possibly reduce their impact by changing your lifestyle such as ensuring you eat healthily, take regular exercise and reduce stress levels. The following are some common lifestyle questions.



Can I sunbathe?

It's well known that exposure to the sun can cause skin cancer. Some survivors of childhood cancer may be at risk of second cancers which includes skin cancer. In order to minimise the risk of skin cancer it is essential to wear sunscreen. This should be a high factor. Don't ever be tempted to use a sunbed! They use very intense rays, which are especially damaging.

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

Does having had cancer mean you get more tired?

Not usually. If you feel 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.

Is it OK to smoke?

Smoking has been clearly linked with cancer. It has been known since the 1950s 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.



Will I have problems with my memory?

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.

I now feel like the luckiest girl in the world who has been given a second chance at life and I don't intend to waste it. I very strongly believe that if you can beat cancer you can do almost anything, and with hard work and determination I can't wait to see what the next ten years might bring!

Lizzie

How will exercise help?

Sports and exercise is important for improving muscle strength, contributing to a sense of well being and enhancing self-confidence. Exercise programmes can also reduce the tiredness and lethargy that some patients experience following treatment. Belonging to a team and incorporating exercise in your life can help you feel more independent.

Exercise combined with healthy eating can also prevent obesity. This is extremely important because obesity can lead to a number of other health problems like high blood pressure and heart disease.





Can I go to the gym?

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 fit and can be fun, especially if you exercise with friends.

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.

Can I go diving?

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

The way I look reminds me of my treatment

You may have been left with some scars after your treatment; you may feel your 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. However, it is natural for survivors to be fearful about the possibility of a relapse or late effects. These worries can make you feel different from your friends. However, the chance of getting a second cancer is very small.

Can my experience of cancer help others?

It is important to find out as much as possible about cancer and its treatment so there are on-going research studies investigating children who are newly diagnosed and young people that have been treated previously. 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 follow-up team will be able to tell you if there are any long-term follow-up studies relevant to you currently being carried out. 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 research enables doctors to help current and future generations of patients.

Can I give blood/donate organs?

If you are interested in giving blood in the future then it is worth remembering that the rules about blood donation following treatment for cancer are constantly changing.

For blood donation, you are currently 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, online registration and telephone number for you to discuss anything with a medical advisor (see 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 (see www.uktransplant.org.uk)



Specific late effects information

We hope that this booklet will help to answer many of the questions you have on surviving cancer as a child, teenager or young adult.

Online factsheets

Specific information on late effects is available at www.aftercure.org and focuses on issues such as:

- Quality of life / emotional / neuropsychological issues
- Second cancers
- Blood and organ donation
- Neurological / neuropathy problems
- Eye problems
- Hearing problems
- Dental care
- Effects of radiation on the brain / bone and other soft tissue
- Effects of treatment and illness on growth and development
- Thyroid gland
- Fertility in men and women
- Spine / heart / lungs / kidneys and bladder / stomach / liver
- Bone health
- Breast care
- Metal bone replacement
- Immunisation and travel advice

The factsheets are continually updated and added to by the CCLG Late Effects Group for use within treatment centres.

These can be downloaded at www.aftercure.org

The quotes in this publication are from survivors. They are personal views and do not necessarily represent the view of CCLG.

CCLG makes every effort to ensure that information is accurate and up-to-date at time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.



Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources

If you have any comments on this booklet, please contact us at the address below.

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

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