

MANAGING THE STRESS OF CANCER

A psychosocial guide for people with cancer



A Y R S H I R E
cancer
Support

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Acknowledgement

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This booklet was written in 2001. It was designed to normalise people's emotional experiences and reactions to having cancer, and to help patients and their partners consider how best to manage various common concerns.

Indeed, it translates some of the key concerns into a more patient friendly format.

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Introduction

For many people, having cancer is one of the toughest experiences they will ever have to face. There is 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 also 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 eventually turn out to be positive in the long run.

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

Cancer treatments may seem complicated at first but, in fact, people's lives are often a lot more complicated. Each of us has our own unique life story and our own unique combination of family and friends and each of *them* has *his or her* own complicated life story to tell.

So is it not surprising that people have very varied reactions and feelings in response to cancer, whether they are a relative, a friend, or the patient themselves.

This booklet is about some of the main feelings and thoughts that people often have during the experience of cancer.

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 have not 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 should always be happy to provide it.

Of course, it is important to remember that only *you* know *when* and *how much* new information you are ready to learn.

Cancer and its treatment are often very complicated and it can take a long time to understand everything about the disease.

General information about cancer and its treatment can be obtained from:

- **Ayrshire Cancer Support.**
www.ayrshirecs.org.
- **Click on links to all national cancer information organisations.**
- Or see the back page of this booklet for local contacts.

Shock

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 curious. 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 is never 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 doctors have to do.

The reason it is so difficult is because the first thing most people think when they hear the word 'cancer' is that they are about to die.

Unfortunately, this still seems to be the public's view of cancer, in spite of all the extraordinary medical advances in the treatment of cancer in the past few years.

So it is not really surprising that people often remember the 'day of the diagnosis' as the most frightening day of their lives.

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.

Changes

It is the start of 'the cancer journey' which can take months to complete. But then, after a while, the world begins to fall back into place, and things seem more familiar again....

Starting cancer treatment is therefore a time of huge changes with much to learn: meeting new doctors and other staff, undergoing 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.

Change is *always* stressful and stress can show up in a number of different ways:

- Feeling fearful and tense
- Insomnia (not being able to sleep)
- Loss of appetite
- Constant worrying
- Feeling sad and hopeless
- Getting cross with others

Do you recognise any of these? If you do it is probably because you have been through a lot of stress recently.

What can you do?

Do not bottle things up!

Talking to someone you trust is one way of releasing your feelings.

Find a good listener.

This may not always be the first person you think of!

Find a time every day when you can relax.

Relaxing does not necessarily mean doing nothing (although this is often the best kind of relaxation) but it does mean doing something pleasant and enjoyable, and giving your mind and body a time in which to calm down.

As you read this, think about where in your body your muscles seem to 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 do not need to be using.

If you feel that anxiety is a particular problem for you, speak to a member of the healthcare team, who will arrange for a specialist to help you

Out of Control.

Once treatment starts, events all seem to happen very quickly and it is 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 don't know what to expect anymore. 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 that is new and strange. The months of treatment ahead can seem endless and there is a longing to feel in control of your life again.

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. 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 (do not 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 you know you are good at. As we will see in the next section of the booklet, it is all too easy to let things disappear when there are so many other things to think about.

However, it is often the activities we are good at(like helping other people, achieving things in our work or hobbies and doing our normal jobs at home) that tell us that we still have control over our lives.

If you are worried about your finances or housing, speak to a Social Worker or a Welfare Benefits Officer as soon as you can. It is reassuring to know that you are getting whatever financial support is available to you.

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. These are activities that tell you every day that you are skilled, or needed, or talented, or funny and so on. They remind you that other people value your personal qualities, your knowledge, and humour; in other words, these activities give you a sense of self-worth.

As soon as you cut down on these sort 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 sometimes makes people feel as if they are 'second-class citizens' and no longer as valuable as anyone else.

They worry that *needing* other people means they have become dependant and that this means they are somehow being 'weak' .

In reality, of course, we all depend upon one another, however much we might like to think of ourselves as independent.

Everyone is a patient at some stage in their life and there is certainly no shame in that; it is just a temporary role in one part of your life.

Adjusting to the loss of a part of the body (for example, a breast or testicle) or having to deal with other changes in the body can leave people feeling bereaved.

In many ways, grief is an entirely appropriate reaction. Like bereavement, it can take a considerable time to adjust to a change in your body and all the implications this has for how you see yourself and your life ahead.

Gradually confronting these changes and talking them through with someone can help the process of adjustment.

But, as in bereavement, time is a great healer.

In addition, the relationships we have with other people are extraordinarily important to how we feel about ourselves.

These relationships change when someone becomes ill and this can cause difficulties and misunderstandings.

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 feel it is unsafe to make *any* plans for themselves because they fear being disappointed or because they worry that, by making plans, they would be tempting fate.

It is an understandable reaction but a dangerous one!

Without things to look forward to and things to achieve, life can feel pointless, and this can lead to people feeling 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 days or months and, considering all this, how well you have coped.

You have had to deal with so many new experiences that it is little wonder that you may feel stressed, unhappy, or even lost at times.

You have 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 have had to cope with, *you are still the same person inside*. Your skills and qualities are still very much there, even if you have not had the chance to use them as much recently.

For many people, the cancer journey can be a time of learning something useful, rather than losing anything within themselves.

However, it is helpful to try *retain as much contact with your normal life* as possible.

Similarly of benefit is *maintaining contact with work colleagues* even if you have had to stop work.

In addition, try to *fulfil your normal roles in life* as much as you wish to (though prevent others from making unreasonable demands of you).

Doing things you are good at and enjoy from time to time; this will remind you that you are still the same person and it will preserve and restore your confidence in your skills and qualities.

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).

Above all, try to prevent your illness and its treatment from becoming the central focus of your life. Instead, see it as something you manage to fit into your otherwise busy life!

Of course, there may be times when you do not 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.

Feeling overwhelmed.

One of the unfortunate consequences of cancer treatments is that they often take 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 is at such times that people feel they want to withdraw into themselves, and to become afraid of doing virtually anything.

If you have reached this point, it may be helpful to remind yourself that it is 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.

The treatment of cancer is very stressful, involving many changes, and there is a good chance that you are physically and emotionally exhausted.

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 your healthcare staff.

Some people find it difficult turning to others for support, but if you are feeling overwhelmed in any of these ways, then it is best to talk about the difficulties you are having with someone neutral and independent who may be able to help.

It may be useful to have an understanding of how your mind is coping with all the changes brought about by your physical diagnosis.

N.B. The following section provides some information about the mind, which you might find helpful to think about.

Making Sense

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 things about the world and how it works.

We develop a sort of mental map of the world and this, of course, includes ideas about how *we* and other people fit into the world.

These mental maps of the world are always changing because everyday something new happens which slightly changes how we see the world and ourselves within it.

Some things in life, of course, are more dramatic and important and may 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 retirement are all life-changing experiences, and there are lots of others.

In all these experiences, we require time to adjust to the many ways in which the world appears to have changed.

Cancer is another experience that involves a lot of change. 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, and even our sense of who we are, ourselves.

Reflecting on these things can be rewarding but stressful, and it may 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 your feelings and thoughts is always so important at times of change. It helps us to make sense of what is happening and find a way forward.

This period of transition in your life will take time, it may have its highs and lows, but it can *also* be an opportunity for something positive to occur.

Taking control

Stay as actively involved with your life as you can.

Try to collect up all the cancer-related bits – the hospitals, the doctors, the tests, the appointments, etc. – and put them all in one small corner of your life.

Make the rest of it 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?

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. It helps us to deal with the implications of the illness and its treatment.

Take control as much as you wish.

You probably know best what you need from the people offering you support, so *make it clear to other people what this is.*

What you need, of course, will change over time, so on several occasions you may have to explain to those supporting you what you require.

Organize your life in a way that suits you. It is *you* who are 'the patient' and it seems reasonable to expect people who love you to support you.

Worrying

Everyone worries. It is part of being human (and is a form of creative imagination). 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.

This section applies to *any* kind of worry, whether realistic or not.

Worry is an unpleasant side effect of our amazing ability to imagine, anticipate, and plan for the future (an ability which has allowed 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 is a helpful, productive way to worry, but also a harmful, ineffective way. 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 are going along in your life quite contentedly when you are reminded about the situation you are in (e.g. having cancer). 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 the event were happening now; you may feel physically tense and anxious, or depressed and sad. It is 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 on.....

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 take a hard look at it.

Often, if we try to look *realistically* at what the future is most likely to hold (although of course we do not 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 it may be.

Of course, really looking at your fears can be difficult and distressing, and you would be best advised to talk all this through with someone you know to be a caring and good listener.

When you think about your worse-case scenario, try thinking about what would happen next... for everyone concerned. What would be happening a week after that? A month? And so on.

Talk or think it all out logically and try to imagine *realistically*, what would happen if your worry, however unlikely, really came to pass.

This may sound ridiculously simple, but the odd thing is that people 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 have thought through the worry realistically a few times with a trusted listener, you may find it does not pop into your mind quite so often.

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

Getting on with living

Sometimes, and quite understandably, people become preoccupied with their worst-case scenario (some imagined future) and spend their lives worrying about this possibility rather than getting on with their lives.

The problem with using your imagination too much is that it becomes difficult to enjoy what is actually happening in the present – you begin to lose sight of the bigger picture.

Read the section on worrying so that you can learn to shelve your worries until those things actually need to be worried about, if ever. In time, you will once again come to appreciate that 'every moment counts'.

It is easy for other people to remind you that it is more important to *live* your life than to worry about when it may end. It is 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 is much more difficult to live by these words when you imagine what it would be like to face the end of your life. But at the same time, a part of us perhaps knows that these words are true.

You may believe one hundred percent that 'life is for living', yet feel afraid to be 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?

Making goals and plans for yourself (with the help of friends) can feel like a risk, even tempting fate, 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, if ever. In time, you will once again come to appreciate that 'every moment counts'.

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 extraordinarily caring, and sometimes people you *thought* would be caring seem to be unsupportive. 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 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:

- Not wanting to create unnecessary distress among people whom you 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...
- 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 your illness and whom you can talk to easily.

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 do not think about our relationship with them and may even take them for granted.

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 often we do not think about this either.

When someone becomes ill, many of their relationships change.

Friends and family often do more for the patient, and although the patient may welcome this, they may also feel uncomfortable or even guilty that they are not doing as much as normal for other people.

Everyone connected to the patient also has their own worries and concerns although these do not always get expressed, and this can lead to tension within relationships.

Husband and wives (and other partnerships) sometimes find that the demands of cancer treatment put considerable strain on their relationship. There seems 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* lead to resentment.

- some people find it difficult to express their feelings (or choose not to because they fear they are being a burden) and this 'bottling up' of emotions can 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 recognize how much they may need their partners.

- 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 if it discourages someone from talking about the things that they want, or need, to talk about.

- being either the patient *or* the partner is exhausting. Tiredness within relationships always leads to more friction.

Cancer can provide 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 they can *also* lead to considerable disappointment and long-term resentment.

Advice for couples facing cancer.

Anxiety and depression are less likely to develop if the couple are able to face the stress of cancer together. Patients can support partners, as well as the other way round.

Try to be clear with each other about what *you* are feeling and thinking, but do not assume you know what your partner is feeling or thinking.

Do your best not to interrupt your partner when they are speaking; try to listen more than talk.

Avoid being critical of your partner; remember that it is a stressful time for *both* of you and that both of you need support.

Words may not always be as important as giving or receiving a hug from your partner.

Being overly positive, giving advice, or finding a solution is not always what is needed; instead, try to find out whatever your partner would find it helpful to talk about.

Do not worry about saying the wrong thing – the important thing is to try to stay involved.

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.

Finally, every relationship is sometimes a journey into the unknown. The measure of any relationship is the support and companionship we give one another when the going gets tough. Couples who face the crisis of cancer together, and who are open with one another about their feelings and uncertainties, are much better able to overcome any difficulties along the way.

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