

Managing the Stress of Cancer

BY

Dr James Brennan
Consultant Clinical Psychologist
Bristol Haematology and Oncology Centre

First published in *Cancer in Context*
- *A practical guide to supportive care.*
Oxford University Press, 2004



3.05

please read this first...

“All experience is an arch to build upon.”

This booklet is based on many people's experiences. Most of these people have attended the Bristol Haematology & Oncology Centre and have told me what it was like for them to have cancer. I have also read about and conducted research in the field of cancer care.

The booklet is an attempt to combine these two valuable sources of information in the hope that it might help you. Please pick and choose the bits that you feel are useful. No booklet can address the needs of everyone, and it is far easier for me to write about what may help than for you to have to put these ideas into practice. Nonetheless I do hope that you find this booklet helpful.

Although it has been revised in the light of feedback, I'd still like to know more about which parts of the booklet are helpful and which are not. If you could find the time to complete the short questionnaire at the back and return it to me I would be very grateful.

Dr James Brennan
Consultant Clinical Psychologist
Bristol Haematology & Oncology Centre

Managing the Stress of Cancer

For many people, having cancer is one of the toughest experiences they will ever have to face. There's probably no getting around this. The months following a cancer diagnosis can be a very stressful time, not just for the person with cancer, but for anyone who cares about them.

It can be a time of many changes from the way people normally live their lives, even though some of these changes may turn out to be positive in the long run.

This short booklet will try to help you make sense of some of the changes and feelings you have had, and to persuade you that you are not alone - other people may have experienced similar changes and feelings.

information

The doctors have told you about your particular illness and how they are planning to help you. If you want to know more, or haven't understood what you have been told, then you should certainly contact the medical team who are treating you. You should always have exactly as much information as you feel you want and the doctors will always be happy to provide it. Of course, it's important to remember that only you know when and how much new information you are ready to learn. Cancer and its treatment is often very complicated and it can take a long time to understand everything about it. It may help to write down your questions before seeing your doctor, and it's often good to have someone with you to help remember the things that are discussed. It's easy to forget details when you are stressed, so don't feel embarrassed to ask the same question twice!

General information about cancer and its treatment can be obtained from the Cancer Information and Support Centre in the Main Entrance of the Bristol Haematology & Oncology Centre (*open Monday to Friday 9am - 5pm*). The Information Centre is staffed by trained volunteers, all of whom are ex-patients or carers themselves. They can help you find the information you want and offer you support if you wish to tell them about your experiences. The volunteers are all trained and supervised by a permanent member of staff and can provide a safe place to talk for anyone who needs it.

Cancer treatments can certainly seem complicated at first but the truth is that people's lives are often a lot more complicated. Each of us has a unique life story and our unique combination of family and friends, and every one of *them* has their own particular life story to tell. It's not surprising therefore that people have very varied reactions and feelings in response to cancer, whether they are a relative, friend or the patient themselves. This booklet is about some of the main feelings and thoughts which people describe during the ordeal of cancer.

getting around this booklet...

The booklet is divided into short sections. It is intended to be read straight through, but if you want to jump to particular sections here is where you will find them:

1.	shock and stress	6
2.	out of control	8
3.	who am I now?	10
4.	feeling overwhelmed	13
5.	think about this	14
6.	taking control	15
7.	how to worry	16
8.	getting on with living	18
9.	other people	19
10.	advice for couples	21
11.	finishing	22

shock and stress

Finding out that you have cancer is a series of events that you will probably remember forever. You found something, or felt it. It seemed odd. Some time later a doctor looked at it. The doctor asked you to have some tests. Later they said that you had cancer... but, of course, it's never quite that simple.

It is often a time which leaves people with many questions, both about the way in which the diagnosis came about as well as the speed with which this happened. Although many doctors do it well, almost all would agree that informing someone they have cancer, is one of the most difficult jobs they have to do.

The reason it's so difficult is because the first thing most people think when they hear the word "cancer" is that they are about to die. For some this is tragically the situation. But, unfortunately, this still seems to be the public's *only* view of cancer, in spite of all the extraordinary medical advances in its treatment over the past few years. So it's not really surprising that people often remember the "day of the diagnosis" as the most frightening day of their lives.

"It felt like a bad dream. One minute life was chuntering on. The next – well, someone switched the reels, the road forked and I didn't notice."

Some people describe the day of their diagnosis as like being plunged into a completely different world – a world in which all the rules seem to have changed. It is in fact the start of a chapter of one's life which can take months to complete and that often involves many challenges, and frustrations. But then, as people to learn to manage the stress of having cancer, the world slowly begins to fall back into place, and things seem more familiar again...

Starting cancer treatment can therefore be a time of huge changes and much to learn. Meeting new doctors and other staff, strange tests and scary-sounding treatments, and *so many* hospital appointments. Your working life may have had to change, your lifestyle may have changed and even your relationships may seem to have changed. There is a lot to think about.

This booklet is about some of those changes and what you can do to manage them.

And it's not just constant change that's stressful. Cancer, like other serious illnesses, creates lots of uncertainty in people's lives. Waiting for treatment to start, waiting to see a doctor or waiting to hear one's latest scan results can seem almost unbearably stressful.

Change and uncertainty are always stressful, and stress can show up in a number of different ways. Look at this list:

- Feeling fearful and tense
- Insomnia (not being able to sleep)
- Intense frustration
- Loss of appetite
- Constant worrying
- Not feeling in control of your emotions
- Feeling sad and hopeless
- Getting cross with others

Do you recognise any of these? If you do, it's probably because you have been through a lot of stress recently. It's quite normal to feel these emotions but there's also something you can do about them.

what can you do?

- Don't bottle up your feelings! Talking to someone you trust is one way of releasing your feelings. Putting feelings into words almost always makes stressful situations seem easier to cope with. (See *Other People*)
- Find a time *every* day when you can relax. Relaxing doesn't mean doing nothing (though this can be the best kind of relaxation) but it does mean doing something that you find pleasant and enjoyable, giving your mind and body a time in which to calm down. Gentle exercise, such as a walk, can also release a great deal of muscle tension. As you do so try to notice the world around you and let your mind become absorbed by it.
- As you read this, think about where in your body your muscles seem to be tense. Now try to release this tension and *get in the*

habit of relaxing these muscles. This is much more important than it may sound. Ask your friends and family to help by reminding you, every now and again, to relax the muscles you don't need to be using.

- Talk out your worries to a good listener (this may not always be the first person you think of). If you can't think of anyone, drop into the Cancer Information and Support Centre (see page 4).
- When managing problems over which you have some control, think less about the problem and more about the solution.
- If you feel that anxiety is a problem for you, pick up a relaxation tape (or CD) and booklet from the Cancer Information and Support Centre. The relaxation tape/CD costs £1 to cover expenses but the booklet is free.

out of control

Once treatment starts, events all seem to happen very quickly and it's easy to feel that your life has been completely taken over and that you are no longer in the driving seat.

"Since my diagnosis, everything has changed. Everything feels upside down – I'm no longer the same person, I seem to have no control over my life, and I just do what I'm told. I want to go back to the person I used to be but I can't."

Some people say that the weeks following their diagnosis are a bit like being in a dream; the life they have known has been replaced by one which is new, strange and uncertain. The months of treatment ahead can seem endless and there is a longing to feel in control of one's life again.

It's easy to imagine that all the other patients one sees sitting calmly in the waiting rooms are somehow dealing with it all so much better.

Don't be fooled by appearances! You yourself probably appear very calm and collected to other people. To feel anxious and uncertain is very natural when there is so much change, so you are probably doing a lot better than you think.

what can you do?

When you are ready, it will be important to take back some control over your life again. One simple way of doing this, *if you feel ready for it*, is to obtain more information about your illness and its treatment so that you have a better idea about what to expect. Another way is to learn what you can do to help yourself and the treatment. For example, think about one thing you could change to make your life healthier. Stopping smoking, if you still smoke, would be a good start, but a healthier diet or starting a gentle programme of increasing exercise can also help maximise your health. Never do more than is sensible (don't become a fanatic) and, if you are not sure, always seek the advice of an expert, like the hospital dietician, a specialist nurse, your hospital doctor, or your GP.

Try to stay involved with things that you know you are good at. As we will see in the next section of this booklet, it's all too easy to let these things disappear when there are so many other things to think about. However, it's often the activities we are good at (like helping other people, achieving things in our work or hobbies, and being useful by doing our normal jobs at home) that tell us that we still have control over our lives.

money worries...

If you are worried about your finances, speak to a Social Worker, or Welfare Benefits Officer as soon as you can. It's reassuring to know you are getting whatever financial support you are entitled to. Having enough money is important in everyone's life and most people worry about this from time to time. If you wish, the Cancer Information and Support Centre can arrange for you to speak to a Benefits Officer - just ask them about this and they will be happy to arrange a confidential meeting.

who am I now?

Another unfortunate consequence of long cancer treatments is that many people stop doing the things that they used to enjoy or do well. You may have stopped work, or cut down activities that involved contact with other people. This is not just frustrating. These are also activities that tell you every day that you are competent, or needed, or talented, or funny, and so on. They remind you that other people value your skills, knowledge and humour; in other words, these activities give you a sense of self-worth. As soon as you cut down on these sorts of activities, you are likely to feel less good about yourself and, surprisingly quickly, you may begin to lose confidence in yourself.

Another change that many people find difficult is seeing themselves as 'a patient', or 'a cancer patient'. It is as if being in the role of a patient somehow makes people feel as if they are 'second-class citizens' and no longer as valuable as anyone else. They worry that, because they need other people more than normal, this means they are somehow being 'weak' and dependent. In reality, of course, we all depend upon one another throughout life, however much we may like to think of ourselves as being independent. Everyone is a patient at some stage in their life and there is certainly no shame in that; it's a temporary role in just one part of your life.

A Changed Body

Adjusting to the loss of part of one's body (for example, a breast, testicle or larynx) or having to deal with other changes in the body, such as a disability, can leave people feeling bereaved. In many ways, grief is an entirely appropriate reaction. It can take considerable time to adjust to a change in your body and all the implications this has for how you see yourself, what you can do, your life ahead, as well as getting used to how other people react to you. Gradually confronting these changes and talking them through with someone can help the process of adjustment. Like bereavement, time is also a great healer.

Who am I for other people? Who are other people for me? The relationships we have with other people are extraordinarily important to how we feel about ourselves. Because these relationships are forced to change when someone becomes ill, it can lead to difficulties and misunderstandings (see *Other People*, page 19). So this can also have an impact on how we feel about ourselves.

Finally, some people find that when they think about the future all they can see is months of treatment ahead and little else. Tests, treatments, and hospital appointments seem to dominate their lives, making it difficult to plan pleasant things to look forward to, or things to achieve. In fact, some people find it frightening to make any plans for themselves because they fear being disappointed or because they worry that, by making plans, they would be tempting fate. These are understandable reactions but dangerous ones! Without things to look forward to and things to achieve, life can feel pointless, and this can lead people to feel apathetic and depressed.

what can you do?

- A good place to start is to **recognise how much your life has changed over the past few months and, considering all this, how well you've coped.** You've had to deal with so many new experiences that it's little wonder that you may feel stressed, unhappy or even lost at times. You've never had to cope with anything quite like this before. So, all in all, perhaps you should even feel proud of how well you have coped!
- **Remember that, in spite of all the losses and changes that you may have had to cope with, you are still the same person inside.** Your skills and qualities are still very much there, even if you haven't had a chance to use them as much recently. Many people find that having cancer is a time when they learn something useful about their lives, rather than lose anything within themselves.

- Try to **retain as much contact with your normal life as possible**. For example, if you wanted to, you could maintain contact with work colleagues even if you have had to stop work. Try to fulfil your normal roles in life as much as you can (though prevent others from making unreasonable demands on you.)
- **Do things you are good at and enjoy from time to time**; this will remind you that you're still the same person and it will preserve and restore your confidence in your skills and qualities.
- As far as possible, **confront the changes that have been thrust upon you, rather than avoid them**. Avoiding difficult situations is easier in the short-term but can make things even harder later on. Instead, think about where you want to be and plan out the steps you will need to take to get there. For example, if you are concerned by your changed appearance, gradually get used to going out again and begin to learn how this feels.
- Try to **maintain activities that give you a sense of pleasure or fun**; this will give you something to look forward to (something we all need), as well as providing a short 'mental holiday' from the stress of thinking about cancer (e.g. reading a book, seeing a film). Plan a treat for yourself!
- Above all, **try to prevent your illness and its treatment becoming the central focus of your life**. Although it may seem to dominate your life at first, increasingly try to see your treatment as something you manage to fit into your otherwise busy life! Of course, there may be times when you don't feel up to being as active as usual and at those times it is important that you listen to your own body and do what you feel you need to do, even if this means disappointing others. Only *you* know what you are capable of doing. So try to achieve a balance between looking after yourself while having the treatment, and carrying on with life as normal as far as this is possible.

feeling overwhelmed

One of the unfortunate consequences of many cancer treatments is that they take such a long time. In fact, cancer treatments can sometimes seem so long and so exhausting that people end up feeling lost, frightened, and overwhelmed. It's at such times that people feel they want to withdraw into themselves, and soon become afraid of doing virtually anything.

If you feel you've hit this point, or even heading this way, it may be helpful to remind yourself that it's not your fault. Feeling very low or afraid does not mean you are 'not coping', or that you are weak, or that you are letting anyone down. You have probably never had to manage anything like this in your life before. The treatment of cancer can be very stressful, involving many changes, and there's a good chance that you may be physically and emotionally exhausted. Getting reconnected and involved with your life again takes courage and time, so *be patient* with yourself!

If you are concerned about how withdrawn you have become, or how hopeless you feel at times, or if you feel constantly tense and anxious, you should tell a member of staff or someone at the Cancer Information and Support Centre that you would like to see someone about it. There are clinical psychologists working at the Oncology Centre who specialise in helping people with cancer; they are also there to help you. Finally, there are hospital chaplains and other spiritual advisers.

If you find it difficult turning to others for support, or you think you may be at risk of feeling overwhelmed, then it's best to talk through your concerns with someone neutral and independent *as early as possible*. It is important to remember that you are not the only person to have experienced these feelings. Drop by the Cancer Information and Support Centre and meet one of the trained volunteers, most of whom have had cancer themselves in the past, or phone to arrange an appointment.

It also may be helpful to have an understanding of how your mind is coping with all the changes brought about by your diagnosis. The following section provides some information about psychology which you might find helpful to think about.

think about this

From the moment we are born, we try to make sense of the world around us. As babies, our ideas of the world are very simple but throughout our childhood we learn more and more complicated ideas about how it all works. We develop, if you like, 'mental maps' of the world and other people around us and these maps, of course, include ideas about how we ourselves fit into the world. These mental maps are always changing because every day something new happens which slightly changes how we see the world and ourselves within it. Some events in our lives, of course, are more significant than others and they may even force us to change the whole way we look at the world. This kind of change is always stressful. For example, leaving home for the first time, losing someone we love, becoming a parent, and even retirement are all life-changing experiences, and there are lots of others. For all these experiences we require time to adjust our mental maps so they make sense of the many ways in which the world appears to have changed.

Cancer is another example of this kind of change experience. Cancer forces us to look again at the many things we may have taken for granted in our lives: our health, our goals in life, our relationships with other people, our sense of who we are as people, and even our spiritual beliefs. We may also consider where we are in our lifespan. Reflecting on these things can be rewarding but it can also take time to draw the right conclusions. Changing the way you look at your life, yourself, and other people is almost always difficult and this is why getting cancer can be so stressful. Cancer involves so many changes to what is normal in someone's life that most people find it hard to keep up. This is why talking about one's feelings and thoughts is so important during times of change - it helps people to adjust their internal mental maps. This period of transition in your life will take time to work through; it will have its highs and its lows, but it can also be an opportunity for something positive to occur. In many ways the biggest challenge for all of us is how we engage with the rest of our lives, no matter how long or short this is.

taking control

Stay as actively involved with your life as you can. Try to collect up all the cancer-related bits of your life – the hospitals, the doctors, the tests, the appointments etc – and put them all in one small corner of your life. Make the rest of your life count – stay as actively involved in every other aspect of your life as you can. Reclaim parts of your life that you enjoy or which give you a sense of who you are, your family, your colleagues, your friends. And if you have any free time, why not use it to take up something new in your life – something fun or rewarding?

Get as much support as you feel you need. Not just practical help (fetching and carrying), but also emotional support (listening and caring). If you are worried about being a burden, think about what you would feel towards the other person if the tables were turned and they were asking you for your support. Practical support is important not only because it helps you physically but because it takes stress and pressure off you at a time which is already very stressful. Emotional support is often even more important because it is often through talking to other people that we make sense of what we feel, and what is really happening in our lives.

“When you are in your thoughts your mind can go all over the place and I sometimes have the most frightening thoughts about the future. But when I talk about it in words, logic kicks in and it feels easier to handle.”

Sometimes it helps just to be more aware of yourself. Our thoughts are so often taken up with worries about the future or thoughts about the past that we simply fail to notice what is going on in the present. A lot of the time we seem to go through life on automatic pilot! Therefore, as often as possible, try to notice the moment you're experiencing *right now*, how your body feels, what thoughts are passing through your mind, the sounds around you, the taste of food in your mouth, and so on. Just notice, don't judge. This is known as mindfulness and it is a useful skill to practise.

Another way to take control is to make sense of what has been happening by writing it down. Not everyone finds writing easy but, if you do, why not keep a diary of what you are going through (*the quotes in this booklet are from people's personal diaries of having cancer*). Many people find that writing helps them sort out their feelings.

"I found that keeping a diary helped me to organise my thoughts and feelings and to see things more objectively. I found it a useful discipline to confront my feelings on a daily basis – it helps me to remain positive."

Tell people what you need. You probably know best what support would be helpful from other people, so make it clear to them what you do need, even if occasionally this is time on your own. What you want from your carers, of course, changes over time so you may have to explain what you need on several occasions. Organise your life in a way that suits you. It's you who is 'the patient' and it is reasonable therefore to expect people who love you to support you in a way that suits you, while at the same time *you* being sensitive to *their* needs.

Finally, fatigue is a common side-effect of cancer treatment, but simply taking rest isn't always the best solution. Too much rest can lead to general weakness and poor sleep at night and this only makes the situation worse. Instead, try to plan how much activity you can sensibly do each day. If you imagine your energy supply as being limited to one allocation a day, then it's important to work out how much energy you can afford for each activity you undertake. Set yourself small manageable goals that are SMART (Specific, Measurable, Achievable, Realistic and Time-bound) - for example, I'll go for a walk for fifteen minutes every day. As you recover from treatment, gradually try to increase the amount of exercise you take because gentle exercise has been found to prevent long-term fatigue.

how to worry

Everyone worries. It is part of being human (in fact, it's a form of creative imagination). A fear of the unknown is natural, and sometimes getting accurate information is all that's needed. But worry can stop people enjoying and getting on with their lives, and it can also lead to poor sleep and unnecessary stress. So it may be helpful to know something about it.

People worry about things that are very likely to happen, and also about things that are very *unlikely* to happen. But whether realistic or not, worry is an unpleasant side-effect of our amazing talent to imagine, anticipate and plan for the future (a mental ability that has led human beings to dominate the world).

So worrying is a very common and quite normal activity. But if you are going to worry, be sure to do it properly! There's a helpful, and productive way to worry, and also a harmful and ineffective way to worry. The two are very different.

useless (unproductive) worrying

The way most people worry is to focus on a particular moment taken from their 'worst case scenario'. You're going along in your life quite pleasantly when something happens to remind you about the situation you are in. Suddenly, a snapshot of the worst-case future pops into your mind. You imagine how you would feel and begin to get distressed as if it was actually happening now; you may feel physically tense and anxious, or depressed and sad. It's such a horrible, 'catastrophic thought' that you quickly distract yourself by thinking about something else. You calm yourself down and then try to resume whatever you were doing. But a few minutes later the same thought comes crashing into your mind again.

If this sounds familiar, read the next section.

productive worrying

This solution may not be easy, and may even take a few goes, but a lot of people find it helps. Try really looking at your worst case scenario *in detail* for a change. 'Unpack' what you are *really* worrying about and have a hard look at it. Often, if we try to imagine *realistically* what the future is most likely to hold (of course we don't really know) we can begin to feel more confident that we, and other people we care about, will be able to cope with it, whatever the future throws at us. Of course, really looking at one's fears can be difficult and distressing, and you would be best advised to talk all this through with someone you know is a caring and good listener.

When you think about your worst case scenario (your 'catastrophic thought' in the section above), try thinking about what would happen next... for everyone concerned. What would be happening a week after

that? A month after that? And so on. Talk or think it all out logically and try to imagine, *realistically*, what would happen if your worry, however unlikely, actually came to pass. This may sound ridiculously simple but the odd thing is that people usually worry about only the worst possible moment in their imagination. They fail to remember that this snapshot moment in the imagined future quickly passes, and turns into something less unpleasant. Once you've thought through the worry realistically a few times with a trusted listener, you may find it doesn't pop into your mind quite so often.

Finally, if you worry about the possibility of a recurrence of your illness (and most people do worry about this) try to remember that, if this ever did occur, your doctors would re-assess you medically and once again decide the most appropriate treatment for you.

getting on with living

Sometimes, quite understandably, people become preoccupied with their worst case scenario (an imagined future) and end up spending lots of fruitless time worrying about this possibility rather than getting on with their lives. The problem with using one's imagination too much is that it becomes difficult to enjoy what is actually happening in the present - one begins to lose sight of the bigger picture.

It's easy for other people to remind you that it's more important to live one's life than to worry about when it may end. It's easy for them to say "We are all going to die one day, the important thing is to enjoy the time we have while we are alive." It's more difficult to live by these words when you imagine what it would be like to face the end of your life (of course, it's worth remembering that if you were told your illness was no longer curable you would still have lots of time to sort out the things you needed to sort out.)

You may believe one hundred per cent that 'life is for living', yet feel afraid of being really involved with your life again. But would you decide never to go out to see a film, just in case it was sold out? (this example is trivial but it involves the same principle.) Making goals and plans for yourself (with the help of friends) can feel like a

risk, but in time it will help rebuild your confidence and involvement. Read the section above on worrying so that you can learn to shelve your worries until those things actually need to be worried about. Practise spending more time in the present, becoming aware of yourself and the world around you, and you will soon come to live by the maxim that ‘every moment counts.’

And, finally, no matter what prognosis you have been given, there is *always* room for hope and something to aim for. People often complain that the hardest time of the day is when they find themselves at home alone with nothing to do but worry about *worst* case scenarios in the future. The fact that one particular outcome may seem likely does not mean that other outcomes are impossible. For example, buying a lottery ticket doesn't mean that you expect to win, but you can certainly hope to win because the fact remains that people can and do sometimes win.

other people

Other people in your life may have reacted to your illness in ways which have surprised you. Sometimes unexpected people turn out to be extraordinarily caring, and sometimes people you *thought* would be caring seem to be unsupportive or distant. This can be a big disappointment and a source of strain within the relationship. If you feel someone close to you is finding it hard to support you effectively, you may wish to suggest that they also read this last section.

There may also be some people you have chosen not to tell. Whether or not to tell people is a very personal decision. Often this decision is about balancing two genuine concerns:

- (a) not wanting to create unnecessary distress among people who we care and worry about (e.g. the very young, the very old or those who are themselves ill or under stress), but on the other hand...
- (b) not wanting to withhold information from people who really *would* want to know (because secrecy can cause hurt and anger).

Again, in reaching your decision whether or not to tell a particular person, it often helps to talk through the pros and cons with someone who knows about you and your illness - someone you really feel you can talk to.

Changing Relationships

Our relationships with other people often have a long history, so changes within relationships can be particularly difficult and stressful. In fact, we get so used to the people we are closest to that we often don't think about our relationship with them. We also assume lots of things about our relationships that simply may not be true. For example, children grow up and mature, but we often think of them as being younger than they are. We may think of our partners as being competent and strong, while forgetting that they can also feel scared and lost at times too. Over the years we become more dependent on our partners (and they become more dependent on us), but we often don't think about this either.

When you became ill, you may have found that some of your relationships changed. Friends and family may be doing more for you, and although you may welcome this, you may also feel uncomfortable or even guilty that you are not doing as much as you would normally do for yourself and other people. Of course everyone connected to you also has their own worries and concerns which don't always get expressed, and this too can lead to tension within relationships.

Many parents worry about damaging their children by talking about their illness at the wrong time or in the wrong way. This is particularly the case for single parents who may have no one to talk these issues through with. In reality, there is no single 'right' way to keep one's children informed. Like adults, children require time to absorb information, and their need for 'the truth' must be balanced by their need to know they are loved, safe and will not be abandoned. In general, the older the child the more vital it is to keep them fully informed, and it clearly helps if adults can agree a plan before talking to children.

Husbands and wives (and other partnerships) sometimes find that the demands of cancer treatment puts considerable strain on their relationship. There seem to be a number of reasons for this:

- Partners are usually very distressed but most of the support tends to be focused on ‘the patient’; this can sometimes lead to resentment.
- Some people find it difficult to express their feelings (sometimes because they fear they are being a burden; other people worry about being seen to be ‘weak’ in some way) but this ‘bottling-up’ of emotion can easily lead to irritation and anger within the relationship.
- Cancer can lead people to realise how much they need someone else and how dependent they have become on them. Men, in particular, often find it uncomfortable to recognise how much they may need their partners and may feel less skilled at expressing their feelings.
- Some partners believe that their role should be to be positive and cheerful all the time. While, of course, it is helpful to focus on the positive aspects of the situation, “positive thinking” can be overdone when it discourages someone from talking about the things they want, or sometimes *need* to talk about.
- Being *either* the patient *or* the partner can be exhausting. Tiredness within relationships always leads to more friction.

Cancer can provoke changes which sometimes reveal the true nature of long-standing relationships. These discoveries can be positive and even lead to healthy changes within relationships, but unless people are open with one another they can also lead to considerable disappointment and long-term resentment.

advice for couples

1. Anxiety and depression are less likely to develop if couples are able to face the stress of cancer together. Remember that patients can support partners, as well as the other way round.
2. Try to be clear with each other about what you are feeling and thinking, but don’t assume you know what your partner is feeling or thinking.

3. Do your best not to interrupt your partner when they are speaking; try to listen as well as talk.
4. Fear is often be expressed as anger, so think carefully if you find yourself criticising your partner. Remember that this is a stressful time for both of you and *both* of you need support, especially from each other.
5. Words may not always be as important as giving or receiving a hug from your partner.
6. Being overly positive, giving advice or finding a solution is not always what is needed. Try instead to find out whatever your partner would really find it helpful to talk about.
7. Don't worry about saying the 'wrong thing' – the important thing is to do your best to stay involved.
8. If possible, find someone in addition to your partner whom you can talk to, and get support from, on a regular basis. Depending *only* on your partner for support can sometimes be stressful for both of you.
9. Above all, remember that you and your partner (and other family members) may well have different ways of dealing with the situation you both face, and that this is natural. It helps though to acknowledge these differences and to accept that you may each have different needs and priorities at any one time.

finishing

Suddenly having to cope with a serious and complicated illness like cancer is a hugely stressful experience, not just for the ill person but for everyone connected to them. No one can ever be fully prepared for all the changes that follow the diagnosis. People are not only having to manage the fact that they are ill, and having to endure a long and often difficult treatment, they are also having

to cope with many changes to the way they normally manage their lives, their relationships with other people, and how they feel about themselves.

There is nothing pleasant about profound change in our lives but it does seem to carry the potential for personal growth and development. Thankfully, more and more people are surviving cancer these days and even when it is no longer curable, a number of cancers are now considered chronic or long-term illnesses. A lot of cancer survivors describe their illness as a kind of "wake-up call", a reminder that life is ultimately too short to worry about things that are trivial and unimportant. It leads us to think again about what is important in our lives and reminds us to appreciate the simple pleasures that may be all around us. Surprisingly, illness can be a time of positive change in people's lives.

"I'm in that limbo where my cancer is yesterday's news but I'm not quite well enough to take my place again in the normal scheme of things. A few people have said, not in so many words but to the effect that now my treatment is over that's it and I can go back to work, to life again. But there is no going back, only forward I suppose."

Even though cancer can lead to helpful personal developments in many people's lives, it can also leave others feeling lost, desperate and in despair. This can sometimes be felt most acutely at the end of active treatment when one is often particularly exhausted. After so many months of regular hospital contact, it is easy to feel cast adrift from the 'safety net' of healthcare staff and active treatment. You may feel other people are pressuring you to 'be well' again before you have fully regained your strength, both physical and emotional. Although these feelings are normal and understandable, if you do have them, try to talk about them soon with someone who might be prepared to listen. And, rather than worry about being a 'burden', remember that it is always an honour and a compliment to be asked for one's help. If you feel this is difficult to do with your own family and friends, then be sure to speak to someone who can help: your GP, a spiritual leader in your community, a member of the hospital staff, or someone at the Cancer Information and Support Centre at the Oncology Centre.

The printing of this booklet was paid for by
The Friends of Bristol Oncology Centre

The Friends of Bristol Oncology Centre

If you would like to make a donation to The Friends
of Bristol Oncology Centre, please contact:

The Appeals Office
The Friends of Bristol Oncology Centre
Bristol Haematology and Oncology Centre
Horfield Road
Bristol BS2 8ED

0117 - 928 - 3432

Managing the Stress of Cancer

QUESTIONNAIRE

Please return this questionnaire if possible - your feedback will enable me to improve the booklet and this will help other people.
Just fill out as much of this questionnaire as you can. Any comments you would like to make will be very much appreciated.

Tick **one** box indicating *how much* you agree or disagree with **each** statement

- | | DISAGREE | | neutral | | AGREE |
|---------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. I found this booklet helpful | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

What was the most helpful section?

- | | DISAGREE | | neutral | | AGREE |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 2. I found the booklet distressing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please tell me which parts

- | | DISAGREE | | neutral | | AGREE |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 3. I think that all new cancer patients should be given a copy of the booklet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

At diagnosis	<input type="checkbox"/>	<i>(tick one box)</i>
After treatment has started	<input type="checkbox"/>	
When treatment has finished	<input type="checkbox"/>	
Never	<input type="checkbox"/>	

If you would like to see something added to, or removed from the booklet, please tell me as clearly as possible

please turn over...

QUESTIONNAIRE (continued)

5. If you have any further comments about this booklet or if you have helpful tips you feel would improve the booklet, please summarise them here (and on extra paper if you wish).

.....

.....

.....

.....

.....

about you

6. When were you given this booklet? At diagnosis ☐
After treatment had started ☐
After treatment had finished ☐
7. What is your age ?
8. Are you male ☐ or female ☐ ?
9. Are you 'married' ☐ divorced ☐ (tick one box)
widowed ☐ single ☐

Thank you very much for completing this questionnaire.

When you have finished, please cut out this page and either drop it into the Cancer Information and Support Centre, or post it to me at the address below.

Dr James Brennan
Consultant Clinical Psychologist
Bristol Haematology & Oncology Centre
Horfield Road,
Bristol BS2 8ED

Many thanks for your help.

- cut here -

- cut here -

Notes / Thoughts

Managing the Stress of Cancer

