
Caring for Carers

A Guide for
Carers

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

In the journey of a blood cancer patient, you as their carer play a crucial role. However, you may sometimes feel like you are left behind, or your emotions are neglected, and all the attention is focused on the patient. This booklet is designed to provide you with support on how to deal with the emotions you may face as a carer.

A carer is defined as someone who helps another person in their day-to-day life. This could be a spouse, a child under 18, a near relative or a friend.

You may experience all of the emotions featured in this booklet, some of them, or maybe none at all. Experiences vary from person to person.

This booklet and the organisations listed in it are available to help you with whatever you may be facing.

This booklet has been compiled and updated by Amir Ziv, Marie Krnakova, Sarah Fittell, Jennifer Kelly, Dobrin Neykov and Jane Butler from Carers UK. We are also grateful to carers David Pyle, Lisa Goodall and Paula Batman for their valuable contributions as patient reviewers.

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

In this booklet

Introduction	2
In this booklet	3
About Leukaemia Care	4
A note from the Patient Advocacy team	6
Feeling anxious?	8
Feeling stressed?	12
Placing the blame	16
Feeling scared?	18
Feeling lonely?	21
Feeling guilty?	24
Feeling angry?	26
Dealing with practicalities	29
Useful contacts and further support	34

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 Monday – Friday 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.

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: **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.

The title of 'carer' can evoke some very strong and unknown feelings. Someone you care about and love, whether they are your husband, wife, child, family member or friend, has been diagnosed with a potentially life-changing condition. Your first reaction may be to protect them, to shoulder their worries and feelings. But what about your feelings? You will possibly go through the same feelings as the person diagnosed; the rollercoaster journey will have an effect on everyone.

We know that sometimes as a carer you can feel overlooked, as a lot of the attention is directed towards the patient. You may have a variety of emotions and feelings, which you may question, or are unsure of.

In this booklet, we have explored some feelings that carers may experience, and may feel that they need some support with.

Please keep in your mind that everyone's experience is different,

and you may find some sections more helpful than others.

While reading this booklet, you will notice that we sometimes refer to the person you are caring for as the 'patient'. We find this a term that is both friendly and commonly used; however, you may refer to them as something different.

"There is no clear template for carers; it depends on the individual and their situation."

"Our experiences have strengthened us and we can understand the anxieties that carers especially go through."

We have been in contact with a number of carers and patients whilst developing this booklet, to make it as helpful for you as possible.

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 emotional support, which is what we provide in this booklet. We have offered some signposting to other organisations that can also give you practical advice tailored to your exact situation.

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**. A member of the Patient Advocacy Team will be ready to answer your call. Likewise, if you just feel the need to chat, call us on the above number. We are always here should you need someone to listen.

All the quotes in this booklet have been supplied by carers and patients listed below:

Mr Dave Lees

Mrs Suzanne Filson

Ms Donella Meade

Miss Suzanne Harriss

Mr Steve Mcginley

Mr John Watson

Mr Kenny Birney

Ms Elaine Young

Mr Richard Sizeland

Mrs Sally Sizeland

Mr Stuart Johnston

Mrs Madeline Sadler

Mr Jody White

Mrs Trixie Thompson

Mr David Pyle

Mr Chris Lewis

Feeling anxious?

Anxiety can be confused with other emotions, like depression. Anxiety is a feeling of fear and concern (fear, however, is characterised as a dreaded feeling about something which appears intimidating, or is a real danger). Anxiety is the paranoia of something that seems scary but may not be. It could make you feel uneasy, concerned, or make you worry. Many people may experience an element of anxiety in their lives, perhaps before an exam or job interview.

As a carer, you might often face the feeling of anxiety. The experiences you face in your day-to-day life might make you worry, or feel concerned. This is completely valid; being a carer can present a lot of challenges, and new circumstances, that you have to deal with. Sometimes you may be facing these alone, or you may feel like you have to be the 'expert' on the healthcare of the patient. You must remember that doing your best is all those around you can ask from you, and it is perfectly acceptable to not know the answer yourself.

Feelings of anxiety may distract you from your everyday life; people who are anxious often have a feeling of dread that is

difficult to get rid of. This feeling of dread may prevent you from thinking about other things, and may preoccupy your thoughts for most of the time. You may find it difficult to sleep or concentrate, or it may simply tire you out.

It is important that you consider why you feel anxious; is it because of the treatment the patient is on, and its potential side effects? Or perhaps it is because you are planning to leave the person you are caring for with a trusted person whilst you take some time out? Maybe it is because you are thinking about what the future could hold for you and the patient? Whatever the reason may be, if you try and pinpoint what it is that makes you anxious, it will

be easier to calm these feelings.

There are many practical things you can do to calm feelings of anxiety. You could try lots of different things in order to find something that works for you.

Relaxation

Calming your thoughts can be a great way to relieve anxiety. Learning good breathing techniques, or even taking up yoga or pilates can help calm you down, and keep those feelings of anxiety under control. Mindfulness techniques are another way of relaxing; they can help you unwind and de-stress. There are many classes across the UK (www.bemindful.co.uk), or you could try the techniques in your own home.

Mindfulness

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 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.

Allow the breath to settle down into its natural rhythm and trust 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

Feeling anxious? (cont.)

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 don't think relaxation techniques are right for you, why not simply just take time out from the hustle and bustle of everyday life, and allow yourself time for a hobby, or just time to think.

This could give you the space you need to step out of the anxious situation and calm your thoughts down. Moving about more may help you to feel calmer.

You don't have to join a gym to get some exercise; you could buy an exercise DVD or take walks to also get some fresh air. You should not feel guilty about taking this time for your own wellbeing;

everybody needs time out at some point, especially when caring for somebody who is ill.

"Make time for yourself so that you keep yourself well; don't feel guilty for doing this."

Diet

Monitoring your intake of certain foods can help reduce anxiety levels. If you take in a lot of caffeine, you may want to consider reducing it because it can stop you from sleeping.

Alcohol can also increase anxiety.

"Try to stay as normal as you can, and keep life normal."

It might also help you to try and rationalise what you feel anxious about. Thinking about why you feel concerned or are dreading a certain upcoming event may help you see 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 though can help calm you. For more information on

anxiety, take a look at www.nhs.uk/conditions/anxiety

"As a patient I found that my husband didn't talk about how he felt. I know this was because he didn't want to worry me. I am sure this is very common."

Anxiety can often subside when you know how to make yourself feel better, or when the event you were anxious about has gone. However, if your anxiety becomes overwhelming, this could be classed as a generalised anxiety disorder (GAD). GAD can have much more of an effect on your body and mind. You may be restless, irritable, impatient, or have a constant feeling of dread. You may also experience dizziness, pins and needles, an irregular heartbeat, nausea and other physical symptoms. If you experience any of this, you should consult your doctor as soon as possible.

"Anxiety can remain at low levels and is perfectly normal, it will come and go. If you find this not to be the case then talk about it and get help."

Feeling stressed?

Much like anxiety, stress affects lots of people in different ways. It is a fact of life for many people. However, this doesn't mean that you have to live with the effects on your body and mind that stress can cause.

Caring for somebody can present lots of difficulties, challenges and hard times, as well as happier and easier periods. These hard times can affect you in a variety of ways, and one of these can be stress. Feeling under stress usually means that you are feeling like there is too much pressure on you. It may also feel like you are unable to cope, and too many things are mounting up too quickly. For you as a carer, this might be due to looking after the patient as well as juggling responsibilities in your own life, or supporting others that may depend on you, such as children.

Feeling stressed can be a debilitating emotion to live with. Feeling like there is too much to do could stop you from doing any of it at all. It is common to have a feeling of 'not knowing where to start' when you feel stressed. Perhaps the mounting dependence of the person you are caring for, coupled with supporting others who may be affected with the diagnosis of the patient, as well as perhaps trying

to juggle a work/life balance is what is making you stressed. Or it could simply be doing the washing, ironing, food shopping and remembering to make good time for hospital appointments. Maybe you feel stressed because of the emotions you feel as a carer, some of which may be in this booklet.

Regardless of why you feel stressed, it is a valid feeling to have, and there are ways to cope with it. Knowing what is causing you stress will help you learn to deal with it quickly, before it causes you too many further problems. There are techniques you can try to keep your stress at a minimum.

NHS Choices list the ones below:

Be active

Adding exercise into your routine can help you step away from your situation, have some time to yourself, and release some of the emotional intensity that comes with stress. As a carer, with your additional responsibilities, you

may find it hard to find time for this. However, it is important you maintain your own wellbeing, so why not ask a trusted friend or relative to take over your duties for a couple of hours a week? Do not feel guilty for doing this; you can only do your best as a carer when you are healthy and well.

Share your situation with others

As with a lot of emotions that you may feel, it often helps to share your feelings of stress with others. Finding time to spend with family and friends can help you see things in a different way.

Be positive

This can be easier said than done. Sometimes, you might feel that a lot of things are against you as a carer, and you struggle to see what positive things are happening in your life. But even if you can note the smallest of things that might have happened in the past week which are positive, it can help you feel better. Perhaps you had a particularly nice evening with the person you care for, or maybe

somebody made you laugh.

"I found the days hectic and tiring: all the normal chores to do, walking the dog twice a day, going to work, visiting the hospital at least twice a day, finding a parking space, having the right coins etc. In the evening, the phone would ring and it would be relatives and friends asking how [the patient] was. This was the time to unload the day's problems and tell someone. I used to think that it would be good to have someone to do the chores for me, but they were the things that kept me busy, kept things ok."

Whatever it may be, it is important to notice the occurrences in your day-to-day life that make it a little easier.

"Plan trips for when the patient is well. This can help you keep positive. You can also encourage the patient to be involved in planning future events like decorating the house."

Accept that some things won't change

For some, this may be particularly hard. As a carer you may be always

Feeling stressed? (cont.)

working hard to make things better for your patient, and you may always hope that things will get better. Accepting that some things won't change is not defeat, neither should it be pessimistic. However, accepting that the person you care for may not, for example, be able to cook for themselves for a long time may stop it from triggering stress. Concentrate on what you can control; for example, you could make cooking meals easier by freezing a batch, or ordering a takeaway every now and again.

"Laughter, also known as the antidote to anxiety, is a fabulous counter to stress and related very close to crying. I remember doing a great deal of that and it can stop you from exploding."

Stress can not only make your thoughts feel like they are going into overdrive, but can also have an effect on your body. You might struggle to sleep, concentrate, and keep calm, and you might find yourself thinking a lot of the time, mulling things over and experiencing things such as headaches. It is really important that you try and find a way to manage your stress; maybe one of

the above tips will help you do this.

You will not be helping yourself, or the person you care for, by letting your stress get worse, and in turn letting its side effects get worse too. Maintaining your health is very important, and you should not feel guilty for thinking of ways to make yourself feel better.

A new normal

When the person you're caring for reaches the end of treatment, this can bring a whole set of new challenges as you both begin to recover from the physical, practical and emotional demands that the treatment brought. It will probably feel like a relief that the treatment has ended even though there may be ongoing side effects to deal with. Supporting your loved one through treatment can take up all of your energy and it is only when it has stopped that you may begin to deal with the emotional impact of it all. You may expect your loved one to feel back to normal once their treatment finishes, but their body and emotions need time to recover and to work through all that has happened. They may have gone through treatment with the goal

of getting their life back to normal. Now, it is not so much 'getting back to normal' as finding out what is normal for you now, your 'new normal'.

The impact of leukaemia is not something that can be forgotten or left behind but needs to be incorporated into your life story. This is a process that takes as long as it takes and can't be rushed, no matter how impatient you feel to leave the illness behind.

Your life may have a very different outlook because of your loved one's leukaemia and you may be faced with making difficult adjustments. Continue to seek support from those close to you. You might find that making decisions and plans with your loved one and those around you helps you feel more prepared for what the future may hold.

We can put you in contact with somebody who is going through a similar situation to you via our buddy support - call **08088 010 444** or email **support@leukaemiacare.org.uk** for more information.

Placing the blame

Your position as a carer can carry some very heavy responsibility and can cause many of the emotions in this booklet, and perhaps some other feelings too. You may want to try and find a reason for why you are a carer, and why the person you are caring for has been affected by cancer.

Placing the blame is a perfectly natural reaction to the feelings of anger, sadness or stress that you may feel. Many people feel the need to place blame in many different situations, and as a carer you might feel this need quite strongly. Finding someone or something to place the blame on may give you a direction to target your anger or sadness, and allow you to feel better for a short while.

Perhaps you feel that trying to place the blame would help you make better sense of the situation you are in as a carer, and perhaps of the person who you are caring for. Maybe you feel as though it would help you get over your situation and find dealing with it easier.

Cancer happens for many reasons, many of which cannot

be explained by us or even by a medical professional. It can affect people completely at random, for no reason. Whilst this may not make you feel better, it might help to know that the person you are caring for, and yourself, are not being targeted in any way, and have done nothing wrong. Due to this, trying to find someone or something to blame is very difficult, and may make you feel even more angry or frustrated.

It may also have negative effects if you blame somebody who is not to blame. It may cause friction with family members or friends. This is where placing the blame can have detrimental effects, and it may upset others. It is important you try to accept that sometimes, there is no answer for certain circumstances in life.

"It is important to have people around

you that can be 100% honest, perhaps not family as they can be too bound up by emotions, but perhaps friends."

If you are finding it difficult to move away from trying to place blame, it might help to talk to your patient's medical team to understand as much as you can about the cancer.

This may help you to see why cancer has affected the person you care for. Remember only to take on as much information as you feel comfortable with, and stop your medical professional when you do not need any more information.

"Researching the condition to increase understanding is excellent, to enable the carer to ask about new drug trials or treatments or even a referral to a specialist centre."

Always get as much information as you need from responsible sources

Looking for information can be a difficult job to undertake. Ask your medical professional, or go to one of the sources in the back of this

booklet.

Share your concerns

You might find talking with your friends and family helpful, as they may be feeling the same. Talking through your situation, and the situation of the patient, with those you trust may help you make sense of the circumstances, and understand that placing the blame may not be the answer.

"Nobody was to blame. It is part of life's lottery. If you look to blame someone or something then you miss the problem. All diseases cause a wide range of emotional stress and trauma. A neutral perspective will help to keep things in balance. The sooner you accept what is going on, the sooner you can provide the help that is required. This is a two-way street that benefits both the carer and patient."

Feeling scared?

Fear is often a feeling felt by the patient; they can be scared of what may happen during treatment and afterwards. They may even fear the unknown. However, as a carer, you may also share these fears, as well as have ones of your own.

Fear can be a very unsettling feeling if you are not sure why you feel like this. Could it be because you are worried about how to care for the patient, or maybe that you might hurt them physically when you are trying to support them? Or perhaps you have the same fears as the patient; a fear of the unknown, or a concern about how treatment might affect them. Are you fearful when you leave them with somebody else, do you fear hospital appointments, or do you fear that you may not be able to cope with any side effects the patient may have?

Living with a loved one who has a diagnosis of blood cancer can be filled with fear, whether you are their carer or not. Cancer can be a scary subject to talk about and understand, as well as all the other practicalities that come along with it. You may need to take time to think about how

much information you want to take on; some people like to know as much as possible, but some people become more fearful the more they know.

It is best to avoid searching the internet when you have questions about treatment, and instead stick to well-known websites and information booklets. If you do search the internet, some of the information may not be relevant to you, and you could come across some negative content that might fuel your fear even further.

"My carers read lots on the internet, and something they said when I spoke to them was to only read information from official sources. They found a lot of websites terrifying!"

As a carer, you may have some extra responsibility. You may want to know as much information as possible in order to care for the patient as best you can. This

might make you feel scared. It is best to be completely honest with the patient's medical team and ask them as many questions as you can to reduce these fears. Often, there will be ways of dealing with, for example, symptoms and side effects.

If you are unsure of the unknown, asking your medical team for more information will lessen this feeling.

"Fear, I was taught, was perfectly normal, and designed to feed on the unknown. Knowledge dispels fear."

If you are worried about hurting the patient, express these fears to the medical team. They will be able to prevent you from doing this, and share tips on how to best care for the patient.

"We had total faith in the doctors and medical staff. We followed their advice in every way based on the fact that we knew nothing about what was going on inside our bodies, but they had years of experience in treating cancers like ours."

Fear can also stem from what might happen to the person

you care for in the future. You may create a close bond with the person you care for, if you were not already close before the diagnosis. To be fearful for this person's future is normal, especially with something as potentially scary as cancer. Maybe you could share these fears with the patient, as they may be feeling the same. Sometimes it can feel like a weight has been lifted off your shoulders if you share this fear you have for the future.

Alternatively, you may not feel comfortable talking this over with the patient, and instead would like to share your feelings with somebody else. You could talk to a trusted friend or relative, or you could seek a person who is outside of your loved ones. You could try an online forum where you might find others who are going through a similar situation, such as the Carers UK forum at www.carersuk.org/forum. Alternatively, we have a freephone helpline should you need to talk to somebody; call **08088 010 444**.

As a carer, you have to take on a lot more responsibility than

Feeling scared? (cont.)

others that may be in contact with the patient. It is only natural to be scared of numerous different things and the best way to deal with this is to talk with others. Here are our key ideas for calming any fears you may have:

- **Share them** - Whether that may be with the patient, medical team or somebody outside your family. Counsellors are also available if you would rather speak to someone unconnected to your situation.

"Consult other families for mutual support. Talking to families who have been through similar experiences (with positive outcomes) is reassuring."

"Don't be afraid to call on extended family for support. "

"To be able to tell someone all about the issues and get a bit of sympathy or an encouraging word is worth a great deal."

- **Learn from your medical team** - Taking on a lot of information can be scary, but there is often good advice that can be taken from the medical team so you don't feel so worried.

- **Break down your fears into manageable chunks** - Dealing with one fear at a time will help you to move forward. This may also help you understand your fears, and help you feel better. There may be many reasons why you are scared; all of them are completely normal.

"My carer suggested that her job, or routine, was a real help... something to immerse herself in, so there was little time to think or dwell on my illness."

Feeling lonely?

As a carer of somebody who has been diagnosed with a blood cancer, you may feel that a lot of the attention from medical professionals, family members and friends is being directed towards the patient. Maybe you rarely get asked ‘how are you?’ as many people around you may be concerned about the health of the patient, and just expect you to cope.

When you are a carer, your life may revolve around the patient. From first thing in the morning to last thing at night you may be supporting the person you are caring for, and helping them have the best quality of life possible. Even if you are not spending all day with this person, chances are you spend a good chunk of your time thinking about them.

"There is a total overwhelming feeling of helplessness and being out of control of your normal everyday life but having to carry on regardless for everyone else."

Due to this, feelings of loneliness may also come from the lack of ‘me time’ you may have. It is important for everyone to think of themselves from time to time, and consider how you are feeling.

You may also feel lonely because

of the unknown; it can be very difficult to relate to the person you are caring for because you don't know what their illness feels like. You may even feel like you can never do enough because you can't know how they feel, or even if they are being completely honest with you.

"It can be harder for carers to cope with the cancer journey than it is for the patient; after all the patient knows exactly how they feel; it is their cancer. You, however, can only guess as to what is being felt. The unknown can increase any sense of isolation further with the very person you care for so very much."

Loneliness can also stem from the lack of time you have to see your family and friends. When you do see friends and family, you may find that discussion is steered towards the patient, as the people

Feeling lonely? (cont.)

around you are understandably concerned about their health. You may even find that some friends, and perhaps family, do not come to see you as often as before you were caring.

"Carers need someone to talk to because friends can desert you, mainly because they don't know what to say."

Feeling lonely is a normal reaction to all of this, and it is important to recognise that how you are feeling is perfectly normal and valid. Whilst you love the person you are caring for, you need time to be your own person outside of your carer role. This is not selfish, but something that every person needs, regardless of the roles in their lives.

It may not be loneliness that you feel, but perhaps isolation. Maybe you feel disconnected from the world around you, or the life you had before you became a carer. Your priorities may have changed since you started caring, and the hobbies or free time you once enjoyed may be now taken up by the person you are caring for.

You may even feel that those

around you perceive you differently and see you now as a carer, and may have forgotten the interests you used to have that defined you as an individual.

"Being out of control of your normal everyday life, but having to carry on regardless for everyone else - this can lead to overwhelming isolation."

Again, this is nothing to be ashamed of, and it does not make you a selfish person to feel this isolation. It is important you recognise your feelings so you can address them. It is not healthy for you to ignore these feelings, and it will not help your patient either.

Once you have understood what exactly is provoking your feelings of loneliness or isolation, it may be worth taking time to see if you can make things better. Maybe you need to make time for a bit more of a social life, or maybe you need to develop relationships with others who may share your feelings, so you can offload to others.

If you miss your social life...

Why not think about taking a

small amount of time out every week to see friends? You could ask somebody you trust to look after the patient whilst you do this. If you find your friends are keen to talk about the patient, why not let them know that you are looking for some socialising away from your duties as a carer?

They will be happy to be able to support you in this way.

If you need to share your feelings of loneliness or isolation...

It might be good for you to develop relationships with people who are going through a similar experience. Carers can support each other in a similar way to how you are supporting the person you are caring for. Why not try an online forum? Carers UK has a good forum if you wish to share your thoughts and feelings in this way (www.carersuk.org/forum). This may alleviate some of your loneliness.

"Men and women differ... in their communications, and sometimes it is harder for men. It's kind of tough male blockage."

If you need time to yourself...

Though you may be feeling lonely, time to yourself might help you feel better. As we have mentioned, loneliness or isolation can stem from feeling disconnected from yourself and the world around you.

Indulging in what you enjoyed doing before caring may help you feel grounded again, and give you time to think outside of your caring duties. Getting out of the house might be key to this; or maybe you just need to pick up your hobbies again. Why not ask a trusted person to look after your patient for just an hour a week, leaving you some free time to think outside of caring?

These are just some ideas, and maybe you have thought of a few of your own. There is no right or wrong way of alleviating feelings of isolation or loneliness, but it is important to consider ways of doing this. Addressing these feelings will enable you to be happier in your role of caring.

Feeling guilty?

You could be feeling guilty for a number of reasons, and it could stem from other emotions that you are experiencing.

Perhaps you have been feeling one of the other emotions in this booklet, and maybe this is making you think about your role as a carer. Maybe because you are feeling lonely, angry, or another negative emotion, you are questioning how happy you are as a carer and this might impact on the way you feel or think about the person you are caring for.

You may feel guilty for even thinking of yourself when you can see what the person you are caring for is going through. Maybe you find your mind wandering to your own feelings when you are with the patient, and away from thinking of how the patient may be feeling.

"Life goes on all around and everyone else is oblivious to the trauma you are going through. As hard as you pray or wish or bargain, it will be your loved one and not you that will be going into battle. Hello and welcome to guilt."

Alternatively, you may be thinking

of the patient, but maybe these are negative thoughts. You might resent the patient for relying on you, or you might even resent them for not thinking about how you are feeling. These thoughts of resentment might make you think you no longer want to be a carer.

This can then quickly turn to feelings of guilt.

"I sometimes found it difficult to keep my mental focus on the events during the day at hospital. This made me feel enormously guilty. My unconscious mind was looking for distractions, probably in an effort to keep me sane and positive."

Perhaps you feel like you can't do enough.

"I felt that my pathetic input was pretty useless. This I found out was quite common with carers and can lead to greater feelings of guilt. You can only do what you can do, that will be understood. Talking about how you feel, not just to your loved one but to someone who can listen well and be

empathetic, will help and you will find strength. You will have automatically underestimated your value as a carer; you're not the first and won't be the last."

The best thing to do if you are feeling guilty is to try and pinpoint why you may be feeling like this. Is it because you resent the person you are caring for, or do you feel bad for giving yourself time to think about yourself? Understanding why you feel this guilt is important for you to overcome this feeling, and become more comfortable in your role as a carer.

Feeling guilty is a perfectly valid emotion; many people feel like this when they experience a negative feeling towards somebody who may have done nothing to warrant it.

Your role as a carer is a very important and special one, and as much as you can do is completely enough. You must remember to credit yourself with the good job that you are doing, and that your best is all that the patient can ask for.

"It was very hard for my carers when they were unwell and had to stay away from me because of that. They felt guilty that I would be on my own."

Talk to others close to you

It might help to share your feelings of guilt with other people close to you who have experience of your situation. You will find that they may also feel guilty, or they will be able to show you why you shouldn't feel guilty.

Accept that some things are out of your control

You must accept that it is not your fault. You should only do as much as you can, when you can. You cannot control why the person you are caring for has cancer, you can only do your best to care for them. If you are able to accept this, you will find your feelings of guilt will ease away.

Feeling angry?

Anger can be a difficult emotion to make sense to somebody, or to try and address. It is essential that you are completely honest with yourself about why you may be feeling angry, before you can think about moving on from these feelings.

Perhaps you could sit down and consider when you feel angry, and what might have triggered it. You could note down what happens when you get angry. Whatever your way of addressing why you are angry, knowing the trigger is the best way for you to try and calm these feelings down, and finding a good way of dealing with them when they do arise. Always remember that anger is part of everybody's life, and is completely natural.

Anger can be a common feeling for many carers, especially when there are any unanswered questions, and both the carer and patient suffer from high stress levels. You may be angry because of the situation the person you are caring for is in. Maybe you question 'why him/her?' and are angry because there seems to be little answer for this.

It is common for carers to feel frustrated that the person they

love is going through a diagnosis and treatment of cancer; however, there is rarely an answer for this that will satisfy you. An illness like cancer will usually affect people at random, and it can feel very unfair. It is likely that others around you may have similar thoughts, so don't feel ashamed for thinking it too, and talking about it.

"Cancer at the moment is a very random illness. We meet people from all walks of life with cancer."

On the other hand, you may, as a carer, think 'why me?' and wonder why your life has also been affected by the patient's diagnosis. You may feel confused, or you may seek an answer by questioning what else you have done in your life. As we mentioned above, cancer affects people largely at random, and it is important to remember that you shouldn't try to pinpoint something you have done as the

reason why you are a carer.

"When someone close to you gets cancer, the natural questions are: Why? Why us? Why now?"

In these circumstances where you are questioning why cancer has come into your life, it might help to speak to a medical professional who can shed some light on the medical reasons why the person you care for has cancer. Please remember though that they can only tell you as much as they know; sometimes cancer cannot be attributed to a certain aspect of a person's life, and may be completely by chance.

Perhaps you feel angry because of smaller, everyday instances, such as questioning why the person you are caring for cannot do certain tasks themselves. This might be a result of stress that you are already feeling, which has developed into anger. Consider why you are stressed, and why it is developing into anger; maybe you could consider some of the de-stress tips in our 'feeling stressed' chapter to help you unwind and prevent anger from developing.

Whatever the reason for your feelings of anger, you should try not to bottle it up. If you feel angry, try to let it out, and perhaps talk it over with someone. Keeping it to yourself could mean that you end up targeting somebody who may not understand how you are feeling. It may also mean that you become even more angry than you were before. As you begin to learn what may be triggering your anger, you can learn to deal with it in the healthiest way possible.

Relaxation

Concentrating on your breathing is a good technique for when you begin to feel angry, as it gives you a chance to calm down. Perhaps you could also try listening to calming music, or counting to ten. Yoga and meditation can be a long-term way of dealing with anger. For more information about this and mindfulness, go to page 9.

"What, if and when also come to mind when you talk about anger and being angry. The important factor here is to keep things in perspective and in the present. Live for the moment and not in the past or future."

Feeling angry? (cont.)

Look for information from reputable sources

If you feel you need more information in order to feel less angry and to understand your situation, always make sure you go to responsible sources. Your medical professional is a good starting point, and we have listed some organisations at the back of this booklet.

"My advice to those who find themselves caring for someone with cancer:

- *Make plans. Big plans. Even when things look bleak making plans for the future: holidays, new house, car etc, provides both a distraction and hope for the future. Hope breeds success and everything you do as a carer must be centred around helping the patient to a successful outcome.*
- *Trust the doctors and nurses as they know exactly what they are doing. Placing trust in them takes pressure off you as a carer. You cannot control everything.*
- *Take care of yourself. You have to make sure that you, as a carer, stay*

healthy and rested. This will seem to you as a selfish thing to do. It's not, you have serious obligations and responsibilities to someone else and you must do everything you can to keep yourself in a condition to meet them. "

Dealing with practicalities

As a carer, you may not only face emotional obstacles, but also practical and financial issues. In many cases, you may have to combine working and earning an income with your role as a carer. This section focuses on your legal rights as a carer.

Who is a carer?

Someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally or through a voluntary organisation.

A carer is someone who cares for:

- Their spouse (husband, wife, partner or civil partner)
- A child under 18 years of age
- Someone who lives at the same address as the carer
- A near relative (parents, parents-in-law, adult children, adopted adult children, siblings, brother and sisters-in-law, uncles, aunts, grandparents and step-relatives) or friend.

Financial support

Being diagnosed with cancer can be expensive for both the person you care for and for you. There can be extra costs when caring for someone with cancer: (1) additional costs of travel to hospital, car parking, eating out, etc. and (2) income reduction as a result of reduced working hours and/or giving up work all together.

The following information summarises the help available to you:

Carer's Allowance

To be eligible for this you must look after the person for at least 35 hours a week, be aged 16 or over and not in full-time education. The person who is being cared for must be getting one of the following:

- Disability Living Allowance at mid care rate or above
- Attendance Allowance
- The daily living component of Personal Independence Payment (PIP)
- Constant Attendance Allowance

Dealing with practicalities (cont.)

at the normal maximum rate paid with the Industrial Injuries or War Pensions schemes

- Armed Forces Independent Payment

They must also not be in gainful employment, which is defined as earning more than £116 per week (as of April 2017). Pension income doesn't count towards the earnings limit. If you are getting a State Pension, then you might not be able to be paid Carer's Allowance at the same time, but you might be able to get an underlying entitlement to Carer's Allowance which can influence other benefits.

Another thing to note is that receipt of Carer's Allowance can affect the benefit entitlement of the person being cared for, so it is best to check with a benefits specialist first or go to www.gov.uk/carers-allowance for more information.

Independent Financial Advice

Another source of support and advice is an Independent Financial Adviser (IFA). These advisers can help you in

assessing your financial situation and recommending the best course of action. Such advice pertains to financial products e.g. investments (not to be confused with welfare benefits advice), and would refer to people with disposable income who are looking to buy a financial product. There are also Independent Financial Advisers who focus specifically on care funding advice.

You can find your local IFA by contacting the Personal Financial Society, the Independent Financial Advisers Promotions Ltd. or take a look at www.unbiased.co.uk. For welfare benefits advice, you can refer to your local Citizens Advice Bureau, Macmillan or get in touch with your local carers service which can be found at: www.carers.org/search/network-partners

Other Advisers

Specialist care fees advisers have particular qualifications (CF8 and CeLTCI) that demonstrate their understanding of the many issues you might have to consider when it comes to funding long-

term care. You can use The Money Advice Retirement Adviser Directory to find a specialist care fees adviser in your area.

You can also visit the Society of Later Life Advisers (SOLLA) website. SOLLA advisers undertake extra training and professional development before becoming full members.

Business finances – Self employed

Self-employed carers might have more control over their working life, but unfortunately fewer rights and protection than a person who is employed. There might be three scenarios, which will require some considerations:

1. If you plan to carry on working as usual on top of being a carer, you should be aware of the extra pressure on you and your family and be realistic about your business demands and your finances. A good source of advice is the GOV.UK website: **www.gov.uk/business**. This is the government's online resource for business.
2. If you plan to temporarily

or permanently reduce your working load, this can have a big impact on your financial situation. You may have to think about your cash flow, how to plan the business finances and how much money you have available to meet your business expenses, including your personal income. A good source of support is your own accountant and/or bookkeeper, if you have got one. If you do not have one, it might be a good idea to find an accountant who will save you more money than you pay him/her. Your local Chamber of Commerce might be able to provide you with a list of providers of these services. Furthermore, the GOV.UK website: **www.gov.uk/business** or the Institute for Chartered Accountants (ICAEW) website: **www.icaew.com** might be helpful in your situation.

3. If you decide to give up work completely you need to be aware of the financial implications of this move. Further information and advice can be obtained from the Macmillan Support Line

Dealing with practicalities (cont.)

on **0808 8080000** or **www.greatbusiness.gov.uk**

Legal rights as an employee

If you are employed and have become a carer, you should be aware of your legal rights. Information about your employment status can be found here **www.gov.uk/employment-status**

As of June 2014, you don't have to be a carer to ask for flexible working. As long as you have worked for the company for at least 26 weeks, you are entitled to apply (one request a year) to make changes to the terms and conditions, permanently or temporarily. This is based on the Work and Families Act 2006 and the Employment Rights Act 1996.

Flexible working arrangements include:

- Flexible starting or finishing times
- Working from home
- Working your normal number of hours in a shorter time

- Job-sharing or working part-time
- Flexible holidays to fit in alternative care arrangements

Requests for flexible working arrangements should be approved by the employer. The employer can refuse a request if he/she feels it is not in the best interests of the business. In that case, the employee has the right to appeal this decision. The appeal has to be made in writing and within 14 days of the refusal decision. Sometimes the employer is unable to accommodate the request for flexible working, but a compromise might be reached. In this case, it is strongly recommended to get advice and support from a union representative or the human resources department.

Furthermore, you have the right to take time off to look after a dependant (i.e. mother, father, son, daughter, spouse or civil partner, or anyone who lives with you, other than a tenant or lodger) in case of emergency. This is known as 'time off for dependants.' These include:

- The person cared for becoming ill and/or admitted to hospital
- A breakdown in current care arrangements
- The need to make longer term care arrangements

In most cases, one to two days is the likely amount of reasonable time you will be given. You may not be paid for this time off but you should check with your employer to see what their policy is. These rights are covered by the Employment Rights Act 1996, which was amended by the Employment Relations Act 1999.

In general, if you feel that your employer behaves unreasonably and unfairly you might consider lodging a formal grievance.

A staff or union representative might provide advice on your grievance policy.

If you find your employer's dealing of the grievance unreasonable, you have the right to complain to an employment tribunal.

If you are considering taking a complaint to an employment tribunal, it is strongly

recommended to get advice from a union/representative, or a solicitor specialising in employment law.

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.leukaemiacare.org.uk
support@leukaemiacare.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

Carers information

Carers UK

Carers UK is a charity set up to help the millions of people who look after an older, disabled or seriously ill family member or friend. Carers UK provides information, advice and support for carers.

0808 808 7777

www.carersuk.org

Carers UK: **020 7378 4999**

Carers Northern Ireland: **02890 439 843**

Carers Scotland: **02920 811 370**

Carers Trust

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

0844 800 4361

www.carers.org

info@carers.org

Carers Scotland: **0141 445 3070**

Carers Wales: **02920 811 370**

Carers Direct

Free, confidential information and advice for carers.

0300 123 1053

www.nhs.uk/carersdirect

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 a 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

