After the treatment finishes then what? (Dr Peter Harvey)

01 Overview

This section of the website is designed for people who are regaining their life after treatment for cancer has finished.

This can be a particularly difficult time, often made worse by the feeling that support is no longer available, needed or your right.

The ideas and information that follow are designed to help and support you in dealing with the challenges that this period brings. Although written primarily for people who have experienced treatment directly, it may also be helpful for relatives and friends (and perhaps even for healthcare professionals).

It is important to stress that the information on this part of the site relates to adults who have been diagnosed with cancer as adults. The psychological issues for children and younger people dealing with cancer, its treatment and the aftermath is not covered here.

Imagine a roller-coaster. Some of you will find this an exciting and thrilling image: others of you will find it terrifying and beyond belief that anyone in their right mind would willingly subject themselves to the torment of being transported at high speed and with great discomfort in this manner. Some people find this a helpful image to represent the process of the diagnosis and treatment of cancer.

On a roller-coaster, you are strapped in and sent of into the terror, knowing that there is nothing you can do about it until you emerge, wobbly and battered at the other end. You manage by getting you head down and dealing with it as best you can at the time. It is only afterwards, when you are back on solid ground again, that you can look back with amazement and view what you have experienced and marvel at your courage.

This seems to be an analogy for what happens after diagnosis of, and during treatment for, cancer. The end of the ride is equivalent to the end of treatment. And this is where we start - after the treatment has finished and at the point where you can begin, bit-by-bit, to deal with all that you have been through and all that is to come.

You may have had to endure months of treatment by knife, chemicals or radiation until you are probably sick of the whole business, both literally and metaphorically. Now is the time to heal, both body and mind.

02 Background

The material presented here has been adapted by Dr Peter Harvey from two presentations which he gave initially at the request of the National Conference of Cancer Self-Help Groups in 1999 and 2002.

He presented a version of ‘After the treatment has finished, then what?’ at the inaugural conference of the European Federation of Psychosocial Oncology Societies in Glasgow in 2003. A version has been available on the Cancer Counselling Trust’s website since 2004.

The content has emerged over the years from a variety of sources - from individual conversations with patients, as result of discussions with support groups, by reading about patients’ experiences in books and articles. This means that the tone and themes of what follows are primarily patient-focussed and experiential rather than academic and research-based.

Where there is evidence and and there are useful theoretical ideas to support what is reported then this is included or the reader is directed to further reading.

Because of the author’s background and training, the content is strongly influenced by psychological thinking and ideas.

The scientific literature and other information can be assumed to be correct as of May 2008.

The authors

Dr Peter Harvey was a clinical psychologist until his retirement in September 2007. He has worked with adults with cancer for 15 years, first in Birmingham and later in Leeds.

He also served as Chair of the British Psychosocial Oncology Society for four years, was on the Clinical Advisory Board of CancerBACKUP for six years and was associated with the development of the CancerHelp UK website.

Dr Jane Haworth works full-time as the Principal Clinical Psychologist in Oncology at the Leeds Teaching Hospitals NHS Trust. She has worked for several years in cancer services and has special interests in body image, adapting to changes to the body, survivorship issues and supporting and training healthcare staff.

Her current role in oncology involves a wide range of work both directly with patients and their relatives, and also with staff. She has also been involved with training Breast Cancer Care volunteers.

The artist

Joan Newall BA (Hons) MSDC is a Textile Maker / Printmaker who began her textile career by studying City and Guilds Textiles at Craven College in Skipton and has since gone on to gain a first class honours degree in Art and Design from Bradford College, where she specialised in Textiles and Printmaking.

In her final year she was awarded sponsorship by Madeira Threads, was accepted as a Licentiate of the Society of Designer Craftsmen and has since been accepted as a full Member.

Joan's art work deals with the presence of breast cancer in our culture, how we perceive it and how we deal with it. She feels fortunate that she can use her work as a means of expression and has been able to confront her own breast cancer using image and narrative. These images, some of which are featured on this section of the site, can be seen on **www.art-connections.org.uk**

Her main interests are in the construction of 3D objects using hand made paper and wax with stitch and beading. Her main subject matter is the politics and presence of breast cancer in our culture, the way that it is perceived and its causes.

As well as continuing with her own practice she is now working as a part-time tutor in Textiles within North Yorkshire and in schools, providing a textile input to the GCSE art courses in the form of day workshops.

Joan is a founder member of Textilia III, a Skipton based contemporary textile group whose aim is to bring textiles to a wider audience and to further their own practice. She is also a member of Paperweight, an international group specialising in working with paper.

She exhibits widely with Textilia III as well as in private galleries. Examples of her work can be found at **www.textilia3.co.uk/joan_newall.htm**

Acknowledgements

Extracts from “Ups and Downs: An Average Rock Bun” by Alan Bennett from Untold Stories (© Forelake Ltd. 2005) are reproduced by permission of PFD (www.pfd.co.uk) on behalf of Forelake Ltd.

03 Introduction

Imagine, for a moment, that your progress through life is like being on a small boat.

For most of the time you sail along weathering both the expected and unanticipated storms that occur in every life. Then, all of a sudden and without warning, the most horrendous storm blows up - much worse than any you have experienced before and completely unexpectedly.

Your boat is tossed all over the place, you are lashed by rain and wind, the waves crash about you, their size obliterating the horizon and restricting your vision to the immediate surroundings. You fear for your life and hang on to whatever is to hand to stop yourself from being washed overboard.

This rather dramatic narrative attempts to put into words what the experience of being diagnosed and treated for cancer might be like for some of you. Whilst not everyone goes through it in this way, the enormous upheaval and threat that many people report seems to be echoed in that brief description.

But, like treatment, the turmoil subsides and there is the beginning of the calm after the storm. You look around at your boat, battered and damaged though it is, and it is still afloat.

There is a need to repair and mend those bits that have been broken or damaged. Some items may be lost, washed overboard and you will have to find ways of proceeding in spite of these losses. Once you have looked over the boat, you gingerly look out to sea. But instead of a clear blue ocean and cloudless sky you see little but mist and fog. Your sea charts have been lost in the storm. You are not really sure of your position, whether you are in the same place as before, pointing in the same direction. You may also wonder whether you want to go on along the same path as before.

The sea, though calmer, is still unsettled and your world feels unstable under your feet. Thoughts of where to go, what next, how to get help assault you and add to your worry and uncertainty.

This may be what it feels like for you when your treatment ends. Still reeling from the physical, emotional and practical demands of treatment you are left contemplating an uncertain and possibly frightening future. The end of treatment may be one of the most difficult and complex times for you.

It may make demands on you that you could not imagine whilst you were undergoing treatment. And it may be the time when you feel the most in need of support but least able to ask for it and when it seems least available.

This section of the website is designed to help you deal with some of these demands and pressures, to guide you and support you. How you use it is entirely up to you. It has been divided up into easily digestible chunks so that you can take things at your own pace and follow things up in a way that suits you.

Whenever possible some more theoretical points have been added as has some evidence from the scientific literature, but looking at this is an optional extra!
The part of the site is organized in to a number of sections (**Back to Index**).

You do not need to read all of this at once. You can take it one step at a time depending on how you feel. Because it has been designed to be read in independent parts you may find some repetition - this is unavoidable as these issues overlap and inter-twine.

04 The tasks of recovery

It may seem a bit daunting to see a heading like this - after all, you’ve just come through months of treatment and you were looking forward to bit of a break and now you read that you have even more work to do in order to recover!

This is not quite as frightening as it seems. One of the emotional threads that runs through much of the period from diagnosis to the immediate aftermath of treatment is that of loss.

There are many parts of your life that you may feel you have lost completely or partially, temporarily or permanently.

Often, one of the first things to go is a sense of control. For some of you the whole process from discovery of a symptom through to treatment was so fast that it must have felt as if you had no time to draw breath.

For others of you the process might have been a much more tortuous process. But in these and in many other cases there is an over-riding sense of loss of control of your life.

All of a sudden your life is taken over by a system (admittedly there to help you) but which works to its own rules and timetables. Your diary becomes filled with hospital appointments and clinic visits, often reaching well into the future if you are on a long course of chemotherapy.

Cancer itself sometimes produces a strong sense of uncontrollability and if you add that to the surrendering of control to the healthcare system, it is hardly surprising that there is such a overwhelming feeling of being out of control.

There are other losses, too. The treatment itself can produce losses of body parts - either permanent or temporary and a consequent change of body shape and sense of bodily integrity.
There may be a loss of independence as you become reliant on others to ferry you about to appointments or to get your shopping for you. This may also reflect a loss of position or status - your position in the family, as provider (financially, emotionally, practically) to your loved ones or your rôle at work may feel diminished by your new role as a 'cancer patient'(**see Survivor - what's in a name?**).
If your diagnosis has been a struggle and you feel people may not have taken you seriously (**see Regaining trust in your body**), or if you experienced a series of problems with the actual delivery of your care (cancelled clinics or lost scans, for example) you may be feeling that a system that you have trusted previously is not as robust and helpful as you had thought (**see Regaining trust in the system**).
You may have found that some people in your social network have not been as helpful as you wanted or might have expected; you may have found who your real friends are - and are not (**see Regaining trust in the outside world**).

During your treatment you may have found that the best way to deal with everything is to put your head down and just get on with it. You may not have had either the time or the energy to spare to try to deal with all the emotional and other issues that have arisen - you may have put them on one side to be dealt with at the time when you are feeling more up to it.

This is not a bad way of managing things. It is certainly true the the demands of treatment can take all your energy and there is simply no spare capacity to deal with anything else. Likewise, not everything needs dealing with right now - you can defer some problems until you need to.
A good example of this is concern about returning to work. If you are in the midst of a long treatment regime going back to work may be many months in the future. Unless there are work issues that absolutely must be dealt with now, it is sensible to approach them once your treatment has finished and you have more time and energy to focus on this important issue (**see Returning to work**).
Of course it's not all about loss and gloom. There are other aspects of cancer, its treatment and the aftermath that can feel very different - positive and uplifting (**see It's not always all bad**) but for many people these are offset by some less pleasant experiences.
One of the important aspects of dealing with cancer and its treatment is to acknowledge the losses (this is also covered in the **section) as once these are acknowledged then it becomes easier to deal with the rebuilding and recovery process.**
This website is aimed at helping you do this by addressing the tasks ofrebuilding trust in your body, in **yourself**, in the **healthcare system** and in your **social world**.

As everyone is different you may only need to dip into the parts of this that you feel are relevant to you, but there is extensive cross-linking as very few of these losses occur in isolation.

05 Beginning to recover & Recuperation

It is important to emphasise that recovery is a process, not an event. It's not something that just happens - it takes place a bit at a time - and often takes much longer than you expected and almost always takes much longer than you had hoped.

Once your treatment has finished there is often a sense of pressure to be as you were before all this happened. One of the key messages of this guidance is to point out that this cannot happen immediately - and, as we shall see - may not happen in the way that you might have expected.

Before you can begin the main part of your recovery you need to ensure that your energy and strength (both physical and emotional) are in place for the tasks ahead. For this you need to do two things - recuperate and convalesce.

Recuperation

It is a widely held belief, often correct, that the treatment of an illness is meant to make you feel better.

One of the many paradoxes of cancer is that, more often than not, the treatment makes you feel worse. This is not surprising - you are cut and possibly mutilated, injected with poisonous and powerful chemicals, subject to dangerous rays all in the name of treatment.

The aggressiveness and power of the treatments are a necessary response to the power of the disease but this very power takes its toll in other ways.

These interventions place enormous physical strains on the body. There is often little time to recover from one treatment before the next one starts.

The treatments themselves may make it difficult for you to sleep and eat properly - two critical parts of the body's defence and recovery system. Some of the treatments drain your energy and resources to such an extent that it’s as much as you can do to put on the kettle. Add to this the emotional turmoil - dealing with the impact and implications of the diagnosis, the uncertainty, the upheaval, the additional burden that you feel that you are imposing on family and friends, the loss of so many aspects of your routine.

Emotional stress can be as energy consuming as any physical activity. You also need to remember that your time in hospital may have been quite short - these stays have been reduced over the years as anaesthetics and procedures have improved - but this does not mean that the operation you have experienced was minor or that your recovery should mirror the brevity of the hospital stay.

Surgical procedures may have shortened, but our bodies haven’t yet caught up! They still need time to recover. After all that, is it any wonder that you feel wrung out and exhausted, without resources or reserves?

For quite understandable reasons people want to get back to doing the things they used to before the diagnosis but find themselves falling at the first hurdle because they simply find the whole thing too much.

However smoothly your treatment has progressed and however well you have tolerated the various indignities to which you are subjected, sometime simply to recharge and recover - to recuperate - is absolutely essential. This is the necessary foundation on which to build recovery. There is no one right way or length of time to do this. It may be a few days or a few weeks - how long will depend on your state of health before your diagnosis, your age, the intensity, frequency and length of your treatment and so on.

Recuperating is the very first step in a process of rebuilding. Take however long you feel you need. And, most importantly, give yourself permission to take this time.

06 Convalescence

This is a rather old-fashioned term, and in some ways it’s a shame that it has fallen into disuse, despite its association with bath chairs, rugs, bracing sea air and strengthening broth.

The word has a Latin root meaning 'to grow strong' - rather apt under the circumstances. How is this different from recuperation?

In some ways they are very similar, but the distinction is based on time. Recuperation is the immediate period following the end of treatment when you can begin to replenish you reserves of energy.

Once you have recharged your batteries, then you can begin to build up your physical and emotional strength - the process of convalescence.

Again, there are no set rules or guidelines for how long this can take, and the two processes merge into one another. But it is vital that you allow yourself time to re-build the foundations and recover the energy you need to start doing those things that you want to do - and, perhaps, to stop doing those things that you don't want to do.

This is well illustrated by the woman who, once she had completed her treatment for her breast cancer asked for help to '.. sort out her job, her marriage and her cancer - and in that order.' After eight sessions with a clinical psychologist, she had decided to change both job and husband.

Now that dramatic and planned rehabilitation programme will not be to everybody's taste or need, but all changes - however big, however small - require energy, time and commitment - which is why you need to ensure that you have allowed yourself time to recuperate and convalesce.
You will note that the phrase ‘getting back to normal’ has not been used in this section. This is quite deliberate and because it is such a tricky issue, the topic has a section to itself (**see Getting back to normal**).

07 Getting back to normal

It is important at this early stage to address the common hope on the part of patients and those close to them to ‘Get back to normal’.

If taken too literally, this can be more of a hindrance than a help and may become a burden which gets in the way of progress.

The reason for suggesting this is based on the observation that once heard, the diagnosis of cancer is unlikely to be forgotten. Whatever the prognosis, whatever your hopes, whatever your personality, the moment that you hear that you have cancer your life changes.
For many people their hope for the future is compromised, their trust in their world denied. Alan Bennett calls it ‘...the collapse of any imaginable future...’ (**Bennett, A. (2005). Untold Stories - Ups and Downs p 599**).

For many people the diagnosis produces a seismic shift in their feeling of stability - of faith in a stable and just world. We all make assumptions about our future and about our place in the world.

Whilst we all know at some level that our time is limited, the stark realisation of the possibility of our life’s foreshortened span in the form of a diagnosis of cancer brings us up short with a terrible and awesome shock.

To imagine that we can somehow forget the impact of that news or return to a state when that realisation did not have a tangible form is beyond most of us. We cannot return to that state of safety and stability - going back is not an option.
Dealing with the threat of the sense of a future denied is covered elsewhere on this site (**see Living with uncertainty**), but for now it may be important to acknowledge that to 'get back to normal' with the implication that nothing has really changed may be an unlikely hope.

Apart from the sense of vulnerability noted above, the whole process from diagnosis, through treatment to completion is entirely and utterly abnormal. For months your life is taken over by what must seem like an endless stream of clinic visits, of being prodded and poked, scanned and punctured, of waiting and watching, of hopes realised and hopes dashed.

Your life has been taken over by others, run to someone else's timetable. There is every reason for wanting to get back to something that is yours to control, yours to manage, back to something familiar. However, to try to do that when so much has changed is a difficult, if not impossible task. The trick is how to regain control and stability in a changed world. And the world has changed not just for you but for those around you.

There is another phrase that is sometimes bandied about in a way that is not always helpful along the lines of ‘You need to put this all behind you and move on.’

The suggestion here is that you can somehow pack all your fears and experiences neatly away in a little box, never to visit them again and to act as if nothing has happened. If only life were that simple!

No-one can simply forget things that have happened to them, particularly not the shock of diagnosis and the demands of treatment. Furthermore there are often very powerful reminders of what you have experienced in the form of changes to your body or clinic visits for check-ups or anniversaries of significant events such as the date you were diagnosed, had your surgery or finished chemo.

Forgetting about such a powerful set of experiences is not an option.

Time and effort will help the memories change - some of the worst experiences may fade and lose some of their intensity, some of the best may become embedded in your personal history, some will simply become so distant that they become unclear and inaccessible. They become incorporated into your life story, changed perhaps, but not forgotten.

'Moving on', a fashionable phrase applied to all sorts and manner of troublesome experiences, is often used to shut down and to close off thinking (and feeling) about painful events prematurely.

It more like saying 'Let's move away from this painful topic because I don't want to talk about it'. Of course it is possible to move on from painful memories, but only after they have been dealt with and confronted in a meaningful way. Leaving them behind untouched is often not the best way of dealing with them.

When people around you use this phrase it's often to save their pain rather than an attempt to help you - they can't bear to listen to your hurt because it causes them pain in response, so they react by attempting to shut off conversation completely.

This is a difficult issue to deal with sensitively and calmly. One way is to be absolutely frank and open about it and deal with it directly: one phrase that might be useful goes along something like....'I know this is painful for you to hear but I need to let you know how I feel. I am not expecting you to make things better and I am not telling you this to gain sympathy or to hurt you but I really need to say how I feel and let go of some of my distress.'
Yet another phrase of dubious help is 'Coming to terms with cancer'. It's worth spending a little time on this because the phrase is used in all settings when people are having to deal with the most appalling and overwhelming trauma. In the section on coping (**see What do we mean by coping?**) it is suggested that you ask yourself 'How would I be if I was coping?'.

In a similar fashion, if you feel that you are not coming to terms with cancer, ask yourself the question ' How would I be if I had come to terms with cancer?'.

Most people find his an impossible question to answer and it often leads into quite unrealistic expectations - almost acting as if cancer had never happened and that it was just another of life's little problems.

Time and effort can alter how you feel about cancer, can allow you to put it in its place in your own life history as we have noted when talking about 'Putting it behind you'. Coming to terms with anything is not about forgetting, it's more about incorporating the experience, smoothing off the rough emotional edges and trying to incorporate it in your own life experience.

A similar phrase is the you must '..learn to accept the cancer..' This often comes with the implicit suggestion that you should also feel OK about the cancer.

This is another example of asking or expecting too much. It is one thing to acknowledge the fact of the cancer, quite another to expect to welcome it which is what is often associated with the idea of acceptance.

Yet another word used in this context (often by health-care professionals) is adjustment and some psychiatrists may use the phrase adjustment disorder (sometimes this is used as a psychiatric diagnosis) to describe serious emotional distress.
The problem with this terminology is that it implies that there is a 'correct' adjustment - a sort of standard against which you can be judged. James Brennan (a clinical psychologist who has worked extensively with people with cancer) discusses the whole of the issue of what we might mean by the term adjustment (see **Brennan, J. (2004). Cancer in context. Oxford: Oxford University Press**). and, drawing on both his clinical experience and psychological theory, describes a model of what he calls a Social-Cognitive Transition model of adjustment which he notes '...is a model of normal adaptation in which the individual and their social world struggle to make sense of changes imposed by the disease and its treatment...'. [Brennan, J. (2001). Psycho-Oncology, 10, 1-18.]

Of all the words that won't do, is there one that will? Perhaps the word ordinary fits the bill. After all, your life from diagnosis to now has been quite extraordinary. You have been catapulted into a strange and overwhelming world of hospitals and clinics; of new, unfamiliar and frightening words; met hundreds of new people; had to confront issues that you have not faced quite so starkly and brutally before - and if that's not extraordinary, then it's difficult to imagine what is.

So rather than trying to 'get back to normal' your aim might be to 'regain a sense of the ordinary'.

08 Surviving cancer - some figures

Looking at statistics is not for everyone, so if you are one of those people for whom the survival figures are more frightening than helpful, then go no further.

09 Survivor - what's in a name?

So who is a survivor? This is a controversial area and there is no real agreement as to who fits this description. In the US, where the **survivorship movement** has been developing since 1985, it has been suggested that survivorship begins at diagnosis.

Not everyone agrees with this and one of the reasons that this site hasn't used the words survivor or survivorship is because this is such a problematic area. And the names we use matter.

Using such a term universally may not be to everyone's liking. From the moment you are diagnosed your rôle and position in your world changes. You start out as an ordinary person going about your business as usual. Once you go to see a doctor and become a patient then certain things change - the roles of 'doctor' and 'patient' give people permission to act in different (and socially approved ways) that are not acceptable in more everyday circumstances.

Just imagine a friend or neighbour asking you some to the questions that your doctor or nurse may ask - or them doing some of the things to you that you allow a doctor or nurse to do to you. So becoming a patient changes how people behave towards you and how you may feel about yourself.

If we now move on a stage and you are diagnosed with cancer, you become a cancer patient. This again changes things and you move into a different category of patient - perhaps people will react to you in a new - and not always helpful - way.

You may even get tagged with the label 'cancer victim', a term much used by the tabloid press to refer to celebrities with cancer. This is an awful term, implying as it does passivity and helplessness. Another result of media interest is becoming a cancer hero - someone who battles against all the odds and does truly heroic physical feats despite their diagnosis.

These labels are often thrust unwillingly upon an individual who is put in a difficult situation where they may be trying their best to deal with their cancer without the added pressure of the glare of publicity. It can become an enormous burden on the individual, their family - and on other patients all of whom feel that they must live up to this standard but for good reasons are not able to.

The last of these labels is cancer survivor - someone who has successfully overcome the hurdles of treatment. But this is not without its problems. Look at the list below:

- Ordinary person

- Patient

- Cancer patient

- Cancer victim

- Cancer hero

- Cancer survivor

Two observations - first, where is the person in all this?

All the labels are roles, not individuals. Second, cancer always comes first. If we talk about people with cancer then we don’t put the cancer first and, when we take the cancer away, we are left with a person. And this matters.

There is a common conflict once treatment has finished summed up by a women who was struggling with how she wanted people to respond to her. She - understandably - wanted some acknowledgement and respectful sympathy from friends for what she had been through. But she also didn’t always want to be known as ‘that women who had cancer’.

Often people wish to simply to acknowledge that the cancer was part of their life but is now longer a central issue. Yes, they have had cancer but it can, hopefully, be relegated to a less central position.

10 Regaining trust in your body

For many of you, your cancer will have been discovered whilst you were feeling reasonably well and healthy - either through some sort of screening programme, through investigations for another illness or for a relatively innocuous symptom.

You may have had few - if any - times when you felt ill or had very troubling symptoms (this is not true for everyone, but it is a common experience nonetheless).

How is it possible to have the disease that so many dread without feeling sick? This is another of the many paradoxes of cancer.

Surely if you are ill then you should feel ill? This doesn't last long however, because you then start treatment - and for most people that's when they do start feeling ill.

All the treatments change your body in one way or another, sometimes permanently and often for a period of time that lasts much longer than the treatment itself.

One of the consequences of all this is that you may lose faith in your ability to recognize when something is wrong with your body. After all, you may not have been able to tell that you had cancer in the first place and your body is now significantly changed so that there is a whole set of new and unusual sensations to experience.

This is most marked in the period after treatment when the anxieties are still high and the uncertainty at a peak. Is this lump the cancer coming back? What does that pain mean? Should I go back to the clinic, just in case? Such anxieties are perfectly understandable under the circumstances. Alan Bennett wryly observes that ‘...Cancer licenses hypochondria. Watchful for the disease’s recurrence, one feels that there is no ache that can be safely neglected or symptom ignored. In early detection lies the best hope of cure...’. (**Bennett, A. (2005). In Untold stories Ups and downs, pp 613-614.**)

The rules have changed and you need to learn a new way of handling the aches and pains, lumps and bumps that you would not have given second thoughts to before all this started.

This will all be made worse by a perceptual bias and hypersensitivity to these changes. All this means is that you will be on the lookout for them in away that you were not before. You may be monitoring your body in a much more intense and detailed way than previously.

This is a combination of doing what you have probably been told to do by the clinical staff and your own real anxieties and fears. Previously insignificant and benign bodily changes become magnified and interpreted as a result of your immediate past experience.

It is important to keep this in check and to give yourself some guidelines to manage your fears. For example, if the pain lasts for more than a couple of days or gets worse, if there are symptoms associated with the site of your surgery for more than a certain length of time, only then might you need to call your doctor.

Your consultant and specialist nurse will be able to give you guidance as to what they think will be important.

Whilst many people quite naturally, and over time, learn to manage this unpleasant and frightening experience, some will not, especially if they have always been a 'bit of a worrier' about their health. In this case, it is important that you have very open conversations with your consultant, your GP and specialist nurse about how you can access expert reassurance quickly and without having the sense of being a nuisance.

Just as you have learned about your body whilst you were growing up, so you can re-learn about it in later life.

This lack of trust in your body may be made worse if you have been through a difficult diagnostic process. Whilst it is possible to make a speedy and accurate diagnosis, some of the presenting signs and symptoms (a breast lump, bleeding from the back passage) are often associated with problems other than cancer.

In order to exclude these more common problems and to avoid over-worrying patients, doctors sometimes will play down the possibilities. This may not always be the most helpful thing to do but it is sometimes seen as a way of protecting the patient.

However, this really does become a problem if it develops into a bit of a battle between you and the doctor. If you feel that you haven't been taken seriously and you feel that your concerns have been brushed aside then this creates a whole new series of hurdles.

A good example is of a woman who had a history of lumpy breasts. She had been seen regularly by her clinical team and, as with many women with this condition, her lumps were benign. However, she noticed that one lump felt different and this worried her greatly. In her view, this lump was different. Unfortunately this opinion was not held by the medical team who assured her that it was benign and that there was really nothing to worry about. Whilst this went some way to relieve her worries, she still felt that there was something wrong. She returned to clinic but got the same ‘don’t worry’ message.

This went on for some time and her worries increased because she still felt that this lump was different. She decided that enough was enough and demanded that the lump was more fully examined. With some reluctance the team arranged for a biopsy. When she returned for the results she was told ‘Well, you’ve given us all a bit of a shock’ as the lump was, in fact, cancerous.

This outrageously insensitive statement is a prime example of how not to tell someone they have got cancer. But there is another important issue here. She had gone to the ‘experts’ with a problem. In her judgement, there was something wrong with her body, but the ‘experts’ had told her something different. Who should she trust - herself, with all her knowledge of her own body acquired over many years, or the ‘experts? It took a good deal of courage on her part to disagree with her clinical team and she got no satisfaction from finding out that she was right and they were wrong. But it undermined her judgement both in herself and in the system that is meant to be here to help. Not only was she left with a loss of trust in system but she also was left feeling uncertain about how to read her own body.

11 Regaining trust in your body - Managing the fears

A fairly common experience when people become frightened by unusual and unexpected changes in their body is that they wonder whether it’s a sign of the cancer returning. As we have seen, this is not an unusual or an illogical thought to have - it makes sense. This can become a problem when your thoughts change from wondering to expecting.

Let’s look at this in some more detail. You notice an ache or pain. Before your diagnosis, you might have thought briefly about it, perhaps decided to ignore it, perhaps found an explanation but dealt with it without very much additional thought.

This all changes after your diagnosis because the possibility now exists that this might be a sign of something more sinister which cannot be just brushed aside. This much is quite understandable and no-one can tell you that your worry is silly or unrealistic.

The danger comes when your thoughts immediately turn into ‘This is the cancer coming back’. A fear has changed from a possibility to a certainty, from ‘might’ to ‘will’. If this is happening to you, then there are a few simple steps that might be helpful to reign in your fearful thoughts.

- First, you must not tell yourself that you are being silly! It is true that an ache or pain might be a sign of the cancer coming back so to worry about it is not worrying over nothing.
- Second, focus on the word might. If you can accept that word rather than the word will, then there is an opposite thought to contemplate ‘the cancer might not have come back’. For every might there is a might not. This is very important, but it is risky. You may feel that you are somehow tempting fate - if you believe that it is not cancer then it will turn out to be malignant.
- Third, and most difficult, is getting a sense of probability - might and might not are expressions of chance and balance. Is it more or less likely that this is the cancer returning? The aim is get a sense of balance that you can live with without your fears dominating and overwhelming you. You can do this in a number of ways. You can ask yourself if you have had a pain/symptom like this before you were diagnosed. If so, try to remember what it was caused by and what you did to manage it. You may also need to remind yourself that many symptoms have more everyday causes than cancer - a headache, for example, can be due to dehydration, lack of sleep, tension, that extra glass of wine last night. It can be helpful to think of other causes before including the possibility of the cancer's return.

In going through a process like this you may well find that you feel in a bit more control of your fears - those fears may still be there but they may feel less overwhelming. This process is simply taking your fears seriously by acknowledging their basis in reality, but then dealing with them in a direct way.

12 Dealing with a changed body

One of the many possible consequences of treatment for cancer is a changed body - either temporary or permanent. Such changes can be very obvious - such as hair loss during chemotherapy, the loss of a breast; less obvious to others - a reconstructed breast, a colostomy, a scar hidden under clothing, loss of a testicle, erectile difficulties; or essentially hidden - and internal - removal of a woman's reproductive organs.

All such changes are likely to affect how you feel about yourself and how you relate to your body and to the outside world. How you react to these changes will depend on a number of factors - how permanent the changes are, how obvious to others, how embarrassing you find them, how important your looks are to you generally - the list is long and individual. But there are some general issues that might be important to deal with here.

It may be helpful to emphasise that whilst much of the research in this area has concerned women, how we look and how we feel about our bodies and ourselves applies to men as well.

- Firstly, it is not ‘mere vanity’ to be worried about how you look. How we see ourselves and how we feel about how we think others may see us matters. And whilst we may not like it there is a strong tendency these days to be over-concerned with looks - you only need to scan the covers of the so-called celebrity magazines to see this. So to be worried about wearing a wig or a headscarf or prosthesis makes sense - it’s about how we see ourselves and about how we present ourselves to the outside world.
- Secondly, it’s more about what you feel than about what others say. Your partner may express no concerns about your surgery scars, but if you feel that it is disfiguring then that feeling will over-ride any reassurance that others may offer.
- Thirdly, some people struggle with the issue of a part of their body not being ‘theirs’. This is fairly obvious when it comes to wearing a wig, however life-like or true to your own hairstyle it is. You are always aware of it, it may be uncomfortable in hot weather, you may worry about it blowing off in a wind or being awry so people notice it - you are never as relaxed with this addition to your head as you will be with your own hair. But what about other additions - a breast prosthesis or reconstruction, for example? This is more difficult because it may be permanent and, in the case of a reconstruction, part of your body being used to replace the removed tissue. For some women the new breast may not feel as if it is part of them, even if it is a part of their own body that has

been used. It may feel just a little bit unnatural, especially at the beginning. This is not altogether surprising and may be a lot more common than we think - because it may be something that is not talked about very much.

An unwillingness to talk about these issues is sometimes felt to be a sign of feeling ungrateful or over-complaining. After all, a great deal of effort has been put into saving your life by a team of skilled and dedicated professionals. To say that you are somehow dissatisfied suggest that you may be criticising their efforts to help you.

You may also feel that the changes may be a small price to pay to a life-saving intervention - and this is something that you may have been told by others. It is quite possible to feel gratitude for the care you have received at the same time as feeling unhappy about the results. The two are separate issues.

You may well wish that you were not in the position where surgery had been necessary and regret the consequences. You can still be grateful for the skill of the surgeon and the care of the staff in looking after you despite what they had to do.

13 Dealing with Fatigue

Of all the many consequences of cancer treatment, fatigue may be one of the most common and the most difficult to deal with. It is hidden from the view of others and is often difficult to describe.

Those people who have not experienced it may simply think of it as a sort of over-tiredness which will be solved by a few good nights' sleep. But as you know it's not like that.

Cancer-related fatigue is not like anything you have experienced before.

Even the simplest of tasks feels as if you are wading through treacle. Because it doesn't show on the outside both you and those around may feel that it's something that you should be able to get over simply by trying that bit harder.

The trouble with that is you are trying as hard as you can and you don't have the energy to put in any more effort. If you had a seriously broken leg and were hobbling around on crutches, not only would others see your predicament but you would as well and wouldn't expect yourself to have the mobility of someone without a hulking great plaster cast on your leg.

With fatigue you have the equivalent of a plaster cast around the whole of your body which hinders you from doing as much as you want.
What research there is into fatigue suggest that up to 90% of patients report some degree of it during their treatment - particularly chemotherapy.
After the treatment has finished, it is suggested that about a third of people report some degree of continuing fatigue. **A recent long-term study** of women treated for breast cancer suggested that around 20% had problems with fatigue up to ten years after treatment was completed.

So how do you deal with it? Perhaps the first and most important thing is to acknowledge that this is real, that you are not slacking or not trying hard enough and to stop telling yourself off.

Secondly, it is a helpful general rule to break tasks into easily manageable pieces - 'bite-size chunks'. Use a walk to the local shops as an example. Before your treatment you may have been able to do this without a problem. Now it's an uphill struggle and you either can't face it or you come back exhausted.

Don't even attempt to do the whole journey yet. Work out how far you can walk without over-tiring yourself - say it's 100 yards (or metres for those amongst you who are more up-to-date!). Then set yourself the target of walking 50 yards (which, of course makes 100 yards there and back).

You may do this easily and feel that you could have done more. Great! It's always better to feel that you could have done more than come back feeling that you have done too much. You can always walk further tomorrow.

Each time you try it and feel OK then walk a bit further the next time until you get to the shops and back without exhausting yourself.

It might be helpful to think about this using a sporting example. If you were a top-class athlete who had injured themselves you would not expect (nor would be allowed) to get back to top form straight away. You would be put on a gradual programme of exercise and jogging before even thinking about sprinting.

It very much the same with getting back to doing things after cancer treatment. You cannot expect to get back to doing ordinary things straight away - you have to allow yourself to build up your strength bit-by-bit, literally one step at a time.
There is some evidence to suggest that mild graded exercise can help with exercise capacity and muscle capacity, although the benefits are less clear-cut in the case of fatigue.
There is also evidence that **cognitive behaviour therapy** can be of help. Before taking any of this on, however, it is important to get appropriate advice from your care team.
Find out more

Is it fatigue or am I depressed?

This is a difficult question to answer. One of the features of severely depressed mood is lack of energy - a feeling rather like that experienced by people with fatigue.

However, an important difference is that with depression there is often an additional lack of motivation - rarely present with post-treatment fatigue. You may want to do something but simply feel that you haven’t the energy to do it. One of the effects of fatigue is a sense of frustration and annoyance with yourself which can, in turn, lead to a feeling being heartily fed-up and down. And because you are fatigued, you cannot do the things you did before which gave you a boost - going out shopping, meeting friends, hobbies and such like.

This lack of opportunity to enjoy yourself as you used to can also lead to feelings of despondency and lowered mood. So it can be a bit circular, with each aspect - fatigue and low mood - amplifying the other. That’s one reason for not telling yourself off unduly for not trying hard enough or expecting yourself to be living at the same pace that you did before the treatment started.
Taking on a gradual programme of activities, a bit at a time, step-by-step, can increase your sense of doing something and getting somewhere. Dealing with the seeming slowness of your progress is an important aspect of **regaining your sense of mastery and control**.

14 Dealing with ‘chemobrain’

A number of people report that their brain doesn’t seem to work as well during chemo - a phenomenon that may last well beyond the duration of the treatment for some. This is probably a more common experience that is generally reported.

There are so many things going on in your life, so many changes, so many unpredictable events that it probably seems quite natural that you feel a bit muddle-headed. However, once things begin to settle a little as the treatment ends, you may find that there are some residual problems which cause you concern - you may feel that your memory is not working as well as you remember or that your concentration is all over the place or that your motor co-ordinator is a bit awry.

Whilst there is little doubt that many people experience a loss of mental sharpness, just why this should be is not an easy question to answer. Many factors can affect how we think and act - as well as how we assess and judge our own performance.

The stress and worry of the diagnosis, for example, can send you into a state of extreme worry which can have profound effects on your thought processes as well as being a powerful distractor. This distraction can mean that you pay less attention to things which will affect your memory as things do not get properly registered.

You are also in a situation which may be quite unfamiliar to you, having to grasp a huge amount of new and complex information which may be difficult to understand. In some cases, the cancer itself may have had subtle effects on other bodily systems which may affect cognitive processes.

If you are finding the problem worse on returning to work it may be a symptom of simply being out of practice - many of us experience a problem settling back into work even after a short holiday - and your break has been neither short nor a holiday. Many of us also experience a loss of clear thinking if we have a relatively minor illness - so if that happens after a dose of the ‘flu, think what could happen after a much more significant disruption to your health.

The problem can be amplified by our awareness of it. You may be - quite understandably - fearful that your memory is not as good as it was and that it will not only not get better, but may get worse. In turn, this may lead to you to feel that you will never be able to function normally again. So you are not only monitoring each ‘failure’ and becoming very aware of these (and will probably take less notice of any ‘successes’) but your worry and anxiety will also make your performance less effective, so you get caught in a self-defeating loop.

All-in-all, therefore, there are many possible explanations for the cognitive decline that you may be experiencing, and the effects of chemo may be just one of them. There is some scientific evidence beginning to accumulate on this problem, but like the phenomenon itself is does not give a clear or straightforward answer.

One problem is that it is actually quite difficult to measure accurately, easily and quickly what are quite complicated functions. There are also important individual differences - we all have different strengths in our cognitive system and our performance itself can vary over time (for example, you may be better in the morning whereas your partner may be better in the evening). So any formal testing has to take account of these factors as well as all the many disease and treatment differences that might influence test performance.

What does seem to be emerging is that for some people there are quite small, but measurable, effects on memory and some other cognitive functions some of which are detectable for a number of months post-chemotherapy. The evidence so far does not suggest that these effects are major or serious.
Most of the studies have been done with women treated for breast cancer and most have not looked at time periods longer than two years after the treatment has finished so we are still a long way from having a clear idea of just what is going on. Recent research on the effects of 5-FU (a commonly used drug in chemotherapy) on the central nervous system of mice gained quite of lot of **coverage in the media in 2008**. Whilst these findings are clearly important, it is vital to remember that the distance between mice and the complexities human behaviour is considerable and a great deal more work needs to be done.

So is there anything that you can do about this? The short answer is yes. Perhaps the most important first step is (as with many other issues we have discussed here) not to be cross or annoyed with yourself and think that if only you tried a bit harder it would all come good. These effects are real and there are quite logical and understandable reasons for why they might be occurring as we have seen.

It is also important to look at the time since your treatment finished. What you have experienced in the first few weeks post-treatment will be very different from what you experience twelve months later.

It is also very important (and much easier said than done) not to worry overmuch about this - worry will make things worse rather than better. You do need to ask yourself some questions, however. Have you actually forgotten anything very important (an appointment, a birthday or anniversary, for example)? Are you able to function on an everyday level reasonably effectively?

Remind yourself that before your diagnosis and treatment you forgot things, mislaid your glasses or car keys - many of us have lapses of memory and concentration in everyday life irrespective of whether we have been treated for cancer or not.

For a few weeks you may have to make lists or keep a diary - which is quite normal and may just give you the confidence you need to trust your own thought processes.

If you are really worried that your are not functioning as well as you used to or you feel that your mental processes are getting worse than you should discuss this with your specialist. It is important to bring some evidence of what you experience in some detail so they are able to decide whether to refer you on to a clinical neuropsychologist who would be able to assess your cognitive function in greater detail.

15 Regaining trust in yourself

Many people, from all walks of life, say that one of the most difficult consequences of their illness and its treatment is their loss of confidence. It seems to make no difference if you are a woman or a man, old or young, have a high-powered demanding job or are retired.

Cancer is a great leveller in this as in many other respects. Of course one of the great problems with confidence is that no-one else can give it to you: you cannot get your doctor to write a prescription or buy it in a bottle from the supermarket.

You gain confidence by doing things and developing your sense of self confidence - but how do you start when you are not confident enough? It's very easy to get trapped in a self-defeating and immobilizing loop from which there seems to be no escape. Exactly why this should happen is not entirely clear.

Part of it is probably due to the sense of uncontrollability and the experience of powerlessness that cancer and its treatment engenders. Another factor that will undoubtedly contribute is the sense that the world is not a safe place any more - that you are vulnerable and at risk is brought home to you with a terrible certainty.

This can manifest itself in a number of ways, but one that seems very powerful concerns holidays. Many people have the idea that what would be really nice at the end of treatment is a real holiday. You or your relatives may plan to have a break very soon after treatment ends. But when it comes to it, when you have finished, perhaps the prospect doesn't seem so attractive after all. For many people, the period immediately after treatment is marked by real feelings of vulnerability and of not wanting to stray too far from home or from the easy reach of medical and nursing care.

Apart from the tiredness and fatigue, the feeling of not being entirely safe is powerful - powerful enough to spoil a holiday or break. There is also the sense that you cannot afford to look too far into the future, that planning too far ahead brings its own worries and fears.

Your time horizon has been understandably limited to the next treatment, the next clinic appointment. You may have been living one day at a time. To switch suddenly to planning six months ahead seems to be a task too much.

The point at which you can look forward to and plan a holiday is a key milepost in your road to recovery. It doesn't always happen quickly and often not as quickly you might like, but happen it does.

One way to manage this particular issue is to plan for short trips away - perhaps a couple of hours - to places you know and with which you are familiar. Once you can do that without too much anxiety, then perhaps a few trips for a bit longer - but not staying away from home overnight just yet.

When that is done to your satisfaction, you can plan to spend one night away - and not too far away - and so on, building up gradually, one a step at a time.

That model is the key to many aspects of the rehabilitation programme which will rebuild both physical and emotional strength - one step at a time. It is much better to set yourself an easy target which you know you can achieve and end up saying to yourself - 'That was easy, I could have done more of that' rather than going too far too fast and feeling that you have failed.
Breaking down all the tasks of living into easily manageable chunks - a step at a time - is a well tried and tested route to success (see also Dealing with fatigue).

In our enthusiasm we often forget just how complex and difficult this life business is, and it's only when you have to get back on the roundabout that you realize this.

Sometimes living is like competing in an Olympic event - but because we take it so much for granted we forget how demanding and tiring it can be, even at an ordinary, everyday level.
Let's take this analogy further and pretend that we are all Olympic sprinters who have had a serious injury (see also section on **Fatigue**). We would not consider getting back to running the 100 metres until we had fully recovered. We would put ourselves on a gentle retraining programme, beginning with gentle walks rather than sprints.

Getting back to living life should be done in the same way - a gentle build-up to the main event.

16 Why don't I feel happier?

There are two sets of feelings that commonly arise at the time of treatment finishing which need to be talked about.

The first of these is a sense of abandonment. This makes sense. After all, for many weeks - if not months - you will have been cared for by a large number of people, all of whom have your welfare and well-being at heart.

You may have met other patients and relatives with whom you have been able to swap stories and get powerful support from someone who really understands. There has always been someone there to check out that little niggling pain or troublesome symptom. There has been a routine, a structure for you to trust in. Then all of a sudden, it goes.

One patient described it like this: 'I got the impression of being balanced on a plank somewhere high up and with nothing to grab hold of. I felt as if I were about to fall off into some abyss.'

Such feelings of aloneness and abandonment are not in any way a criticism of the people who have been caring for you. It is simply a reflection of the fact that they now have to focus on those who are starting out on the process that you have completed.

The second set of feelings that some people experience is a sense of disappointment that they don't feel more joy and happiness at the end of treatment, but rather a sense of let-down, anti-climax almost. This can be in marked contrast to what they might have expected. How it is that hoped-for happiness does not arise?
There are a number of plausible explanations. One of these is that it hasn't actually finished as you may still be experiencing the effects of treatment even though its delivery is complete. You may also be still visiting clinic for check-ups so you are never really free of reminders of what you have been though. And there is the uncertainty and sense of threat that may continue well beyond the actual end of treatment (see **Dealing with uncertainty**). There is also the fact that you may be completely de-energised - plain exhausted - which does not leave much spare capacity for unrestrained ecstasy (see **Dealing with fatigue**).

In addition, you will have been looking forward to the absence of something unpleasant rather than the eager anticipation of the arrival of something pleasant. So perhaps it's not such a surprise that that there is lack of elation as treatment finishes.

17 Regaining trust in the 'system'

It is an unfortunate truth that some people have very bad experiences at the hands of the health-care system. While this happens to a minority of people, the fact that it happens at all is a bad reflection on the system as a whole.

The sorts of things that happen include a diagnosis being missed, investigations being delayed or cancelled, notes/scans/test results going missing or being held up, clinics being cancelled, treatment being delayed.

Some people feel that they have not been given the best treatment available or that their treatment has been carried out incompetently. For many people, complaints about the care they receive revolve around the communication process - what they are told and how they are told.

For some people, such negative experiences may never happen, for some it may happen so infrequently as to be tolerated, but for others it can leave a scar which may lead to resentment and distrust. It can also amplify problems in self-confidence (see **Regaining trust in yourself**) and trust in your own ability to monitor your health (see **Regaining trust in your body**).

If you are one of the unlucky ones, then it is not surprising that your faith in the system might be at a very low ebb. You may find yourself being wary of going to the doctor, being guarded in what you say or in need of some sort of redress for your hurt and pain.

All these sorts of feelings are unpleasant and can get in the way of how you access help and support. Because everyone will have a different set of experiences, there is no one answer to this and how to deal with it. This may be even more difficult if the reason for your upset lies within the people who you might have to keep seeing after your treatment has finished.

You may be able to request seeing a different doctor or nurse at the clinic and you can change your GP if you feel that this is the answer for you. You may make a formal complaint to the hospital or seek legal advice if you feel that there is an issue of professional competence to be addressed.

For many people, taking this course of action is to prevent something untoward happening to someone else. You may choose to do nothing.

Whatever you do it’s probably helpful to talk over you concerns with someone who you trust and can be a sounding board. One of the decisions they may be able to help you with is sorting out how much priority you give to the issue if there are lots of other things going on.

Dealing with issues like these is tiring and energy-sapping, as well as taking you back to re-live experiences that may be painful and distressing. You may wish to conserve your energies for more pressing or immediate issues and deal with this at a later time. Talking it through with someone who will take it seriously will help you decide what you want to do next - if anything.

18 Regaining trust in the outside world

You won't need to be reminded just how helpful a kindly word or supportive act can be. Likewise, you will need no reminders as to how hurtful and insensitive other words and comments can be.
We have already quoted one phrase which could be classed as not only impossible but unhelpful and insensitive as well - trying to 'forget all about it and put it all behind you - move on' (see **Getting back to normal**).

This, of course, is often just what the person saying it to you wants to do and it can make for significant difficulties in communication if you want to talk about your worries whilst they want to act as if nothing has happened. Although it is important to acknowledge other people's fears and anxieties which often provoke overly optimistic or excessively reassuring statements, it doesn't make them any easier to bear or tolerate.

It is quite probable that you will already have developed a mask that you put on in some situations in order to hide some of your real feelings. Most people need to defend themselves against the unwittingly hurtful or the crudely insensitive remark. Many of you will have learned to smile sweetly as someone says brightly to you "My, you look really well' when you actually feel terrible.
There will be times you will need to keep this defence going because people will still say unhelpful things. There are people who catastrophize for you...”I really don’t know how you cope. If it had been me I’d have gone completely to pieces" ; or those people who know someone..."My auntie/uncle had what you’ve got...they died of course" ; or people who tell you..."look on the bright side.. There are many worse off than you" ; or people who tell you (or order you!) that "You must be positive" (see **On being positive and thinking positive**); or those who completely ignore you, saying that they thought that you probably had enough on your plate of that "I didn’t know what to say".

You may well have you own horror stories which will leave their own mark on you and your future relationships.

Re-instating you social network - or re-configuring it - can be a difficult task. How do you feel about those people who left you well alone during your treatment? Do you want to start over again with them? What about those people who - perhaps unintentionally - hurt you with some of the things they said to you when you were struggling?

What about your fellow patients with whom you may well have shared some very close moments during your treatment - do you want to keep up a friendship that might remind you of those difficult times? There may be people around you who, in their anxiety to be helpful, actually get in the way of your recovery by doing too much and rather over-protecting you. Their offer to put the kettle on to make a cup of tea might be welcome but it can also undermine your ability to regain the ordinary. Putting on the kettle may be a symbol for you of regaining confidence and trust in yourself and may also be the limit of what you can do.

Over-helpful people may not be as supportive as they imagine! Perhaps the way to deal with this sort of problem is to be quite-direct in asking for what you want - not allowing them to give you what they think you want. The best sort of support seems to come from those people who ask you the question "How can I help?" and who are prepared to follow your request.

There is no easy or universal answer to these questions and they are decisions that only you can take. You may not feel able to confront these things right away - especially if it might lead to conflict with friends and loved-ones. But there may be a time when it does have to be dealt with if your feelings become ones of resentment or having been let down by people who you thought that you could trust.

People have often said that they find out who their real friends are during treatment for cancer. You do not want to add to your burdens by having to pretend and act as if nothing as happened when you meet people who have not given you the support you feel you need or deserve. So it may be that you have to be very straightforward with some people - and may even lose a friendship because of that.

These are not easy decisions to take and they may require a great deal of thought and discussion with trusted confidants before you commit yourself to doing anything.

19 Getting back into the ‘ordinary’ world

Most people think that cancer is like other illnesses - once treatment is completed, the disease is cured and then you are 'better'.

As you know only too well, the situation with cancer is infinitely more complicated than this simplistic analysis. However, how you manage the transition back into an ordinary world from the extraordinary one of diagnosis and treatment is not at all straightforward.
It is important that you do not allow yourself to think or feel that you ‘ought’ to be back to your old self immediately that you leave clinic after your last treatment. Apart from the need to recuperate and convalesce, the old self may well have changed and the idea of ‘getting back to normal’ may not be achievable (see **Getting back to normal**).
There may be some specific issues that confront you in this process.
One is about identity (see also **Survivor - what’s in a name?**). It’s all very well for people to say you have to put it all behind you when they still see you as somone who had cancer. As far as they are concerned, cancer is still a part of the way they see you however hard you want to be rid of it. There is an understandable tension - you may wish to be treated with some sympathy and understanding for what you have been through but you do not always want to be seen simply as that person who had cancer.

As with so many of the issues dealt with here there is no one simple answer and, again as with other issues, it’s about balancing a tension. One of the things that you can decide on is just how much (or how little) you want to talk about your illness and its treatment.

One of the problems that some people report is that they are met by a wall of silence when they may want to talk about their illness but people around them clam up - and sometimes stop you from saying what you want to say by reverting to the ‘putting-it-all-behind-you’ ploy.

Alternatively, people may feel they have some kind of right to know how you are and your life can become much more public than it was before. But you have a right to keep your life private (see also **Protecting your Privacy in the section on Coping**) . Sometimes it can help to distract people onto other topics to refocus their attention.

There will be times when you need to talk things through and there will be times when you don't - it really is in your control to decide this. But you may have to be quite assertive in managing this and this may not be easy for some of you.

20 Going back to work

This particular problem (how you identify yourself and how you talk about your illness) has a special relevance when talking about returning to work.

But before moving into the problems of managing your first day back there is a decision to be made before that - do you want to go back to work and, if so, when? Now this will not be a problem if you were not working before your diagnosis.

Likewise, the decision to return to work or not will be influenced by practical issues like money, especially if your income has dropped significantly during your treatment (an all too common problem). However, you may be in a position where you have some choice in the matter.
For many people, getting back to work is a key part of their return to 'normality' and the ordinary. This sometimes becomes an overwhelming pressure and can force people into returning too early, before their strength and stamina are back. But, as with regaining your energy and managing fatigue (see **Dealing with fatigue**), taking things in a step-by-step fashion is a helpful approach.

The first stage, of course, is the be realistic about what is and is not possible. Questions about changing jobs or working part-time may not be an option if your financial situation does not allow it. Whilst this is not the place to offer financial advice it is important to acknowledge that economic hardship is counter-productive to psychological well-being.
It may be that you would benefit from unbiased advice about this if it worries you and some support centres have welfare rights advice, as do some charities (see **Further help and support on the Resources page**).

So, if you are in a position where return to work is something you may have some control over, what decisions do you have to make? For some people the time after treatment has finished is an opportunity to decide whether they wish to stay in their old job, make a career change or stop work altogether.

These are not always easy decisions as so much of our identity, self-esteem and self-worth is tied up in what we do. It is important not to rush any decisions like this and it may be helpful to talk through the pros and cons with someone neutral who you can trust.

If you have a sympathetic employer (a luxury unfortunately not available to everyone) it may be helpful to talk about any alternative jobs that they might have. You may have been in a very stressful and demanding post and would prefer to take on something less pressurised, for example.

In this situation it is important to see a change as not giving in or being weak. It can be a very creative step in terms of taking care of yourself and ensuring that your future health is not compromised in any way. Whilst there is no strong evidence to suggest that stress on its own is a direct cause of cancer or its recurrence it would be foolish not to accept that over-exposure to high levels of difficult-to-control stressful situations will have a negative influence on general health.

So the first set of decisions revolves around whether to return to the same job or not. The next set of decisions is about how you manage your return.

Let's look at two different scenarios, one where you return to your old job, the other when you go into a new job. We will look at leaving work entirely separately. One important assumption - that you have given yourself enough time to build up your strength and that you have recuperated and convalesced.

One of the most disheartening experiences occurs when people return to work before they are ready and have to take more time off because they are not fully fit.
Going back to your old job after some months off is not going to be easy. Many of you will be familiar with the length of time it can take settling back in after even a short break like a holiday, so the length of time itself can be a major problem. Systems, procedures and people can all change and leave you feeling isolated and unsure, feeding into any residual lack of self-confidence (see **Regaining trust in yourself**).

Many of the more responsible employers will not allow people to return to work full-time after a significant period of sick leave and insist on a phased return. While the details of this will vary from company to company, the principles are very much in line with the one step at a time model outlined here.

It may start with a morning or afternoon, then a day, then two days and so on until you are ready to face the full week. Many people are surprised at how exhausting this process is and find that it can take some weeks before they can come home and not fall asleep immediately.

During this time you can familiarize yourself with the new routines and processes if you need (again, a good employer should ensure that proper training is in place to help you) or to re-acquaint yourself with former work practices.

These are relatively straightforward issues to address - a much more problematic one concerns how you want people to react to you and your time off sick. There can be embarrassing and uneasy silences when people may feel unable to talk about cancer or ask how you are. You may feel inhibited, not wanting to upset people or to feel that you are playing for sympathy. This is a decision only you can make. Sometimes it is possible, especially of you are in a relatively small and cohesive workgroup, to start out be setting down your ground-rules.

You may be the sort of person who is quite happy to talk about your diagnosis and treatment to whoever will listen; on the other hand you may find talking about the whole affair unpleasant and distressing. This is your call but it is often better to tell people how you want them to behave rather than assuming they know.

You yourself may have been in a position before your diagnosis when you were faced with someone who had cancer - did you feel confident in having a conversation with them? You may want to think ahead. Because cancer is so common, it may well be that one of your colleagues or one of their relatives or friends is diagnosed. Would you like to know or not? Again, by giving guidance on what you would like you are helping both yourself and those around you.

If you starting a new job then you will have similar additional burden to that you would experience whatever your history - how much do you tell of your immediate past? As before there is no single answer to this.

Honesty is generally the best policy and being open with your new work colleagues in the same way as outlined before avoids potential pitfalls. One advantage of beginning a new job is that you can start afresh with your own work discipline. Perhaps you will want to address that currently fashionable issue, the work-life balance.

One of the phrases that people use after the treatment finishes is the ‘Life is too short’. Taking this seriously can benefit your health and well-being in a significant manner.

21 Leaving work

For some of you, the decision about work will be to leave completely. Again, this may not be a realistic choice for some of you but for those of you for whom this is a real option it will need careful and thoughtful management.

We have already noted how much of our identity and life is tied up with work and leaving it for whatever reason can be a trying and challenging process. As before it is important to see this as a step towards something which will benefit you rather than as a failure of strength, courage, effort or will.

This is not to say that you need not go through a proper leaving process and acknowledge the real losses that giving up work may entail.

Retiring early on grounds of ill-health is undoubtedly different from retiring at the conventional retirement age - for one thing it is something that may have been forced on you and you may not feel ‘ready’. But you alone will know what is right for you and your future well-being, both physically and psychologically. Leaving work may be an investment you have to make for your future.

22 Living with uncertainty

This is one of the most difficult aspects of living with the aftermath of cancer. You will note that the phrase 'coming to terms with' uncertainty is not used, because the reality is that this is something to be lived with and managed, not 'come to terms with'.

For those people not living with this threat, this Sword of Damocles, truly understanding what it feels like is almost impossible. The nearest that we can get to it is to think about that phrase so often used lightly and as banter - 'See you tomorrow unless I get run over by a bus.’

The difference between those living with the threat of cancer returning and those free from it is that you have seen the bus coming and don't know whether it will stop in time. Until you can be given a 100% cast-iron, gold-plated, rock-solid guarantee that your cancer is completely gone, never to return, then you will have that nagging worry gnawing away at you.

Again, immediately after treatment finishes, these fears may be at their worst, compounded by the lack of trust in your body and the lack of confidence that you may be feeling. It makes sense that you would feel that way and the reality and power of your feelings need to be acknowledged by all around you, both lay and professional.

As time goes on, you may well find that the terrors inspired by the uncertainty reduce and are sent to the back of your mind rather than residing in its forefront.

However, it may not take much to restore them - clinic visits, milestones and anniversaries, high profile celebrities with cancer - can all serve as potent reminders of what you have been through and may bring everything flooding back with a vengeance. It would be surprising if this were not the case. Your experiences cannot be expunged or erased from your memory banks - they can be made less accessible, less easily revisited, but there they will be.

It would be impossible to simply 'Put all that behind you and forget about it' as some of you may have been exhorted to do. If only it were as easy as that. What is often helpful, to balance your understandable pessimistic and frightening thoughts, is to remind yourself of any helpful comments that your doctors and nurses have made. These are constructive alternatives that are not about naively 'looking on the bright side' but are real counters to equally real fears.

Imagining the future

We noted **Alan Bennett’s** comment earlier about the ‘..collapse of any imaginable future..’ and the problems of looking ahead to plan a holiday.

One of the things that often changes for people with cancer is a loss of future time horizon. Before all this happened you could think easily about doing things in the future - buying some expensive furniture, a wedding, a special birthday party, a significant wedding anniversary two years hence.

You think differently now - perhaps the new sofa will outlast you, perhaps you won’t be there to see your daughter married, to join your friends in celebrating their silver wedding. These thoughts are distressing and disturbing as they remind you that you have had a warning about your future.

Those close to you may try to dismiss these fears with a blithe ‘You’ll be alright’ but such glib phrases can be cold comfort if you are imagining a world without you in it. This is the time to remind yourself of the difference between ‘might’ and ‘will’, and to think in terms of hope rather than expectations.

It is not silly to be fearful of the worst outcomes - it would be very odd if you were not. As we have seen the way of managing these very real terrors is to confront them but to counter them with your optimistic ‘mights’ to achieve a sense of balance.

This idea of a sense of balance is important because it reflects the changing nature of your feelings. For most of us, most of the time we are not in a completely emotionally balanced state - there will be times when we feel better or worse, more or less at ease and stable even without all the demands of having come through cancer. Because you may be living with reminders of what you have been through, these are likely to raise fears and concerns, which is hardly surprising. But if you think about these as being things that alter your sense of emotional balance, it is possible to re-balance, if not immediately, at least after the worst of the fear has subsided.

It is not unreasonable or silly to be fearful of an upcoming clinic appointment for a check-up. You cannot be certain what will happen and you have to allow for the possibility that you may have further bad news. But, on the other hand, there is also the possibility that the news may not be bad (see **Managing the fears**).

As you gain more distance from the immediacy of the experiences, you will find that their power to terrify and disturb becomes less potent and powerful and that you are able to draw on your own, new, experiences of better clinic visits and less bad news, for example. These add to the store of 'good' experiences that you can remind yourself of to counterbalance the less good ones.

23 It's not always all bad

Some people report that the overall experience of cancer is not all bad or negative and that sometimes the diagnosis acts as a sort of 'wake up call' to review their life and its direction.

That is certainly not true for everyone and it's extremely important that you and those around do not expect that this will automatically happen - rather like the patient who was told minutes after her initial diagnosis "Now my dear, you can go off and do all those things you've always wanted to do".

A diagnosis is not a liberator, at least not initially when it constrains and narrows down options and possibilities. And to expect that people either can or should turn their lives around whilst they are struggling with the impact of the diagnosis and the demands of treatment is really beyond belief.

Some people seem to look for positive outcomes as means of coping with disappointment - the 'Every cloud has a silver lining' argument. This can be true and there is no doubt that some people can find some significant benefits as a result of a cancer diagnosis - but what happens for one person will not necessarily be true for another. And to be told that you should be finding benefit is an insensitive and unhelpful thing to hear. Benefit and growth do not justify pain and suffering, even though they may happen as a result of misfortune.

This is part of the process where you are more in control - you can chose to change as much or as little as you want at a time and in way that suits you. You need to remember that any changes to your life, whether planned or not, take time and energy and both those commodities may be in short supply especially during treatment.

One of the important opportunities that convalescence gives you is the chance to do some quiet reflection on what is important to you. One of the most common consequences of a major life event (especially a life-threatening event such as a diagnosis of cancer) is that people get a strong sense of their time being limited ('Life is too short') which in turn can lead to a sense of pressure to do things differently, to tie up loose ends, to settle old scores or to bury the hatchet, the list is endless.

These are intensely personal matters and only you can sort out what needs doing (if anything) and when. This is certainly one area which you should take slowly and gently, making sure that you have enough energy and commitment to carry things through.

There is a scientific literature developing in this area which goes under a number of names - post-traumatic growth and benefit finding being the two commonest. The fact that they have become higher profile is a sign that there is an important shift in how we look at people in general and trauma in particular.

In the past (particularly in psychotherapy and psychiatry) we have looked at things going wrong and an assumed lack of psychological resource. The ideas of human resilience in the face of threat and a positive psychology movement (looking at peoples' strengths) are a welcome change of direction (see **Further reading** for more on this).

24 What do we mean by coping?

The concept of coping is not specific to dealing with life after the treatment has finished but there are some general hints and tips that may help those of you who feel that you are not coping.

People mean very different things by this phrase and it is important to try and clarify just what you mean by it. Perhaps a good place to start is to ask yourself - what would I be like if I was coping?

Many people imagine that coping means being very stiff upper-lipped, tough and emotionless, dealing with every crisis without any difficulty. Whilst this may be a slight exaggeration, for many people coping has that sort of 'I should be able to deal with anything life throws at me' attitude - which is not always realistic! Note the use of the word 'should' in the previous sentence - this is one of those rather unhelpful words (along with 'must' and 'ought') that lead to unrealistic beliefs and the setting of unreachable targets.

Thinking like this can often lead to a sense of failure, of not doing well enough, or of not trying hard enough, all of which adds to the burden of feeling that you are simply not coping.

Another useful technique is to ask yourself the following question: ' If I was listening to a friend of mine describing all that I have been through, would I feel as critical of their coping as I am of my own?' Most people, when they do this, find that they are a lot more sympathetic with others that they are with themselves. If this applies to you then you really do need to ask yourself why you should treat others better than you treat yourself.

Returning to the phrase 'not coping', it is often used when the going is really tough, when you are feeling pressured on all sides, perhaps feeling as if you and the world around you is in complete turmoil.

Again it's worth taking a bit of time to ask yourself - is this an accurate reflection of my life at the moment? Is it actually in turmoil and, if so, might it not be OK to feel a bit in turmoil myself? This is what happens when you are engaged in the process of coping - it happens when you are called upon to mobilize all your resources to deal with demands and threats. You are only called on to cope when there is something to cope with and that process of coping may well feel very uncomfortable.

Coping is not a single process but a multi-stranded one, making use of a variety of strategies to deal with a variety of challenges. We select the strategy to suit the purpose - there is no one right way of coping that we can use all the time for all situations. Furthermore, coping is not an all-or-nothing event - it is a process which requires effort and energy.

The process of coping can be fatiguing, uncomfortable and very difficult. You cannot expect yourself to able to cope easily and without some cost. Too often people tick themselves off for not coping well enough when sometimes they should congratulating themselves on coping at all!

There are some general strategies that may be useful - this is not an exhaustive list and may not apply to you all of the time but may provide a helpful framework.
Confronting the issues
Openness to feelings
Privacy
Informing yourself
Networking
Grieving

Let's look at each of these in more detail.

Confronting the issues is a critical first step in the coping process. Most of the psychological research on coping has been informed by the idea that at least one of the key aspects of the coping response is an appraisal of threat.

That means that when we need to cope - that is to deal with a threat - we have to be able to try to understand the threat and what it means to our physical and psychological integrity. Only by doing that can we decide how to deal with the threat. We have to engage on a cognitive and an emotional level - with our head and with our hearts

- with the threat: ‘ Know your enemy’ if you will excuse the rather militaristic phrase. Once we have some sense of what the threat is, then we can mobilize our resources to deal with it.

Clearly, cancer is a major threat both physically and psychologically. Part of the process of dealing with the physical threat is to have treatment to remove the tumour and control the physical processes that underlie the growth of cancer cells.

A complementary and equally necessary process is to mobilize our psychological resources. These resources are scarce and need to be well-chosen and well-used if we are to maximize their effectiveness - so we need to confront, plainly and honestly, what the psychological threats are.

This does not mean spending all your time ruminating on what might happen. Threats need to be kept under constant review and this is one of the most difficult aspects of dealing with cancer as the nature of the threat is ever-changing and unpredictable.

One of the things that often catches people by surprise is they still need to keep this process up once the treatment is finished. An important theme of this site is that, even when the treatment has finished, you still need to maintain a watchful coping style to deal with the challenges that life after cancer treatment brings.

Confronting the issues can be a painful, distressing business and that is one reason why it is often better to do this a bit at a time. But confronting is necessary and one of its costs is the emotional upheaval that can result.

Part of the coping response is being open to feelings - all of them, good or bad, constructive and destructive, hurtful or helpful. As noted before, coping is sometimes characterized by being stiff upper-lipped, stoical and accepting. But if you think about the threats that you confront during cancer and its treatment would that be a normal way of acting?

For many people living with cancer their feelings are often confused and in turmoil, all-or-nothing, veering from one powerful emotion to another like some horrendous roller-coaster from which there is no escape. This should come as no surprise. Cancer brings with it threats to our very existence and being - not to be upset by this is the abnormal reaction.
A useful phrase to remember when you are berating yourself for being upset or for not coping is to say that you are experiencing ‘..expected reactions to extraordinary events’ (coined **by Michael Stewart and Peter Hodgkinson** in their work with people surviving major disasters). This encapsulates the emotional rationality of the feelings and the sheer terrifying uniqueness of the threat. So when you are feeling despondent or tearful or frightened please do not give yourself a hard time and tell yourself you are not coping. True courage comes in the face of fear, not pretending that fear is not there. The bravest people are those manage despite fear, not those who claim fearlessness.

One of the common experiences of being diagnosed with cancer is that you become public property - everyone wants to know how you are. One of the coping strategies, therefore, is to protect you privacy. There are a number of reasons for this.

First, there is the problem of repetition. Telling the same story over and over again does not necessarily get easier - sometimes it has the opposite effect and becomes harder the more you do it, particularly if you are talking about painful or difficult issues.

Secondly, not everyone who asks how you feel really wants to know the answer. This may have happened to you during treatment. One of the cruel paradoxes of the disease is that you may look very healthy whilst feeling absolutely dreadful.

So when people pre-empt you by saying ‘ You look well’ it is sometime difficult to say you feel rotten. Similarly you may feel unable to give an honest reply to ‘How do you feel’ question so you say “just fine”, a mask of social acceptability to protect the feeling of others - which is something that takes energy and eats into your psychological resources. And it hurts. This does not stop when your treatment has finished and can even get worse. You have a right to control what people know about you. It’s your body, your life - guard it well.

One of the most important changes that has occurred in the field of cancer care has been in the area of communication and information. There is now an abundance of information from an equally abundant variety of sources - although, it must be said, less so in the case of dealing with life after treatment. So an important part of coping is about informing yourself. The wording is important here - informing yourself. This is something that can be and must be within your control and yours alone.

The key to this is selecting the amount of information you need at the time that you decide upon and which is presented in a manner that suits you. While some friends try to be helpful by giving you books or pieces from the papers with the instruction ‘You really must read this’ you can chose whether or not to read them.

You know yourself and what you need better than they do. And remember your information needs will change over time - sometimes you may need lots, other times very little so be aware of your own changing requirements.

In order to make the acronym work the word networking is used rather than social support but they are really one and the same! Finding and developing strong and constructive support networks is a powerful element in the repertoire of coping strategies. The important word here is constructive. We have already seen how an insensitive and clumsy remark can trample hob-nail boots through your carefully constructed support strategies. There are people who catastrophise for you.."I really don’t know how you cope. If it had been me I’d have gone completely to pieces" ; or those people who know someone...”My auntie/uncle had what you’ve got...they died of course" ; or people who tell you...”look on the bright side.. there are many worse off than you" ; or people who tell you (or order you!) that "You must be positive" (see **On being positive and thinking positive**); or those who completely ignore you, saying that they thought that you probably had enough on your plate of that "I didn’t know what to say".
The final word - grieving - perhaps needs some explanation. Giggling, grinning and gallivanting could have completed the acronym and are all perfectly good coping strategies in some circumstances, but addressing the issue of loss addressed right at the start (see **Beginning to recover**) is a key element of the coping process. The losses that cancer can bring - independence, physical integrity, sense of self, sense of masculinity and femininity, self-confidence - are real and to be dealt with.

This ties in with confronting the issues. You cannot grieve for a loss unless you acknowledge it first. The loss of a body part, even if diseased and damaged is still a loss of part of you. The grieving process does not have to be long and drawn out, nor does it have to be shared. But it may be an important part of your overall recovery.

25 Do I need therapy?

There may be times when you feel that everything is getting on top of you and that you would benefit from some outside help. How do you know what you need and how do you get to it? This is a difficult decision to make and this brief section will only serve as the barest of outlines of what can be a bit of a minefield.

Perhaps it is important at the outset to set down some basic principles. First, asking for help is not a sign of weakness. Some people still think that going to see someone like a counsellor or a psychologist or a psychiatrist smacks of personal failure and lack of moral fibre.

This in no more true than thinking you a failure if you ask a mechanic to repair your car or a doctor to examine you. Sometimes we all need to seek help from someone with specialist knowledge. Particularly in the case of emotional distress, it can be very helpful to share your thoughts and feelings with someone neutral, outside of your family and friends, to whom you feel you could say anything without fear of upsetting them or of being criticised.

Second, if someone suggests that you might find it helpful to talk things through with a professional, this does not necessarily mean that they think you are ‘cracking up’ or ‘mad’. It may feel like this to you sometimes, but remember that when you are faced with overwhelming stresses and you feel that you are in turmoil, these may be appropriate feelings that reflect the situation that you are in.

It also does not mean that they think that what you are experiencing is ‘all in your head’ and somehow imaginary or unreal. They are picking up very real, very powerful feelings that might be useful to discuss in a safe, secure setting.

Third, you will not be committing yourself to weeks and months of lying on a couch talking about your dreams - the cartoon stereotype of a psychotherapist or psychiatrist.

There is not enough space to go into all the reasons why this is not accurate for the vast majority of professionals who use a variety of different approaches and techniques to help you. And in many cases, it may involve a couple of sessions talking about those things that matter to you.

You need to be able to have a very rough idea of what you might want ‘therapy’ to achieve. It might be a relatively straightforward matter of helping you to sort out the confusion and distress, to help sort out your priorities or it might be that you want a more in-depth understanding of yourself and what has happened in your life more generally.
We know that a variety of psychological interventions can make a meaningful difference to the well-being and quality of life of people with cancer and if you are interested in looking at this in more detail there is a section in the**section.**

So once you have made the decision, what can (and more important what can’t) interventions like these do? The primary aim for most professionals working in this area will be to help alleviate the distress that brought you to them in the first place.

They may also want to help with specific problems if needs be - extreme fear of needles, for example, or prolonged low mood that might stop you participating fully in your medical treatment. They may do this in a variety of ways, but all should involve listening to you in a non-judgmental and empathic way.

They should allow you to tell your story from your point of view. They may ask some gently probing questions if they need, but they should enable you to feel safe enough to talk about things that matter to you.

Being able to put your story together for a sympathetic listener may be all that you need - this may the first opportunity that you have had to do this, as your life has been so chaotic until this point. In fact, doing something like this after the upheaval of treatment can be a good way of starting to put things into place.

Sometimes your therapist will be able to tell you that what you are experiencing are expected reactions to extraordinary events and may be able to reassure you by validating your feelings. They may let you know that many people who have gone through diagnosis and treatment experience similar feelings so that you can feel that you are not the only one.

It may be that during this talk you or your therapist identify some issues that either of you feel might benefit from some further exploration. It will be your choice as to whether you want to pursue these at this time, later or even at all.

If you feel that this might help you, how do you find someone? Some cancer centres have good access to a variety of professionals such as counsellors, clinical psychologists or psychiatrists. Such people may be available to you even when your active treatment has finished.

The advantage of accessing someone who is part of the overall team managing your treatment is that they will be familiar with the specific issues surrounding cancer and can keep in close touch with other members of your care team.
Some cancer support centres either have people who work with them or may have lists of people who they know to be helpful and experienced. Sometimes other patients can tell you if they have found someone who they have found helpful. More information about this is available in the **Resources section**.

26 On being positive and thinking positive

There may have been times (indeed, there may still be times) when you have been told/exhorted/ordered to be think/feel/be positive as being the way to beat cancer. This may have happened more than once and from many people as it has become a sort of mantra in the field of cancer care.

The trouble with this phrase is that it means many different things to different people. Furthermore, it is often delivered at a time when you may be feeling quite vulnerable and low as it is often said in reaction to a sad or difficult conversation that you may be trying to have. It has the effect of telling you off and it may feel as though you are not trying hard enough or that you somehow shouldn't be sad or talk about painful things - it essentially closes down further discussion.

One of the problems is that being positive is often equated with cheerfulness, on being jolly and happy rather than sad or depressed. Some people use it in a ‘look-on-the-bright-side’ fashion, trying to convince you that things are not so awful as they seem and if only you would stop looking at the upsetting things you would be fine.

Whilst we may all want happiness, it is by its very nature, a transient emotional state. Very few people are happy all the time (whether they have cancer or not) and to be alongside someone in a perpetual state of mild euphoria (whatever the situation) would be very tiring (and probably rather annoying). This is an important issue because if you feel that you should be positive - in other words, happy - but are finding it difficult, it can add to your sense of frustration and failure and can, at worst, make you feel that you are not doing enough to fight the cancer or to prevent it coming back.

At this point it might be worth looking at some of the reasons why the use of the term positive thinking has come to be so important in the language of coping with with cancer. One reason has already been mentioned - it is used by other people who don’t want to hear you talk about upsetting things.

For example, many people with a diagnosis of cancer may want to talk about making a will - this can happen at any point from diagnosis to well after the end of treatment. This is not an easy topic for any of us at any time but when the threat of an untimely death (a common fear) looms large it is particularly upsetting.

However, it can be an important practical issue to be dealt with but for some people, discussion like this are thought of as morbid and should not be talked about openly, almost as if talking will hasten the unwanted event. So rather than have a sensible conversation, you are told ‘You mustn't talk like that, you’ve got to be positive” - in other words, "Keep quiet and don’t upset me."

There is another set of reasons arising from two separate lines of psychological research involving people with cancer. One arose from an unexpected finding in an American study study looking at the effects of group psychotherapy for women with advanced (metastatic) breast cancer.

When this group of women was looked at ten years after the end of the study it was found that the group who had received therapy survived, on average, much longer than those who had not. This was an unexpected finding and had not been part of the original experiment which was really set up to see if therapy improved psychological well-being. The finding itself caused quite a stir as you can imagine and there has been a good deal of controversy about it ever since. What it did do, however, was to feed the idea that being emotionally healthy could prolong cancer survival.

A different strand came from work carried out by Stephen Greer, Maggie Watson and colleagues in London. They looked at how people coped with cancer - their coping style. One of these styles they called ‘Fighting Spirit’ which was characterized by an outlook which aims to try and beat the cancer, to confront it head on, to acknowledge its existence as part of life but not to let it take over, to be an active participant in treatment decisions. You will note there is not a word here about happiness or not talking about upsetting issues - in fact, you can hardly take this stance without some pretty tough confronting of difficult themes.

At that time, there was some suggestion that people with this coping style had better medical outcomes that those with other coping styles. These two themes have both been used to bolster a view of dealing with cancer which suggests that emotional factors can have direct influence on the development of cancer and on its progress. At its most extreme, this view gives as much force to emotional causes of cancer as all the physical ones. It is important to state very clearly that there is no evidence for this view at all.

Clearly our thoughts and feelings have an effect - a powerful one - but to suggest that these influences on outcome are as great as, say, chemotherapy is simply not supported by the evidence.

There have been many attempts to reproduce the results of the original American study on the influence of psychological therapy on disease outcome and not one study has found an effect similar to that originally reported - psychotherapy helped people feel better (a good enough outcome in itself) but none showed an increase in survival time.
Similarly, long-term follow-up in the London group of Greer and Watson’s showed no survival advantage to the fighting spirit group. There is now such a strong evidence-base undermining the idea that psychological intervention prolongs survival that **some people** suggest that this particular research avenue should be closed down. BUT this must not be taken to mean that psychological intervention of a variety of sorts should not be given to people with cancer. Quite the opposite - its means that efforts should be directed towards such issues as coping and quality of life - where it is known that these efforts make real difference to people’s lives.
Find out more

So if the word positive is not helpful are there words and ideas that might be more useful? Two related ones that many people find comfort in are ‘optimism’ and ‘hopefulness’. You can be both without feeling obliged to be happy. And amidst all the uncertainty of cancer, its treatment and the aftermath, it seems quite legitimate to hope for good outcomes - and it is important that we do not confuse hope with expectation. You can hope for a lottery win - but you do not necessarily expect it.

27 Regaining a sense of mastery and control

The overall theme of this site is summed up in this phrase. We have seen how some of the losses that you may have experienced can be regained a bit at a time and how some of the losses have to be acknowledged and incorporated into your new life view.

This is not a simple process nor a speedy one. It will take time - and probably much longer that you imagine. It will not be a smooth passage either - there will be ups and downs as in any life. You will begin to feel more confident over time and as you gain some distance in time from all the stress and trauma of your diagnosis and treatment.

What this site has tried to do is give a sense that the end of treatment can be as challenging a time as any that you experience. It is made more difficult by the profound physical and emotional assaults to which you have been subjected. And it is the time when the obvious sources of support are unavailable.

There is every reason for feeling frightened and out of control at this time. But you can manage this process in a way that may avoid some of the pitfalls. Regaining and rebuilding your strength - both physical and emotional - is a task that cannot be emphasized enough. That is your foundation. And taking the time to reflect, either with someone or on your own, about where you want to go from here, can begin to give you the sense of mastery and control that you may have been denied during the treatment itself.

One part of this is the process of putting the experience of cancer in its right place in your life. For months, it has dominated, been in control. Now is the time to begin the long, slow process of putting in it right box in your life - not forgetting about it, not denying its importance or power, not pretending it didn't happen. It has to be incorporated into your own life pattern and experience in such a way as to not interfere and interrupt any more than it has to. You accommodate and assimilate it into your self, not come to terms with it.

The reflective process may face you with choices about where to go from here. The exact path you choose (or the one that you have already chosen) is entirely a matter of personal choice and circumstance.

Some of you will become stalwarts in the voluntary sector, helping others by running and managing support groups and becoming activists in cancer care and cancer politics - others will want to leave that part of their lives in a separate compartment and distance themselves from that experience. There may be constraints on what you can and cannot do, and that has to be built in.

Running the London Marathon may not be everybody's dream and it may even be a physical impossibility. But there are other aspirations and hopes that you will have fostered during your life. This may the time to review those and make some choices - some may remain dreams, some will be less important than before, some may take on a greater value, some will become a reality. They are yours and yours for the making.

28 Closing words

We have made a number of references to **Alan Bennett's** description of his experience of cancer, a moving, perceptive and wonderfully honest account as you might expect. He describes his feelings after his five year check-up revealed him clear of the cancer like this

‘And yet, more than anything else that I have written or otherwise achieved in my life, against all sense and logic, I feel pride in having come through, or come this far. Unlike so many others, much worse afflicted, I did not even have to fight. Yet I am thereby enrolled as a member, I hope a long-term member, of the exclusive aristocracy of those who have survived cancer.

Thankfully, it's a growing aristocracy, and one day, I’ m sure, such survival will seem commonplace and hardly worth mentioning. Meanwhile, I am one of the many who are here when they did not expect to be here. Take heart.’

29 Further reading and references

‘Patient-focussed’ reading

Find the right heading for this is difficult because you you are not really a patient any more, but as we saw earlier, the use of the word survivor has its own problems. The distinction between this section and the one below is not meant to suggest a hierarchy. Rather it distinguishes those materials that are often written by people who have gone through the the whole process or who have written texts in a style often more accessible that the rather high-flown language demanded of academic publishing.

In his excellent collection of personal writings Untold Stories, Alan Bennett describes his brush with cancer in a characteristically witty piece entitled ‘An average rock bun’. This is well worth a read, not only for the quality of the writing (no surprise there!) but also for the observations and comments.

Bennett, A. (2006). Untold stories. London: Faber & Faber.

There are many memoirs of cancer and its treatment and it’s impossible to give a fair and unbiased opinion of them all. You may well have found some useful that are not listed here.

Carr, K. (2004). It's not like that actually. London: Vermillion.

Dalnow, S., Golding, V. & Wright, J. (2001). 44½ choices you can make if you have cancer. Dublin: Newleaf.

Dunn, N. (2002). Cancer Tales. Charlbury: Amber Lane Press.

One of the academic authors listed later has jointly authored a paperback subtitled ‘The essential handbook to life after cancer’

Feuerstein, M. & Findley, P. (2006). The cancer survivor’s guide. New York: Marlowe & Company.

This has some very helpful ideas although some of the information is only relevant to the USA.

Although primarily written for health care professionals, there are some chapters in James Brennan's book which are very helpful. His writing style is easy and accessible as well as being very well backed up by psychological theories and ideas. The first three chapters are particularly relevant:
Brennan, J. (2004). Cancer in context. Oxford: Oxford University Press.

We have already noted the development of the survivorship movement in the USA and one useful resource is the National Coalition for Cancer Survivorship whose website is
http://www.canceradvocacy.org/

Clinical, academic and research reading

The academic papers referred to in the text are listed later. This section is a very selective dip into what is becoming a more active research field.
Life after treatment is being acknowledged as an important clinical and research area. For example, in the 2006 report of the American Cancer Society, Cancer Survivorship was the second of their Clinical Cancer Advances. A recent editorial in the prestigious Journal of Clinical Oncology identified the importance of developing consensus guidelines for cancer survivors. Both these US-based initiatives reflect how much this issue has taken root there. A very weighty (506 pages - although a shorter version is available!) book was published by the US Institute of Medicine and National Research Council in 2006 entitled From cancer patient to cancer survivor - lost in transition. This aims to map out a properly constructed care pathway for cancer survivors.

Institute of Medicine & National Research Council. (2006). From cancer patient to cancer survivor - lost in transition. Washington:National Academies Press.

A briefer summary and review of the symposium associated with this initiative has also been published under the same title:

Hewitt, M. & Ganz, P. (Eds.).(2006). From cancer patient to cancer survivor - lost in transition. Washington:National Academies Press.

An equally weighty volume - more of a book for professionals - summarizes much of the current research in this area with a strong psychosocial bias. Edited by Michael Feuerstein a clinical psychologist who has survived cancer, it comprises 26 chapters on a variety of important topics.

Feuerstein, M. (Ed.). (2007). Handbook of cancer survivorship. New York:Springer

References

Statistics

There are many sources of statistical information about cancer. the figures quoted here come from the UK Office of National Statistics (ONS) who publish such data regularly

Their website is:
www.statistics.gov.uk

The actual data quoted came from an ONS press release dated 21 August 2007:
http://www.statistics.gov.uk/pdfdir/can0807.pdf

Another very good source of summary statistics for the UK can be found on the Cancer Research UK website in the CancerStats section:
http://info.cancerresearchuk.org

The figures for the USA are taken from

Ozols, R. F., Herbst, R. S., Colson, Y. L., et al. (2007). Clinical cancer advances 2006: major research advances in cancer treatment, prevention and screening - a report from the American Society of Clinical Oncology. Journal of Clinical Oncology, 25, 146-162.

‘Adjustment’

James Brennan’s book is noted above. His earlier paper (again very readable and accessible) is

Brennan, J. (2001). Adjustment to cancer - coping or personal transition. Psycho-oncology, 10, 1-18.

Fatigue

Bower, J. E., Ganz, P. A., Desmond, K.A., Bernaards, C., Rowland, J.H., Meyerowitz, B. E. & Belin, T. R. (2006). Fatigue in long-term breast carcinoma survivors. Cancer, 106, 751-758.

Gielissen, M. F. M., Verhagen, S., Witjes, F. & Bleijenberg, G. (2006). Effects of cognitive behaviour therapy in severely fatigued isease-free cancer patients compared with patients waiting for cognitive behaviour therapy: a randomized controlled trial. Journal of Clinical Oncology, 24, 4882-4887.

Prue, G., Rankin, J., Allen, J., Gracey, J. & Cramp, F. (2006). Cancer-related fatigue: a critical appraisal. European Journal of Cancer, 42, 846-863.

van Weert, E., Hoekstra-Weebers, J. E. H. M., May, A. M., Korstjens, I., Ros, W. J. G. & van der Schans, C. P. (2008). The development of and evidence-based physical self-management rehabilitation programme for cancer survivors. Patient Education and Counselling, 71, 169-190.

‘Chemobrain’

Han, R., Yang, Y. M., Dietrich, J., Luebke, A., Mayer-Pröschel & Noble, M. (2008). Systemic 5-fluorouracil treatment causes a syndrome of delayed myelin destruction in the central nervous system. Journal of Biology, 7:12.

Hermelink, K., Untch, M., Lux, M. P., Krelenberg, R., Beck, T., Bauerfeind, I. & Münzel, K. (2007). Cognitive function during neoadjuvant chemotherapy for breast cancer. Cancer, 109, 1905-1913.

Mehnert, A., Scherwath, A., Schirmer, L., Schleimer, B., Petersen, C., Schulz-Kindermann, F., Zander, A. R. & Koch, U. (2007). The association between neuropsychological impairment, self-perceived cognitive deficits, fatigue and health related quality of life in breast cancer survivors following standard adjuvant versus high dose chemotherapy. Patient Education and Counselling, 66, 108-116.

Stewart, A., Bielajew, C., Collins, B., Parkinson, M & Tomiak, E. (2006). A meta-analysis of the neuropsychological effects of adjuvant chemotherapy treatment in women treated for breast cancer. The Clinical Neuropsychologist, 20, 76-89.

Resilience, Benefit-finding and Post-traumatic growth

Two useful starting points are

Bonanno, G. A. (2004). Loss, trauma and human resilience. American Psychologist, 59, 20-28.

Seligman, M. E. P., Rashid,, T. & Parks, A. C. (2006). Positive psychotherapy. American Psychologist, 61, 774-788.

For good critical reviews see

Hegelson, V. S., Reynolds, K. A. & Tomich, P. L., (2006). A meta-analytic review of benefit-finding and growth. Journal of Consulting & Clinical Psychology, 74, 797-816.

Linley, P. A. & Joseph, S. (2004). Positive change following trauma and adversity: a review. Journal of Traumatic Stress, 17, 11-21.

Two examples specific to breast cancer illustrate some of the complexities of resaerch in this area:

Cordova, M. J., Giese-Davis, J., Golant, M., Kronwetter, C., Chang, V & Spiegel, D. (2007). Breast cancer as trauma: posttraumatic stress and posttraumatic growth. Journal of Clinical Psychology in Medical Settings, 14, 308-319.

Lechner, S. C., Carver, C. S., Antoni, M. H., Weaver, K. E. & Phillips, K. M. (2006). Curvilinear associations between benefit finding and psychosocial adjustment to breast cancer. Journal of Consulting & Clinical Psychology, 74, 828-840.

Psychological interventions and survival

There are a number of papers in this area. The two early studies quoted in the section on 'positive thinking' are:

Spiegel, D., Bloom, J. R., Kraemer, H. C. & Gottheil, E. (1989) Effect of psychosocial treatment on survival of patients with metastatic breast cancer. Lancet, II, 888-891.

Greer, S., Morris, T., & Pettingale, K. W. (1979) Psychological response to breast cancer: effect on outcome. Lancet, II, 785-787.

There have been a number of studies and reviews which have either tried to confirm these findings and have failed or have looked at all the studies and found no impact on survival:

Coyne, J. C., Stefanek, M. & Palmer, S. (2007). Psychotherapy and survival in cancer: the conflict between hope and evidence. Psychological Bulletin, 133, 367-394.

Dalton, S. O., Boesen, E. H., Ross, L., Schapiro, I.R. & Johansen, C. (2002). Mind and cancer: do psychological factors cause cancer? European Journal of Cancer, 38, 1313-1323.

Garssen, B. (2004). Psychological factors and cancer development: evidence after 30 years research. Clinical Psychology Review, 24, 315-338.

Goodwin, P. J., Leszcz, M., Enns, M., et al. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. New England Journal of Medicine, 345, 1719-1726.

Petticrew, M., Bell, R. & Hunter, D. (2002). Influence of psychological coping on survival and recurrence in people with cancer: systematic review. British Medical Journal, 325, 1066-1075.

Ross, L., Boesen, E. H., Dalton, S. O. & Johansen, C. (2002). Mind and cancer: does psychosocial intervention improve survival and psychological well-being? European Journal of Cancer, 38, 1447-1457.

Spiegel, D. (2002). Effects of psychotherapy on cancer survival. Nature Reviews Cancer, 2, 1-7.

Watson, M., Homewood, J., Haviland, J. & Bliss, J. M. (2005). Influence of psychological response on breast cancer survival: 10-year follow-up of population-based cohort. European Journal of Cancer, 41, 1710-1714.

There are a number of reviews looking at the more general impact of psychological interventions for people with cancer:

Andersen, B. (2002). Biobehavioural outcomes following psychological interventions for cancer patients. Journal of Consulting & Clinical Psychology, 70, 590-610.

Meyer, T. J. & Mark, M. M. (1995). Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomised experiments. Health Psychology, 14, 101-108.

Newell, S. A., Sanson-Fisher, R. W. & Salvolainen, N. J. (2002). Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. Journal of the National Cancer Institute, 94, 558-584.

Owen, J. E., Klapow, J. C., Hicken, B. & Tucker, D. C. (2001). Psychosocial interventions for cancer: a review and analysis using a three-tiered outcome model. Psycho-Oncology, 10, 218-230.

Other sources referenced

Hodgkison, P. E. & Stewart, M. (1998). Coping with Catastrophe: A Handbook of Post-disaster Psychological Aftercare (2nd Ed). London:Routledge.

The Cancer Counselling Trust has now closed.