
The Next Stage

Recovery and
Adjustment

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Adjusting back to a normal lifestyle after diagnosis and treatment of a blood or lymphatic cancer can be the hardest part of your cancer journey. This booklet is designed to provide you with information on how to begin rebuilding your lifestyle, and the hurdles you may face.

You may experience all of the problems featured in this booklet, some of them, or maybe none at all. Experiences vary from person to person, and the time it takes to re-adjust to 'normal' can also vary. This booklet, and the organisations listed in it, are available to help you whatever you may be facing.

Remember, you can also find tailored advice for your particular situation from your medical team.

Booklet compiled and updated by Dr John Donohue, Dr Ziv Amir, Anne Crook, Linda Boyne, Amanda Bland, Trish McQueen and Marie Krnakova, Joanna Injore, Nick Trott, Elizabeth Tydeman, Deidre McCarthy, Andy Burman, Eleanor Johnstone, Dobrin Neykov and Harry Huntington. This booklet was medically reviewed by Deborah Stalkartt and Dr Robert Marcus. We are also grateful to Geraldine Dora for her contribution as patient reviewer.

If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 8:30am – 5:30pm and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:30pm.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing nurse@leukaemicare.org.uk or over the phone on **08088 010 444**.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some

way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support. Information about the conferences we have coming up can be found at **www.leukaemiacare.org.uk/support-**

and-information/support-for-you/patient-information-days/

Website

You can access up-to-date information on our website, **www.leukaemiacare.org.uk**.

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemiacare.org.uk**

Patient magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to **www.leukaemiacare.org.uk/communication-preferences**

A note from the Patient Advocacy team

We hope that you find this booklet helpful, and you can relate to some of the emotions we are going to talk about.

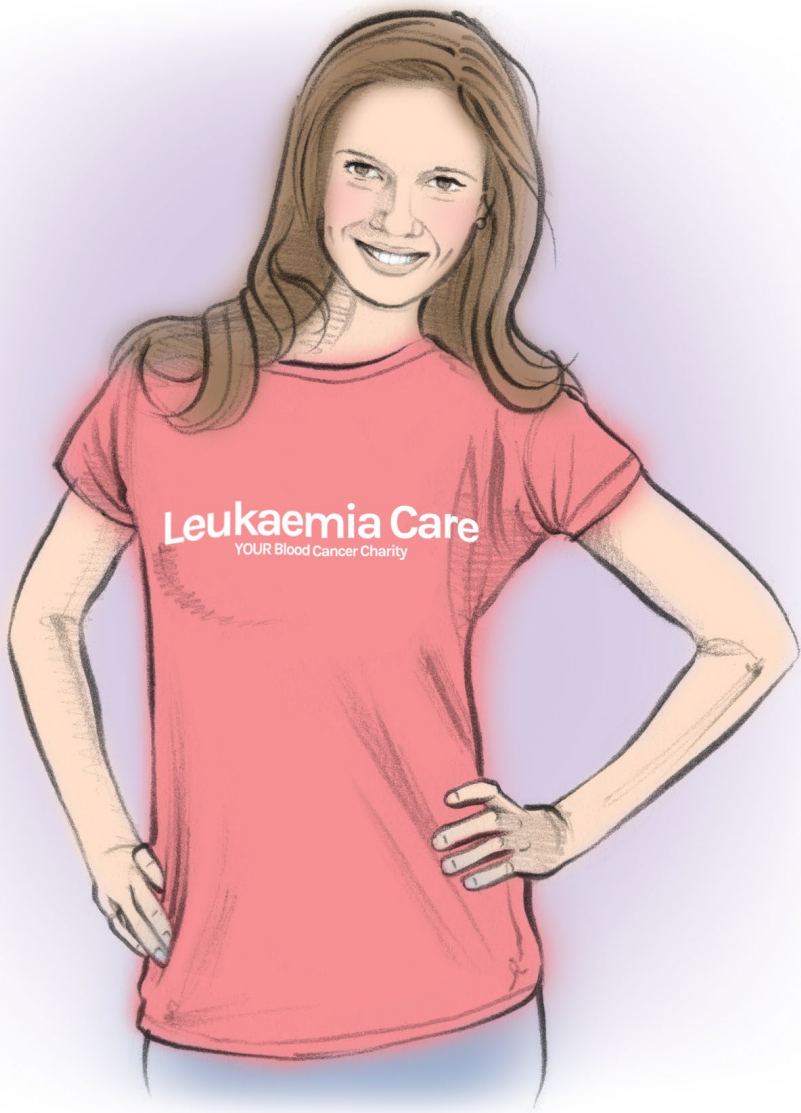
We realise that it can often be hard adjusting when you are at home after finally finishing treatment. You may have suddenly gone from a position of regular monitoring to now being told you don't need to attend for a longer period of time, or even not at all, and are expected to 'get back to normal'. You may have a whole host of questions unrelated to your illness, about your relationships, your feelings or even practical issues like getting back to work.

We have touched on aspects in this booklet that we often find patients ask about. Please keep in mind that everyone's experience is different, and you may find some sections more useful than others.

Always remember that any medical questions should go to the healthcare team you are dealing with. We are a national charity focused on providing information and support, which

is what we have provided in this booklet. We have also offered some signposting to other organisations that can give you practical advice tailored to your exact situation. Likewise, if you just need a chat, call us on the number below.

If you have any questions about the information in this booklet, or you would like to know where else you may find information that you need, just call us on **08088 010 444**.



Effects on your emotions

With thanks to Anne Crook, Counsellor at the Christie NHS Foundation Trust; Dr John Donohue, Chartered Clinical Psychologist, Haematology and Oncology; Marie Krnakova, BA Hons Relaxation and Mindfulness Therapist; and Trish McQueen, patient.

After diagnosis and treatment, adjusting back to normal can have a huge effect on your emotions. Everyone comes through the experience of cancer and its treatment in their own, individual way – there is no blueprint for coping in a particular way. The emotional effects described may or may not apply to you, but they are common to people who have had this experience and are meant to reassure you that you are responding in a ‘normal’ way to a challenge unlike any other.

During treatment all of your emotional energy is focused on getting through treatment and your day-to-day survival. Many people cope with this period reasonably well despite the physical and emotional challenges it brings.

When treatment ends and you are

trying to get back to ‘normal’, you may be surprised to find yourself experiencing strong emotions. This is not unusual because your emotions are ‘catching up’ with all that you have been through. This emotional process helps you to integrate the experience into your life and to gradually move into the future.

Living with uncertainty

It is the case for many patients that the process of treatment is very challenging. You may at the beginning wonder how you will cope with the various procedures. As time goes by, and a routine develops, you may have built a good relationship with your medical team, which can be very self-contained and perhaps a ‘safe haven’. You will know that all that can be done is being accomplished.

However, when treatment finishes, the feeling of security from the team will become less available and often the feeling of uncertainty about the future and the potential of disease reoccurrence can begin to take hold. The thoughts of 'what might be happening in my body' can linger in your mind for quite some time feeding into anxiety, depression and a range of other emotions. Ironically, revisits to see the consultant can be something of a mixed blessing. On the one hand, confirmation that your 'counts' or 'markers' are fine can alleviate worries, but on the other hand, each visit can be hallmarked with anxiety. Sometimes you may worry if 'nothing more can or will be offered' and spur the question 'what then?'. Repeat visits to your GP or self-monitoring can become a way of coping with anxiety and preoccupation with the disease.

You may be faced with gaining a sensible balance between vigilance over the signs of disease recurrence and continuing to live your life as normally as you can, which is perhaps the

most effective armour against unnecessary anxiety.

Information and kind support from your healthcare team can do much to encourage your re-adjustment, and time in this case is 'a good healer'. In some cases, a referral to a counsellor can be extremely helpful in helping you cope with preoccupation and facilitate a rebalance in your life.

Moving away from treatment and back into your normal life can be a very difficult time, and it is important to allow yourself the time to adjust. You may experience a range of emotions but remember that this is perfectly normal.

Finances and mental wellbeing

Many people find that cancer has an impact on some of the practical aspects of their lives. This may be because you have been unable to work for some time, and maybe your partner has had to take time out of work to care for you. Recovering from a financially difficult situation can be a challenging and complicated

Effects on your emotions (cont.)

process that can impact on you emotionally as well as practically.

In some situations, if you are struggling to manage your finances, it can have a negative impact on your mental health and wellbeing which can evoke an emotional response. For more information on the practical issues you may need to deal with, go to page 38, or for tips specifically in relation to your wellbeing, go to: <https://www.moneyadviceservice.org.uk/en/articles/money-problems-and-poor-mental-wellbeing>

Isolation

There is the temptation to quickly put the experience behind you and to move on from it. This process, put simply, takes as long as it takes. It involves the discovery of your 'new normal' because life inevitably takes on a new meaning after serious illness.

You may find that you feel quite isolated and alone during this time. You may miss the security of frequent hospital visits with the support of your healthcare team who could provide reassurance

and fellow patients who could understand some of what you are feeling.

Perhaps family and friends expect you to be "alright" now that treatment has finished and they will be impatient for life to get back to normal. You may not want to worry them by talking about your feelings and may be feeling guilty for what they have been through. You may resent others for not asking how you are or acting as if nothing has happened. Remember that your family and friends are there to support you, so try and share how you feel with them, even if you simply say you still need support from them.

Alternately, you may dread having to talk about your illness and resent being defined by it. These conflicting feelings can leave you feeling tense and confused. You may need to push yourself to talk to others so that they know how you are feeling. If you do not want to talk about your illness, change the subject by asking the other person about themselves.

Probably the best way to deal with

feelings of isolation is to be clear about what you want. Tell those around you that you do/do not want to talk about your illness. Just because you have finished treatment does not mean that you are left alone to resume your life again. Use your family and friends for support if you need to and contact your medical team if you are worried.

Anxiety

Anxiety and fear are our natural responses to when we feel threatened. It is helpful when we are in danger because the physical responses such as increased heart rate, rapid breathing and muscle tension help us to face a danger or run away. It is less helpful when we are preoccupied by anxious thoughts that can affect sleep or cause us to avoid previous activities. When worry takes off it can leave us feeling exhausted.

Each pain, niggle or hospital appointment can set off fearful thoughts about the cancer recurring. This is to be expected and will recede over time as you

pick up your daily life again and plan for some future events to look forward to. If you find yourself constantly checking, seeking reassurance or if the fears stop you from doing things, talk this over with your healthcare team.

Complementary therapies and relaxation exercises can help with the physical effects of anxiety and cognitive behavioural therapy (CBT) can help to get the worrying thoughts back into perspective.

Almost everyone can learn and use relaxation and mindfulness techniques. To get the best results, these techniques should be practised regularly, and if unable to attend classes, CDs are a great alternative.

Mindfulness and Relaxation

Simple relaxation, mindfulness, breathing techniques and exercises may help to calm the mind and release any muscle tension and pain. To start with, make yourself comfortable either by sitting on a chair or lying down on a blanket or yoga mat

Effects on your emotions (cont.)

with cushions supporting your body. Loosen any tight clothing and for a few moments observe your breathing without trying to change anything or make anything happen.

Simply observe how the chest and abdomen rise as you breathe in and out, slowly and calmly, or if you prefer you can focus on the sensation of the air passing through your nostrils and any feelings and thoughts that may arise as you continue with this exercise. Allowing the breath to settle down into its natural rhythm and trusting the process that after each inhale, an exhale will follow guiding your mind and body into a comfortable, quiet pause that naturally happens between each breath.

As you do so, begin to imagine or visualise that the air you are breathing in is pure relaxation and that the air you are breathing out is tension, pain, discomfort or any other negative or unwanted sensations, thoughts or feelings. Keep breathing deeply and calmly, relaxing with each breath you take

and continue to exchange tension and relaxation through your breath for a few more moments.

It is normal and natural for your thoughts to wander during this exercise. Just accept the thoughts as they come and let them pass while you return your attention back to your breathing, noticing how calm and relaxed you feel. When you are ready to finish this exercise, give yourself time to explore and fully experience these new feelings of deep relaxation before you open your eyes.

If you are really worried about something you are experiencing, contact your medical team. They may be able to help you identify what you should be looking out for, if anything.

Share your anxiety with others. You may find that by sharing this you can try and rationalise what you feel anxious about. Thinking about why you feel concerned or are dreading a certain upcoming event may help you say that perhaps it does not warrant such anxiety. This is not to say

that your anxious feelings are not rational; your feelings are important and should not be disregarded. Thinking about why you feel this way can help calm you. For more information on anxiety, take a look at www.nhs.uk/conditions/anxiety

Anger

Anger is an uncomfortable emotion but is a very normal response when we feel challenged or threatened in some way. You may feel angry with yourself, your body, with the healthcare team or with family and friends. This may be expressed through impatience and irritability with those around you and feeling frustrated with things that usually would not bother you.

Try and pinpoint what it is that makes you angry, so you can find an effective solution.

Setting gradual goals for yourself can help you ease any anger and impatience associated with your body and healthcare. As you begin to achieve more and more, you will find that your anger decreases.

Taking part in physical exercise can be a great way to release anger into something that will not upset anybody. It is an effective way to channel your angry energy.

Try to talk through why you are feeling angry. This way, you are less likely to lash out at somebody. This can also calm any anger you may have before you find it too difficult to deal with.

Sadness and depression

Illness brings with it a sense of loss and we can find ourselves grieving for the person we were and the security that we felt. You may feel sad about the impact of illness on yourself and those around you. There may be times when you feel low in mood. This is part of the normal recovery process.

If you find that your low mood persists for some weeks, that you feel hopeless and you have lost interest and pleasure in things, you may have depression. Seek help from your doctor if you or those around you are concerned

Effects on your emotions (cont.)

about your mood.

It might help to take part in small activities that you enjoyed before your diagnosis, as far as your health allows. This can help you connect back with your life before treatment and give you a sense of normality.

Try and talk about your sadness, as sharing this will allow others to try and help you see another perspective. This may help alleviate this feeling.

Self-confidence

You may feel less sure of yourself and your place in daily life when treatment ends, and it can take time to regain your self-confidence. The intrusion of illness in your life and particularly the treatment that comes with it can break down your sense of self-worth and your role in the world.

You could lose confidence and self-esteem as a result of unwanted changes in your lifestyle that your treatment may have caused. For example, limitations in terms of energy can interrupt your time with loved ones, friends, and your ability to

work. Having to conform to your hospital calendar may lead to a feeling that your life is no longer your own, and that it is in the hands of your medical team.

Coming away from treatment can leave you with a sense of loss for your former self.

Your feelings about your body may have changed – perhaps feeling that it has let you down by getting cancer. You may be self-conscious or feel sad about how you look and how you feel, particularly if you are experiencing fatigue. You may no longer feel attractive or sexy. It takes time to gradually come to terms with your appearance and others will be more accepting and reassuring than you may expect.

You could try gradually increasing your activities and socialising so that you regain your confidence in a step by step approach. Doing this slowly will give you the opportunity to adapt back into the lifestyle you had before treatment.

There are ways of making yourself feel better about your looks for both men and women. You could try www.mynewhair.org, or www.lookgoodfeelbetter.co.uk, both

have lots of information that you may find useful.

It is important to acknowledge this time in your life, so you can move on.

Hope

We have concentrated on the more difficult emotions, but you may also be feeling relief that the treatment has been completed and that you can begin to enjoy life again. Coming through treatment brings with it hope for the future. It is often a time when people think about what is most important to them in life and this may result in making changes for the better.

The lighter side of living with cancer

"A cancer diagnosis is not something anyone welcomes into their lives. Firstly, there is the devastation and anger or bewilderment, then the aftermath and knock-on consequences. However, at some point, your focus and outlook could change to become more meaningful and positive than before. So, what is the lighter side of living with cancer?"

Well it is all a matter of perspective. You see, I never really lost anything of value; I still had my children, my fiancé, family and friends. I still had a roof over my head, just not the one I had imagined I would have. I was still alive, just not how I had imagined I would be. I still had a purpose, just not anything great or grand as I had imagined myself to have. I still had me, and I was able to get in touch with myself without all the other stuff getting in the way.

When I think of the stress I was under before my diagnosis, due to my lifestyle, I am not surprised I got ill. My illness was a wakeup call. I am blessed to have been given the opportunity to slow my life down and experience the moment. I now choose who to spend my time around and I ensure the time I spend is of quality. I am no longer striving towards any goals. I have let go of the need for success, and I see it as having little value in life. My children are reminded daily that it is more important that they are nice people than smart people. I experience the moment in a variety of ways throughout each day, which is simply called being mindful. I try my very best to experience the moment. If after getting dressed

Effects on your emotions (cont.)

mindfully, I am driving somewhere or walking somewhere, I do so mindfully, actively dropping into the body and experiencing how it feels to be here, in the body, at this moment. Sounds help to ground you in the moment, whether they are the sounds of your own footsteps, or of other vehicles on the road. Your breathing is also key to this lifestyle. Until recently, I had walked and driven almost everywhere on autopilot, entirely consumed by thoughts, being somewhere else in my head. Being and becoming mindful in your everyday life is so transformative, it is like living in a new world, with a new you.

My most cherished mindful part of the day is preparing and cooking dinner. The stimulus from the ingredients; the aromas, the feel, the noise as you cut through them, and such like, are all entirely pleasurable. It is a wonderful thing to be present with your meal preparations, and not busy in your head thinking about something that doesn't actually exist at that moment. The joy of mindful cooking is something I look forward to each day, and I appreciate every moment of it. I am living with an attitude of gratitude for all I experience in a day. I speak mindfully

with my loved ones and I listen to them carefully, which enables me to have more enriched relationships with them. I try not to react to things which would previously have annoyed me or made me anxious, and when I am unsuccessful in doing this (as I often am), I sit with the feelings and acknowledge them, allowing the drama which is formulating in my thoughts to dissipate and dissolve naturally.

I am still living with an incurable cancer. I have just finished two and a half years of treatment. I by no means mean to down-play the devastating effects of cancer, but I have accepted it and learnt to welcome it into my life. In doing so, I am no longer at war with it, so it no longer gets my attention. Energy follows focus, and so if I am focusing on the little pleasurable moments of life and living them mindfully, I am focusing on something positive and not the cancer. I am free from the shackles of cancer. Acceptance is the way forward. Accept it and then let it go. Devote your energy to the moment and the genuine experiences which exist therein. I am happily living with cancer and I am thankful for the changes it has brought into my life.

Remember these two things; energy follows focus, and you are not your thoughts - you do not have to attach to them. My life has transformed so much, that I am ready and willing to say that my cancer diagnosis has been a real gift." - Trish McQueen

Moving forward

Each person finds their own way of adjusting and coping. Being able to talk about difficult emotions, as hard as it is, makes these feelings seem more manageable. We may be tempted to try and protect others from our negative thoughts and feelings but the energy it takes to stifle such emotions can make coping feel much more difficult. Talking openly about your sadness and fears can then free up energy for a more hopeful outlook.

You may find sharing your experiences on helplines, at support groups or local cancer centres a useful way of moving forward.

It can be helpful to talk through your experiences in confidence with someone who is impartial and experienced in helping people

‘work through’ their cancer. This is not a sign of weakness but a brave and positive step in your recovery process. Your medical team or local cancer support centre may help you to find a counsellor.

Leukaemia Care has support groups based all around the UK. Alternatively, we provide monetary support through our Ann Ashley counselling fund if you would like to speak to a counsellor for support.

Call us on **08088 010 444**, or visit www.leukaemiacare.org.uk for more information.

Effects on your relationships

With thanks to Linda Boyne, Haematology Counsellor.

Re-adjusting back into a normal lifestyle after treatment can have profound effects on your relationships. Your relationships may have changed whilst you were being treated; perhaps your partner took on a carer role, or maybe your children didn't spend the time with you that they did before your diagnosis.

It is important to give yourself time to consider your relationships, and work at rebuilding them. This will not happen overnight and will not be an immediate consequence of coming off treatment. It may require some work, and cooperation on your part, and the part of those around you.

Your partner

You may feel very isolated from your partner and even 'adrift'. They might feel guilty about not contributing as much as they did before your diagnosis.

Often closeness could be missing from a relationship due to a number of factors. You could

feel very tired and drained, and intimacy can be one of the first things to go in a relationship, leaving both of you confused and scared. Your partner may fear hurting you by passing on infections. This can be a lonely place for both you and your partner.

You may feel unattractive due to hair loss, changes in skin and weight reduction or gain. Patients have been known to say things like: "I feel like an old woman and I'm only 34. Will I get my looks back?". This could be a real fear for your partner as well.

It is likely your partner may be feeling a lot of things that you are feeling but may be unable to voice these concerns for fear of upsetting you or seeming ungrateful for their own health.

If only one of you can work, there may be a strain on the family resources. Socialising and holidays may not be taken due to the treatment, and fear of picking up infections, so couples do not

get a break from the routine to go away together. You may have also spent a lot of time at hospital, which can interfere with the smooth running of family life.

Even though you might not spend as much time together as you would like, it is important to still try and factor in some quality time together. Maybe you could organise a 'date night' and spend the evening together in front of the television.

It might help if you could ask a trusted person to look after your children, so you can have some alone time. Remember, you don't have to have lots of time and money to spend some quality time together, and this can help you rebuild your relationship.

It might help for you to communicate with each other; though this may be hard to begin with, it might help alleviate your worries, as well as those of your partner.

If you are struggling with the way you are feeling about your appearance, there are ways to make yourself feel better. You could try www.mynewhair.org or

www.lookgoodfeelbetter.co.uk

Your children

This could be one of the most emotive subjects for you. You may feel desperate around your children. You may feel guilty because you may not be able to fulfil the role you usually play in taking care of your children. You could be frightened of dying and leaving your children on their own without their mother/father.

Your children's lives have changed because one of their main carers is ill. Your children may feel scared of losing their mum or dad. They may even feel affected by the changes that might happen to you, such as hair loss, weight gain/loss or perhaps if you have no energy to do anything. This can be scary for children and unsettling. They may, as a result, be frightened of making any demands and feel that they are to blame for you becoming ill.

Some children may 'back off' from you because of their fears of catching the disease, or lack of understanding. They may start 'acting out' because of fears of other children in school finding

Effects on your relationships (cont.)

out and treating them differently.

It may be best to involve your children in as many aspects as possible of your illness and treatment, especially bodily changes and side effects. This may stop any major surprises.

You may want to inform your child's school so they are aware of the situation at home and can offer the child additional support at school.

You might want to consider planning some small activities to do with your children, so that there is some sense of normality in their lives, and a reminder of life before your diagnosis. This may be really small things like ordering in a takeaway, going to the park for an afternoon or doing some arts and crafts in the house. Only do as much as you feel up to, and don't push yourself. This way, you will have the energy and enthusiasm to share with your children.

If you need more support when talking to children, call us on **08088 010 444** and we will be able to signpost you to the correct organisation to support your needs.

Your friends

A number of things can happen with friends. Some will be hugely supportive. They will keep in touch, visit you in hospital, help out with the kids, cook your meals, babysit, give you lifts to the hospital, be a really supportive listening ear; a general all-round good egg.

They may, however, back off, disappear, not get in touch, and feel like you have enough on your plate without them crowding you. Your friends can also feel confused and scared of catching the disease. It never ceases to amaze the number of people who ask if leukaemia, lymphoma or

myeloma is contagious.

Trying to maintain a friendship during the long and at times difficult treatment pathway can place a burden on you and them. There are going to be times for whatever reason (infection, tiredness, hospitalisation) when it is not possible to be in touch with your friends.

However, it is very comforting to know that they are thinking of you so do try and explain your treatment plan and any pitfalls. If contact is lost for a period of time, they will know you still value their friendship and plan to resume it as soon as you are physically able to.

Various reasons may prevent you from keeping in contact as much as you may like. You could ask a family member to ring them for you to tell them how you are doing.

For those who may not support you as much as you would like, remember that they may be feeling confused, scared or worried. Do not let this concern

you; it is important to concentrate on your own wellbeing, and rest assured that these friends will come back to you when they are ready.

Don't feel afraid of asking your friends to do those things that you can't. They probably feel like they want to help you but don't know how, and by asking them to do practical things you will be able to maintain your friendship and help your own situation.

If you find yourself losing contact with friends, don't let this worry you. They will understand that you have your health to think about. Giving them, and yourself, some time will allow your friendship to naturally reform.

If a family member or friend is your carer you may find that they also need support. We have a booklet called *Caring for Carers*, which you can order by visiting www.leukaemicare.org.uk or call 08088 010 444.

Effects on your relationships (cont.)

New relationships

Forming new relationships can be difficult, as they may not have been around through your diagnosis or even your treatment. It may be difficult to know when to tell a new partner about your diagnosis, as you may be worried about frightening them or complicating your situation. The best policy in this situation is honesty, as new relationships demand time and commitment to maintain them.

In simple terms, explain what is happening or has happened, and that you have received treatment, but your diagnosis can still affect your life. You may want to share how your treatment has emotionally affected you; if not, try and share how it has practically affected your life, maybe due to hospital visits. Do try and share as much as you can as this will help your new partner understand the situation you are in.

You shouldn't put limits on your life. If your new partner is not happy being with you when they

are told what is happening, it might be that they are not the right person for you. Try not to let this bother you, as you will find somebody who does not let your diagnosis affect your new relationship. It can be very sad and depressing if a new relationship doesn't continue due to your disease. Do talk to people and let yourself feel sad, as this is perfectly normal.

Your relationship may flourish; embrace this and continue to share how you are feeling.

Try to share as much as you can with your new partner, but do not rush yourself. Perhaps you could explain that you want to tell them about your experiences but need time to do this. If the relationship has potential to flourish, they will understand your need to take things slowly.

Don't feel rushed to develop new relationships with people; you may need time after treatment to adjust and developing a new relationship may be too much for you. It is important you feel comfortable before you think

about introducing somebody new into your life.

Your sexuality

Your fertility can be affected by developing an illness like blood cancer. This can be distressing for many patients and can make you feel unattractive. Try to focus on the positives at this time.

Remember, many patients who thought that they would be unable to have children have gone on to have healthy babies.

Your sexuality can be affected by chemotherapy and other treatments. You can be left feeling unattractive and undesirable. Remember again that this is a temporary state, and you will return to how you felt before treatment, and able to engage in intimacy again.

You are still you, despite how you may be feeling or looking. You have the same attributes, you may be just lacking in energy, motivation and concentration due to the illness. Once this has been brought under control, you may feel like dressing up and going

out, and finding intimacy.

It is important to take things slowly, and not to feel rushed by yourself or anyone else. Being intimate with someone again can be a difficult thing to build up, and it will take time. Be patient with yourself and go slowly.

Be open and honest with your partner about how you are feeling. This will help them understand why things may have not gone straight back to normal after you finished treatment.

Effects on your lifestyle

With thanks to Amanda Bland, Teenage and Young Adults (Cancer) Clinical Nurse Specialist; Anne Crook, Counsellor at the Christie NHS Foundation Trust; Joanna Injore, Macmillan Haemato-oncology Dietitian (British Dietician Association member); Nick Trott, Haemato-oncology Dietitian (British Dietician Association member); Elizabeth Tydeman, Nutrition Advice Team at Public Health England; and Andy Burman, Chief Executive of the Association of UK Dieticians.

Recovery and adjustment after cancer treatment can have profound implications on your lifestyle. This may result in some changes that you have to make to allow your lifestyle to mould around your abilities as a patient coming out of treatment. We have included some areas that you may wish to consider, including diet, exercise, the implications of fatigue, smoking, drinking and others. Some of what we cover may be right for you, and some may not. It is important you act on those that work for you as an individual and remember that changing your lifestyle to suit you is perfectly normal.

Fatigue

Fatigue is a side effect reported by a high number of blood cancer patients. It can be debilitating and unlike 'normal' tiredness, it is not relieved by rest. The impact of fatigue on your everyday life can be far reaching and you may sometimes struggle to do some things you used to take for granted.

You may feel weak. Muscles can feel heavy, and you may feel washed out or even lifeless. Maybe the simplest tasks you attempt to achieve feel monumental. Fatigue can last well after treatment has finished. Many patients may not report fatigue to their medical

team because they assume it is natural, and something they must deal with. However, there are things that can be done to manage fatigue and the effect it has on your lifestyle.

It is important you inform your medical team of how fatigue is affecting you, so they can produce a management plan with you. You may find it useful to keep a fatigue diary, where you can record your daily energy levels. This is a useful way to identify any particular triggers. This may help you plan your activities and tasks. From keeping records, a number of issues may be addressed to help manage your fatigue.

While there may be different causes of fatigue, a healthy balanced diet can help give you the energy you need to do everyday things and support overall good health.

Some people may not have enough iron in their diet and may develop iron deficiency anaemia. Your clinic can easily test for this at a follow up visit. One of the most common symptoms of iron

deficiency anaemia is tiredness. Foods such as dark green leafy vegetables (e.g. spinach), liver, fortified cereals and pulses are rich in iron and will help to restore iron levels.

There is strong evidence to suggest that maintaining some exercise during and post treatment can help reduce levels of fatigue. You should gradually build up to this so that you do not overstrain yourself. Your medical team can advise you on the best type of exercise to engage in after treatment, your GP should be able to refer you for a prescriptive exercise programme.

It is important that you get the right amount of good quality sleep. Try to avoid sleeping too much during the day as this will lead to broken, shallow sleep at night. You may find it helpful to get into the habit of rising at the same time each day rather than lying in bed and if you do need to have a nap in the day, using an alarm clock to ensure you do not rest for longer than 20-minute intervals may be useful. Relaxation before bedtime, maybe

Effects on your lifestyle (cont.)

through listening to relaxation or guided breathing CD's may help for a better night's sleep.

Some find complementary therapies such as aromatherapy massage, meditation or yoga can be helpful. You must always check with your medical team before you begin any complementary therapies and keep them informed.

It is important to pace yourself and prioritise tasks so that you only have to concentrate on what is important. Plan ahead so that you focus on what needs doing when you have the energy levels to see things through to minimise feelings of frustration. You could prepare meals on the days when you have more energy for instance and freeze them for when you are feeling more fatigued. You could also take advantage of a delivery to your door of your grocery shop from the major supermarkets.

Spread tasks out over the week and don't be afraid to ask family and friends to help with tasks. If you feel you need extra help to meet every day needs such as personal hygiene and housework,

speak with your medical team who may be able to assist you with external help.

Some find it helpful to meet with others who are going through a similar journey. Talking about your fatigue with others who are experiencing or have recovered from fatigue will help you to feel you are not alone.

Remember: Fatigue is a very real result of cancer treatment for some. If you are suffering from it, you should talk to your medical team, and it will be taken seriously. Do not expect the fatigue to suddenly be alleviated; it can take many months to build up energy and strength after treatment.

Cognitive effects

Patients who have had certain types of treatment often describe an invisible side effect called 'chemo brain'. You may notice that you sometimes have trouble with finding words, remembering details, concentrating on a task or you may take longer to finish things. More research is needed into the causes of 'chemo brain', but it is known that the brain usually recovers over time. In the meantime, you may find that it has an impact on your daily life, reduces your self-confidence and may be distressing.

It may help you to try some of the following:

- Write down details. This can help you retain information over time.
- Use a daily planner and make 'to do' lists, so you know what you need to remember is noted down.
- Break up any concentration tasks with physical exercise and get enough rest.
- Tell your friends and family

about how you feel, and they may have further ideas to help you manage. You will also feel less isolated if others know.

- Talk to your medical team so they can check for other possible causes such as blood counts, hormone changes or medication effects.

Smoking

If you smoke, giving up the habit is the best thing you can do for your health. Smoking comes with a whole range of health risks, including cancer, circulatory problems and fertility problems. As a cancer patient out of treatment, it is essential that you consider the steps to stopping smoking, as you are more at risk because of your recent health problems.

For advice on quitting smoking, visit [nhs.uk/smokefree](https://www.nhs.uk/smokefree) or call the NHS Smokefree Hotline on **0800 022 4332**.

Healthy eating and healthy weight

When people have finished their treatment, they are often keen to

Effects on your lifestyle (cont.)



The Eatwell Guide (above): Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland.

get back to normal life as quickly as possible. A healthy balanced diet can play an important part in keeping you well and helping you recover. Growing evidence suggests that if a healthy diet is consumed and a healthy weight is maintained with regular physical activity, this can reduce the risk of some cancer diagnoses (such as bowel, kidney, pancreas, oesophagus, womb and breast

cancer in post-menopausal women). The advice outlined overleaf is suitable for everyone in the general population. However, if you have recently lost weight or your appetite and food intake has been reduced then this requires a different approach. For example, this might mean including more high energy foods and snacks. If this has been true for you it would be important to discuss this with

your hospital doctor and dietitian.

Eatwell Guide

The Eatwell Guide shows the proportions in which different types of foods are needed to have a well-balanced and healthy diet. The proportions shown are representative of your food consumption over the period of a day or even a week, not necessarily each meal time.

Understandably, if you are having financial issues, then this can make maintaining a healthy diet a little harder. For information about making your food go further and reducing your waste, go to: <https://www.moneyadvice.service.org.uk/en/articles/cutting-the-cost-of-cooking>

The information provided in this section shows how you can use the Eatwell Guide to help you to achieve a healthy balanced diet.

Potatoes, bread, rice, pasta and other higher fibre starchy carbohydrates

These foods provide you with a lot of the daily energy you need, as well as some vitamins and minerals. Choose high fibre varieties. Examples of these foods include:

- Wholemeal breads
- Brown rice or basmati rice
- Wholemeal chapatti
- Potatoes with skins left on
- Wholemeal pasta
- Oats
- Wholemeal couscous
- Wholegrain breakfast cereals

Wholegrain carbohydrates tend to be naturally low in fat and rich in fibre. They are beneficial for two main reasons:

1. They breakdown slowly in the body creating a gradual release of energy.
2. They help with digestion and

Effects on your lifestyle (cont.)

prevent constipation.

Including wholegrain cereals and higher fibre starchy foods with each meal is a great way to help you manage and control your weight. Maintaining your weight has been shown to reduce the overall risk of some cancers.

Fruit and vegetables

These foods provide a range of important nutrients including vitamins, minerals and fibre. Achieving five portions a day can help to reduce risk of type 2 diabetes, cardiovascular disease and some cancers.

Variety is the key with this group. Fresh, frozen, tinned, dried and canned, as well as juices and smoothies (150ml maximum per day), all count.

A portion is about 80g or 3oz, examples include:

- 1 banana/1 apple
- About 10 grapes/6 strawberries
- 2 plums
- 3 tablespoons of vegetables
- 1 cereal bowl of salad

- 1 small glass of fruit juice or a smoothie (150mls)*
- 3 heaped tablespoons of pulses* (e.g. baked beans or lentils)

*only count maximum of once a day

The vitamins, antioxidants and phytochemicals in fruits and vegetables protect the cells in the body from damage. Research shows that is why increasing your intake of these can help protect you against cancer.

Fruit and vegetables are also high in fibre and low in calories, therefore they can help to fill you up which can be helpful for weight management.

Dairy and alternatives

Dairy foods such as milk, cheese and yoghurt are excellent sources of protein, which is vital for many of the body's functions particularly growth and repair. They are also rich in calcium, which is essential throughout life to keep bones healthy and strong.

To support weight management, it can be useful to choose low fat

versions of milk and yoghurt and watch your portion size when it comes to cheese.

It is important to meet our calcium needs. You should be aiming for two to three portions a day. A portion is:

- 30g hard cheese
- 2 tbsp cottage cheese
- 200ml milk
- 1 tub of yoghurt

When buying dairy alternatives, go for unsweetened, calcium-fortified versions.

Some cheeses can also be high in salt – more than 1.5g salt per 100g is considered high. Eating too much salt can contribute to high blood pressure. Cheese can form part of a healthy, balanced diet, but it's good to keep track of how much you eat and how often. Check the label and opt for cheeses that are lower in salt. For example, hard cheese such as cheddar and parmesan are often higher in salt compared to some soft cheeses such as mozzarella and emmental.

Beans, pulses, fish, eggs, meat and other proteins

These foods are also important sources of protein and are low in saturated fat. Meats can contribute to your intake of protein too, along with minerals like iron and vitamins such as B12. However, recommendations suggest it is helpful to limit your consumption of red meats (beef, lamb and pork) and processed meats like sausages, bacon, ham, salami and pâtés. Try to eat no more than 70g (or 2.5oz) per day to help lower the risk of some cancers.

In terms of cooking, research suggests that meat cooked using less healthy methods – fried or barbecued, for example – may also increase the risk of developing some cancers. Try to stick to grilling, steaming or boiling.

Oils and spreads

While we need some fat in the diet, it is important to remember that all fats are high in calories (1g = 9 kcal) and should be eaten

Effects on your lifestyle (cont.)

in moderation. Saturated fat can also raise your cholesterol levels and increase your risk of heart disease and therefore it is best to limit your intake.

Unsaturated fats are healthier fats that are usually from plant sources and in liquid form as oil at room temperature, for example vegetable oil, rapeseed oil and olive oil. Swapping to unsaturated fats will help to reduce cholesterol in the blood, therefore it is important to get most of our fat from unsaturated sources. Choosing lower fat spreads, as opposed to butter, is a one way of reducing your saturated fat intake or moving from full fat milk to lower fat milks such as semi-skimmed and skimmed milk.

Foods to eat less often and in small amounts

You do need some fat and sugar in your diet but foods that are rich in them are classed as being energy dense. This means they contain a lot of calories in a small volume. Consuming energy dense foods makes it easier to eat more than your calorie requirements and therefore, increases the chance of

gaining weight.

Particularly if you gain weight around the stomach area, this can increase your risk of some cancers (see the Body Mass Index chart to work out if your current weight is within the health range).

Ways to reduce the total amount of fat in your diet:

- Eat low fat dairy products - reduced fat cheese or 1% fat/semi-skimmed milk.
- Opt for lean cuts of meat - trim visible fat e.g. remove the skin from chicken.
- Limit butter, spreads, mayonnaise and measure cooking oil when used.
- Bake, grill, stir fry, microwave and steam food rather than deep fry or cooking in large amounts of fat.
- Read labels. Where colour coded labels are used you can tell at a glance if they are high, medium or low in sugar and saturated fat. For a healthier choice, try to pick products with more green and ambers and fewer reds.

- Try to limit foods containing added sugar such as sugary drinks, cakes, sweets and biscuits.
- Limiting the amount of sugar in your diet is important in maintaining good dental health and can help to manage your weight.
- Swap to diet or zero added sugar fizzy drinks, no added sugar squashes, no added sugar yoghurts or plain natural yoghurt.
- Snack on fruit and vegetables.
- Avoid adding sugar and syrups to tea and coffee.

For more information about food labelling go to: <https://www.nhs.uk/live-well/eat-well/how-to-read-food-labels/>

Salt

Although there is insufficient evidence to suggest the impact of salt on cancer diagnosis, general intake of salt should not exceed 6g a day (one teaspoon). This will reduce the risk of hypertension (high blood pressure), and as such may reduce your risk of cardiovascular disease including stroke.

To reduce salt in your diet, limit the amount of processed foods you are eating and refrain from adding salt at the table.

What about alcohol?

Research has shown alcohol is linked to the development of certain cancers. Alcohol can also contain lots of calories (energy) so consuming large amounts will contribute to weight gain.

It is recommended to not consume more than 14 units a week and to include two to three alcohol free days a week. It is also recommended to avoid binge drinking, which is the consumption of more than six units in a single session.

One unit is the equivalent to:

- 135ml wine
- Half a pint
- 25ml spirit

Maintaining a healthy weight

It is important to achieve and maintain a healthy weight for overall health. If you are overweight or obese it can lead to many health problems such as high blood pressure,

Effects on your lifestyle (cont.)

cardiovascular disease and type 2 diabetes. There is also increasing evidence that being overweight increases your risk of certain cancers (for example bowel, kidney, pancreas, oesophagus, womb and breast cancer in post-menopausal women).

You can check if you are the right weight for your height by calculating your body mass index (BMI). BMI is a measure of weight in relation to height which can vary depending on natural variations in body shape. Additionally, BMI can be influenced by other factors including the amount of muscle you possess, ethnicity and pregnancy.

Speak to your doctor if you are concerned about your weight, and any weight gain or loss. We should all aim to be in the healthy weight category, which is a BMI of 18.5 – 24.9kg/m².

To calculate your BMI, go to: <https://www.nhs.uk/live-well/healthy-weight/bmi-calculator/>

Tips to maintain a healthy weight

- If you are overweight, aim to lose about 0.5-1kg (1-2lbs) a week. For information about a suggested weight loss plan, go to the NHS website: <https://www.nhs.uk/live-well/healthy-weight/start-the-nhs-weight-loss-plan/>
- Try to eat a healthy, balanced diet as shown in the Eatwell Guide.
- Try to reduce your portion sizes; try using a smaller plate and avoid second helpings.
- Fill up on salads, vegetables and higher starchy foods such as wholemeal products.
- Increase your activity level. Try to incorporate activity into your daily life, for example, take the stairs wherever possible and walk more rather than using the bus or car. Aim to build up your activity level to 75 minutes of vigorous intensity per week or 150 minutes of moderate intensity per week. Maybe think about starting a new activity such as swimming or dancing.
- Try to limit the consumption of foods in high fat, salt and

sugar by having them less often and in smaller amounts. These foods and drinks contain lots of energy, particularly when you have large servings.

- Check food labels and aim for more products with green and amber traffic lights and fewer reds.

Common diet and cancer myths

Nutrition is a hot topic in the news. There always appears to be a new diet or "superfood" in the press that we should be avoiding or eating. This next section looks at some of the common diets/foods that you may hear about.

Low sugar diets

There is no evidence that sugar increases the risk of cancer or encourages cancer cells to grow. However, too much sugar does increase risk of weight gain and, in turn, the risk of some cancers.

Sugar provides "empty calories" so it would be helpful to reduce your intake as it doesn't contain any other beneficial nutrients apart from energy, which you

could get from other sources.

Dairy-free diets

Some studies have investigated dairy intake and the occurrence of cancer, but a clear link has not been found. We therefore do not recommend following a dairy-free diet to reduce the risk of cancer.

Remember dairy products are an important source of calcium so try to include some dairy products or alternatives in your diet, opting for lower fat and no added sugar varieties.

Dietary supplements

A healthy balanced diet should supply almost all the vitamins and minerals you need. Very high doses of any vitamin/mineral are not recommended and can be harmful.

Supplements to consider taking are:

- **Vitamin D** - in spring and summer, most people will get all the vitamin D they need through sunlight on the skin and from a healthy, balanced diet. However, during the autumn and winter we need to rely on dietary

Effects on your lifestyle (cont.)

sources of vitamin D. Since it is difficult for people to get enough vitamin D from food alone, everyone should consider taking a daily supplement containing 10 micrograms of vitamin D during autumn and winter. People whose skin has little or no exposure to the sun, or who always cover their skin when outside, risk vitamin D deficiency and need to take a daily supplement containing 10 micrograms of vitamin D throughout the year. Ethnic minority groups with dark skin, from African, Afro-Caribbean and South Asian backgrounds, may not get enough vitamin D from sunlight in the summer and therefore should consider taking a supplement all year round.

- **Folic Acid** - women who are pregnant or are of childbearing age who could become pregnant are advised to take a daily supplement containing 400 micrograms of folic acid until you are 12 weeks pregnant. This is to help prevent birth defects, such as spina bifida.

If you are finding it difficult to follow a balanced diet you may benefit from a general multivitamin and mineral supplement but check with your GP or medical team. Remember, always inform your medical team if you are taking any supplements.



Effects on practical issues

With thanks to Dr Ziv Amir, Honorary Professor, Cancer Rehabilitation, Salford University, Greater Manchester and Dobrin Neykov, Partnership Operations Executive, Money Advice Service.

Work and employment

This section contains brief information and advice about your employment and financial issues.

It may be important to know that under the Equality Act (2010), you automatically meet the disability definition from the day you are diagnosed with cancer. If you would like more information on anything covered in this chapter, go to: <https://www.moneyadvice.org.uk/en/articles/support-to-help-you-keep-your-job-when-ill-or-disabled>

Information about work and cancer

The problem

Cancer treatment may cause some side effects. Some of them last for the short term and some could last for a longer period of time. Fatigue (tiredness and

weakness) is the most common long-term problem reported by people affected by cancer. This problem affects everyone differently, with some people reporting a strong effect on their ability to work.

These conditions can affect the way you may perform, and your ability to concentrate on anything. Furthermore, these side effects can have an impact on your relationships with your employer/manager and/or colleagues.

Advice

You can:

- Consider taking time off, either as one period of sick leave, or a few days every month for a period of time. Make sure to ask your GP for a Statement of Fitness to work (Fit note), and to check with your employer your eligibility to receive Statutory Sick Pay.

- Talk to your manager and/or colleagues about deadlines and which tasks are more important and how you can manage them.
- Talk to your employer about the possibility of changing your duties if necessary.
- If you have occupational health advisors, talk to them. They might be able to help you.
- Check with your employer/manager whether there is a home-working policy at your organisation, and how this is suitable to your situation.
- Plan a period of rest after activity.

Your manager may be able to:

- Change your hours to make it suitable for your situation.
- Allow you to take short breaks to rest.
- Allow you to work from home, if possible.
- Find you less strenuous work if your job involves physical activity or heavy lifting.
- Ask your colleagues to help with

some of your work.

The problem

Talking about the illness can be very difficult and worrying. You may worry about how your colleagues will react to this information. It is fairly common that some people might choose to avoid you after your cancer diagnosis. This could be because they are not sure what they should say and are afraid of saying the wrong thing.

Advice

You can help them by opening up conversations about the illness and showing that you are willing to talk about your cancer.

However, for some people, a good way of coping is by not talking about their cancer.

You should be aware that your colleagues might realise from your behaviour that something is wrong and may feel awkward if they don't know what it is.

Generally, in case you are unable to discuss your situation with your employer/manager you can always seek external advice, such

Effects on practical issues (cont.)

as by contacting the Macmillan Support Line on **0808 8080000**, or alternatively contact your Trade Union representative.

Looking for work

If you are looking for a new job, you might be reluctant to tell prospective employers about your cancer diagnosis.

You should be aware that under the Equality Act (2010), it is illegal for employers to ask questions about a candidate's health condition during the recruitment process.

However, it is acceptable to obtain information about the candidate's medical circumstances when the job has been offered. If the job offer was withdrawn on the basis of this information, the employer will need to make sure that the reason for that is not discriminatory.

These questions should be used to ascertain your ability to carry out the job BUT not to discriminate against you.

Nevertheless, it is acceptable to gather information about your

health only for monitoring the recruitment process and for confirming that the applicant will be able to do the job.

Financial issues

Financial issues can cause worry when someone becomes ill. Many people affected by cancer report some financial implications as a result of being diagnosed with cancer.

Statutory support

Statutory Sick Pay

Everybody who pays national insurance contributions is eligible to receive Statutory Sick Pay. This should be paid by the employer for up to 28 weeks of sickness. It starts when the employee has been off work for four days and continues until a maximum of 28 weeks. By the end of this period, the employer should provide you with a form (SSP1), which explains that the Statutory Sick Pay is finishing and where to get further help and advice about benefits.

Following a full (28 weeks) period of absence, you need to be back at work for over 8 weeks

before claiming again for the full Statutory Sick Pay.

You should inform your employer about your illness no later than 7 days after you become ill.

You may be entitled to occupational or company sick pay on top of the Statutory Sick Pay. This should be stated in your employment contract. If in doubt, you should contact your Human Resources Department.

Benefits

Information about the most relevant benefits are provided in this section. However, due to the significant changes introduced to the UK benefits system, it is strongly recommended to get help from an experienced welfare rights adviser. To speak to one, you can call the Macmillan Support Line (Tel: **0808 8080000**), or your local Citizens Advice Bureau. You can also get a pack from your local Jobcentre or visit www.gov.uk/browse/disabilities

Employment and Support Allowance (ESA)

This benefit provides financial help to people who are unable to work following completion of the Statutory Sick Pay period (28 weeks). You may also be eligible if you can't claim SSP because you're self-employed, unemployed but not in receipt of Jobseeker's allowance, you earn less than the National Insurance contribution threshold or are under State Pension age. ESA also provides personalised support to those who are able to work.

There are three different types of ESA, each with different eligibility criteria:

- 1. 'New style' ESA** – to claim this you will need to have been employed or self-employed and paid National Insurance contributions, usually within the last two to three years, and now have an illness or disability that affects your ability to work.
- 2. Contribution-based ESA** – this follows the same type of criteria as 'new style ESA', but

Effects on practical issues (cont.)

you also have to be in receipt of the severe disability premium or you should have received it within the last month and still be eligible for it.

- 3. Income-based ESA** – this type of ESA is not related to your National Insurance contributions.

For 13 weeks after your claim you will receive the assessment rate and, if you are entitled to ESA, you will be placed in either the work-related activity group (up to £73.10 a week) or the support group (up to £111.65).

Disability Living Allowance (DLA)

This benefit provides financial support for people under 65, who have had difficulty walking or taking care of themselves for at least three months. These difficulties should be expected to last for at least the next six months. From April 2013, a new claim for Disability Living Allowance can only be made for children under 16.

Personal Independence Allowance (PIP)

This benefit has replaced Disability Living Allowance for adults. It provides financial help to people between 16 and 64 who have found it difficult to get about day-to-day for at least three months. These difficulties should be expected to last for at least the next nine months. This benefit is not means tested, so you could be in receipt of this benefit regardless of your income or savings.

Universal Credit

This is a new benefit rolling out across the country which replaces Income-related ESA, Income-based JSA, Income Support, Housing Benefit, and Tax Credits and unifies them into one benefit. In some areas of the country, you must claim Universal Credit instead of the benefits it replaces. For sick or disabled people, Universal Credit will usually mean less weekly income than the benefits it replaces. If you live in an area that only offers and accepts new claims for Universal Credit, but you still receive the

old benefits, you should seek specialist advice before making any new claims as it could trigger a switch to Universal Credit and leave you worse off.

For more information about Universal Credit, go to: <https://www.moneyadviceservice.org.uk/en/articles/universal-credit-for-disabled-people>

If you have been turned down for a benefit you may be able to appeal against that decision or ask for a review. This should be done within a certain time frame. This is a complicated process, so it is advisable to seek help from the above-mentioned sources.

Financial products

Some people have financial products to cover them for a "rainy day": schemes like life assurance, critical illness and occupational pension. Since each of these have different rules and operate in different ways, it is extremely important to get proper advice to find out about these policies and the best thing to do in your current situation.

For example, if there is an urgent need for money, it might be possible to take out a loan against the life insurance policy, sell it or surrender the policy. Each of these actions has significant implications on your future financial situation, so, prior to making any rushed decision, it would be useful to get advice.

There are a few sources of advice:

- The Leukaemia Care Advocacy team can provide general welfare advice about benefits and signpost to places for financial support. Call **08088 010 444**.
- For a particular financial product; the provider of the product (insurance company, pensions scheme, etc.).
- For advice about investment; an independent financial advisor (IFA).
- For debt advice; independent, free organisations, such as Citizen Advice.
- The Macmillan Cancer Support Line (Tel: **0808 8080000**).
- Find a specialist insurance

Effects on practical issues (cont.)

broker by using the BIBA Find a Broker service.

- See the specialist car insurers recommended by Disabled Motoring UK.
- If you're using a vehicle provided by the Motability scheme, it comes with insurance included.

Being diagnosed with cancer might impact the conditions of buying insurance. Sometimes, people affected by cancer face higher premiums, special conditions or refusal when buying life insurance and some types of health insurance, such as travel insurance.

Since cancer is now considered as a disability under the Equality Act 2010, an insurer can treat a client with a disability less favourably if the disability increases the risk of claiming, but only if the assessment is based on relevant information from a source that is reasonable to rely on (statistical data and/or medical reports).

Insurer decisions can be challenged, and then the insurer will have to provide evidence

to show that the decision was based on the above-mentioned conditions.

Travel insurance

Once you have finished treatment and have recovered to an extent from your experience of diagnosis and treatment, you may want to turn your attention to going on holiday. Though you have recovered from treatment and are on your journey back to recovery, you should always consider travel insurance as part of your holiday plans.

Insurance is especially important if you are travelling to a country with high medical costs, to places outside of the European Union. As you have had cancer treatment, and are recovering from treatment, you may find it harder to get travel insurance because you are perceived to be more likely to need medical treatment abroad.

If you are planning to travel, it is important you take the time to consider insurance, and the best way to cover yourself should you need any medical treatment

abroad. Some insurance providers now operate on a case by case basis instead of declining everyone who has had cancer. You may require a medical certificate to confirm you are fit enough to travel; speak to your medical team about obtaining one of these.

Many providers will only cover you for any treatment you may need as long as it is unrelated to your cancer, which could end up costing you. You will need a policy that clearly states that you will be covered should you need treatment related to your cancer. As long as you have made the insurance provider aware of your history with cancer, they know that it is possible you may need treatment because of it, and they must pay according to the policy agreement. Due to this it is important that you know what is covered in your policy.

When you first begin looking for insurance providers for quotes, be mindful that it will depend on the type of cancer you have had. Be prepared to answer questions about your diagnosis, treatment

and prognosis. Be honest with your answers and be as clear as possible about the treatment you have had, and how long you have been cancer free. If you don't, it will affect the cover you receive should you need treatment whilst you are on holiday. Insurance providers have different policies on those who have had cancer in the past; some companies need you to be cancer free for three months, some for ten years.

The best thing you can do to ensure you are getting the best deal is to shop around, and make sure you are always clear about what stage you are

If you would like further help with travel insurance, you can call us on **08088 010 444**.

at with your cancer. For more information about purchasing insurance, go to: <https://www.moneyadvice.service.org.uk/en/articles/buying-insurance-if-youre-ill-or-disabled>

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer. We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis. Helpline: **08088 010 444**
www.leukaemicare.org.uk
support@leukaemicare.org.uk

Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

NHS.UK

Aims to help you make healthier lifestyle choices regarding your diet.

www.nhs.uk/live-well/eat-well/

Keep Fit Association

A national governing body. KFA classes include teaching adults, older adults, children and seated frail elderly.

01403 266000

www.keepfit.org.uk

Change For Life

A government campaign aimed at children and families, offering a range of free to access tips, resources and tools to help support a healthy balanced diet and physical activity.

www.nhs.uk/change4life

One You

One You is a government campaign that encourages adults, particularly those in middle age, to make changes to improve their health. There is a range of free to download apps and tools covering topics including healthy eating, weight management, smoking, alcohol consumption, sexual health, mental health etc.

<https://www.nhs.uk/oneyou/>

Penny Brohn Centre

The 'Living Well' course can help you to find your own way of living well with the impact of cancer.

0845 123 2310

helpline@pennybrohn.org www.pennybrohncancercare.org

British Association for Counselling & Psychotherapy

Counselling and psychotherapy are umbrella terms that cover a range of talking therapies. They are delivered by trained practitioners who work with people over a short or long term period to help them bring about effective change or enhance their wellbeing.

01455 883300

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by leukaemia.

Around 9,900 new cases of leukaemia are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemicare.org.uk

support@leukaemicare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

