Moving Forward: 1. Introduction and First Thoughts

tickingoffbreastcancer.com/life-after-cancer/moving-forward-1-introduction-and-first-thoughts/

Back in the 1990s there was an increasing focus was on how to live well after an experience of cancer, as the treatment improved and increasing numbers of people were surviving after a diagnosis of cancer. Dr Peter Harvey (Consultant Clinical Psychologist, working in Birmingham and then Leeds) was invited to give a talk in 1999 at the National Conference of Cancer Self-Helps Groups and from here he refined and expanded his work on this important area. Just after he retired in 2007, Peter spent six months updating with work with the help of Dr Jane Clark, another Clinical Psychologist. This was published on the Cancer Counselling Trust's website in 2004.

Dr Jane Clark is now a Consultant Clinical Psychologist in Leeds.

> "*I have had the privilege of working with people who have or have had cancer for nearly twenty years. I originally trained in Hull and worked with Professor Lesley Walker, who pioneered the idea of cancer drop-in centres to provide emotional support to those going through treatment. After qualifying, I moved to work in Leeds and have worked at the Cancer Centre in Leeds since 2004. I have been able to listen and help people to make sense of their experiences and emotions both during and after treatment for cancer.*

> *Everyone's story is different but there are some common themes in the distress and the process of adjustment that people experience. I have noticed that people sharing their experiences helps them to understand that they are not alone and they feel validated in their emotional responses. This has become increasingly common with the advent of blogs and the development of the supportive cancer community.*

> *There are now so many voices of experience from the cancer community that I sometimes wonder if there is still place for a psychologist to provide a perspective. But I think that we can provide some understanding of the range of experiences, as we speak to so many different people, and we can provide a perspective from the field of psychology in understanding reactions to trauma and adjustment after significant life events.*

> *I hope that this series of articles will help by summarising some of the key emotional and psychological experiences and providing a psychological perspective on them. The transcripts from the talks that Peter gave have been shared widely and various forms can be found all over the internet.*

> *Many, many people have found his work to be helpful so Sara – the founder of Ticking Off Breast Cancer – and I wanted to refresh the information and make it accessible and relevant to people today trying to move on the from experience of cancer. Many of the words are still Peter's original work. He has given his consent and support to this refreshed version. We both really hope this is helpful and useful to you*."

So here we go…

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 series of articles

The series of articles forming 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.

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.

Dr Jane Clark, Consultant Clinical Psychologist

Next: 2. The Tasks of Recovery

June 2021

Moving Forward: 2. The Tasks of Recovery

tickingoffbreastcancer.com/life-after-cancer/moving-forward-2-the-tasks-of-recovery/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

It may seem a bit daunting to see a heading like this – after all, you've maybe 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.

A loss of control

Often, one of the first things to go is a sense of control. Think of our boat analogy again, there may have been little warning of the huge storm that was about to blow up and whilst it was raging, you may have had little 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.

> "*The plan for my surgery was in place before I was even aware that it was necessary. In some ways, that's great, you want the cancer out but there was little time for me to process what was happening and even start to take in that it was really happening…and to me!*"

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 an overwhelming feeling of being out of control.

Other losses

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. The loss of a breast can also carry more significance to your sense of self and being female.

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 role at work may feel diminished by your new role as a ‘cancer patient’.

If your diagnosis has been a struggle and you feel people may not have taken you seriously (see Moving Forward: 6: 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 Moving Forward 13: 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 Moving Forward 14: Regaining Trust in Other People).

Putting your head down and getting on with it

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. Think back to our boat analogy and the idea of clinging on, head down, to get through the peak of the storm. 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 that 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 energy and clarity to focus on this important issue.

Maybe some positives

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.

Acknowledging loss and addressing the task in hand

One of the important aspects of dealing with cancer and its treatment is to acknowledge the losses as once these are acknowledged then it becomes easier to deal with the rebuilding and recovery process.

This series of articles is aimed at helping you do this by addressing the tasks of rebuilding 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.

Dr Jane Clark, Consultant Clinical Psychologist

Next: 3. Beginning to Recover and Recuperation

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Moving Forward: 3. Beginning to Recover and Recuperation

tickingoffbreastcancer.com/life-after-cancer/moving-forward-3-beginning-to-recover-and-recuperation/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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 series of articles 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.

> "I found going through treatment very tiring. It wasn't just the side effects of the treatments themselves, but the back and forth to hospital appointments and the emotional energy I used up which drained me."
>
> *Emma Herring, Ticking Off Breast Cancer*

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, and 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. It might be helpful to show this article to your family, so that they also understand that you need to invest in your recuperation.

CONVALESENCE

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. It can be helpful to plan a timetable of what will help you to 'grow strong' again. Think about what will help to rebuild your physical strength (walks, swimming, gardening, mindful movement such as yoga or

Tai Chi) as well as what will nourish your mind (connections with others, reading, music, mindfulness, TV). Be kind to yourself and patient, remember that the path won't be linear, there may be many ups and downs.

> "Recovering from treatment took much longer than I had expected or anticipated. Once I'd realised it wasn't going to happen as quickly as I'd hoped, I made sure that I was patient with myself and took things slowly."
>
> *Sara Liyanage, Ticking Off Breast Cancer*

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 15. Moving Forward Getting Back into the Ordinary World).

Dr Jane Clarke, Consultant Clinical Psychologist

Next: 4. Taking Stock Emotionally

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Moving Forward: 4. Taking Stock Emotionally

tickingoffbreastcancer.com/life-after-cancer/moving-forward-4-taking-stock-emotionally/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

Many people describe the process being diagnosed and treated for cancer as being similar to being on an emotional rollercoaster. While you are on this rollercoaster, you are strapped in and sent off into an unknown world that is not of your choosing. You have to go where the rollercoaster takes you and you know that there is nothing that you can do about it until you emerge, wobbly and battered at the other end. It is only afterwards, when you are back on solid ground again, that you can look back and view what you have experienced and start to make sense of everything.

That is why many people need to take stock emotionally once the rollercoaster of treatment has stopped (or paused).

So, alongside your physical recovery, it is important to allow yourself some space to think and talk about the emotional experience of cancer and its treatment.

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.

> "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 Moving Forward 7: Living 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 Moving Forward 10: 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. In other words, the end of treatment is the end of, very probably, a negative and unpleasant time and whilst this may bring a sense of relief, it does not mean the arrival of something positive so may not bring a sense of joy and happiness. (So perhaps it's not such a surprise that that there is lack of elation as treatment finishes.)

KEEPING THINGS ON A LEVEL

Some people worry about celebrating the end of treatment for fear that this celebration will somehow tempt the cancer to return.

“If I truly believe that it's gone then it will bite me in the bum by coming back”

It's almost as if it's too risky to celebrate the success of finishing treatment.

“If I get too high celebrating the possibility that the cancer has gone then it will be too hard a fall if/when it comes back again”

Sometimes it is tempting to keep your emotions on a level as it feels safe. It makes me think of the ‘Heart and the Bottle’ children's book (by Oliver Jeffers, which I highly recommend). It tells the story of a curious and inquisitive child who suffers a bereavement. She decides to put her heart in a safe place – in a bottle around her neck. She thinks this solution fixes things but, over time, she realises what she is missing out on. I would encourage you to think about what you lose by trying to stay on a level in a bid to protect yourself from the potential falls. We are vulnerable when we live, love and experience the highs and lows of life but can you tolerate that vulnerability (and the possible lows) in order to feel the full joy and possibility of life?

Only you can make that decision but consider the possibility that you can define your life and your emotions rather than the cancer.

Dr Jane Clark, Consultant Clinical Psychologist

Next: 5. Getting Back to Normal and Other Potentially Unhelpful Phrases

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Moving Forward: 5. ‘Getting Back to Normal’ and Other Potentially Unhelpful Phrases

tickingoffbreastcancer.com/life-after-cancer/moving-forward-5-getting-back-to-normal-and-other-potentially-unhelpful-phrases/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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’. Since the COVID-19 pandemic, this has been something that we have all had to experience…there is no going back. The term ‘new normal’ was first used by the cancer community and then suddenly the rest of world has had some sense of normal life being whipped out from under their feet, with no return of normality in sight.

If taken too literally, the idea of getting back to normal 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 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. Psychologists who research the impact of trauma on people talk about how assumptions can be shattered by a traumatic event.

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. Consider the idea of a shattered vase, although it can be re-built, it might never be the same again.

Dealing with the threat of the sense of a future denied is covered elsewhere on this site (see Moving Forward 7: 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.

PUTTING THIS BEHIND 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

‘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.’

COMING TO TERMS WITH CANCER

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 Moving Forward 8: Coping after Cancer) 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 this 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.

ACCEPTING CANCER

A similar phrase is that 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.

REGAINING A SENSE OF THE ORDINARY

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’.

Dr Jane Clarke, Consultant Clinical Psychologist

Next: 6. Regaining Trust in your Body and Managing the Fear of Recurrence

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Moving Forward: 6. Regaining Trust in Your Body

tickingoffbreastcancer.com/life-after-cancer/moving-forward-6-regaining-trust-in-your-body/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

REGAINING TRUST IN YOUR BODY

For many of you, your cancer will have been discovered while 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?

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 a way 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. (If you want to educate yourself more about the signs of secondary breast cancer see our sections on: Key Things to Know About Secondary Breast Cancer and Questions to Ask Your Oncologist about Secondary Breast Cancer.)

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.

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. Acknowledge your fears in a kind and compassionate way.
- 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 can feel 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 to 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.
- Fourth think about what the effect of checking yourself too regularly might be having on your mind and body. After cancer in one breast, it is common for women to check the other breast for lumps. Sometimes this checking can happen a bit too frequently. By over-checking (e.g., daily checks), you could reduce your ability to detect changes in your breast and also you can make the area sore and tender, which can lead to more worry. It's worth asking your doctor or nurse specialist what they would advise in terms of how often you should check.

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.

Dr Jane Clark, Consultant Clinical Psychologist

Next 7: Living with Uncertainty after Cancer

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June 2021

Moving Forward: 7. Living With Uncertainty after Cancer

tickingoffbreastcancer.com/life-after-cancer/moving-forward-7-living-with-uncertainty-after-cancer/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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’.

Understanding uncertainty

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 how long it will take to reach you and 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 (which can rarely happen), then you will have that nagging worry gnawing away at you.

Uncertainty immediately after treatment

Again, immediately after cancer 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.

Uncertainty as time goes on

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.

The river analogy

To use another analogy, if life is like walking along a path by a river. Prior to your cancer diagnosis, you might not really have been aware of the river and felt able to choose the path ahead and felt in control. The diagnosis of cancer is the river level rising and breaking its banks so that your path ahead is flooded, and you cannot go on as planned. For some of you, the path may be flooded for longer than others and all your energy has had to go on dealing with the immediate flood management.

Then as treatment ends, it is as if the flooding recedes, and the river levels return to normal levels. You have to re-build and repair your path in life. But you know the river is still there, sometimes it is louder than others (scan, check-ups) and the threat of flooding feels closer than ever. But sometimes, you can barely hear the river and you can focus on your path ahead.

Learning to live with the uncertainty is like learning to live alongside the river. You can stand and stare at it to check the river levels…but the cost is that you don't move along your path and really live life. You can try to get as far away from the river as you can but that again can lead you away from your path and like trying to get through thick bush and vegetation, can make life hard work and unpleasant. So, is it possible to live alongside the river, knowing that sometimes, the levels will rise, and it will feel worrying, and at other times, knowing that the levels will drop, and you can enrich your path ahead?

You can try to have some degree of control over the river by attending scans and looking out for signs of recurrence (the same as having an alarm for rising water levels and a plan for if the flood comes again) but also letting go of the idea that the river can be controlled completely. Being able to switch your focus back to your path and doing what matters to you in life.

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

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 and planning a holiday.

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 one 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. At these times, the noise of the river may be more noticeable, and the fears of flooding may feel more real. 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.

As you gain more distance from the immediacy of the experiences, you hopefully 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.

Stepping back

Another way of managing these very real fears is to try to stand back and notice what is happening with your thoughts and physical feelings. All too often, when we get a frightening thought in our mind, it is impossible not to be taken into the story of this thought. We have a story-telling mind which will fill in the blanks with the worst-case scenarios. Suddenly a thought has become a reality and we experience the anxiety and worst-case scenario viscerally. If you can calm your mind (often by breathing slowly and focusing on the out-breath) then you can step back from the thought. Imagine your mind is like the sky and this thought (however terrifyingly real) is a cloud blowing across the sky. Is it possible to step back and notice this cloud? Can you say to yourself, “I’m having the thought that…” or “my mind is telling me the story of…”?

It’s possible to learn or develop this ‘stepping back’ technique using mindfulness exercises. Mindfulness has become trendy and is now seen as a bit of a panacea for all things. But the evidence base for this technique is strong, particularly for managing anxious thoughts. Its particularly helpful as it does not tell you that your thoughts are wrong or silly and does not suggest that they need to be challenged (sometimes this can make thoughts stronger). It gives you a way of relating to the thoughts differently so that you can step back and notice the thoughts and see if you can let them pass on by.

Or relating to the river analogy, noticing when the river is noisier and thoughts about flooding are more in your mind (and perhaps this is more in a dark at 2.00am) and thinking about how you take care of yourself when it feels like that. Then noticing when the thoughts about flooding are less and what has happened to allow your mind to be drawn to other thoughts. Then keeping some focus on your path ahead and what matters to you in life and how your daily actions can keep you in line with what matters. These psychological techniques are from a therapy called Acceptance and Commitment Therapy if you want to explore these ideas further.

Dr Jane Clark, Consultant Clinical Psychologist

Next 8: Coping after Cancer

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Moving Forward: 8. Coping after Cancer

tickingoffbreastcancer.com/life-after-cancer/moving-forward-8-coping-after-cancer/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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.

What would I be like if I was 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.

If a friend was going through this…

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!

General strategies

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.

- **C**onfronting the issues
- **O**penness to feelings
- **P**rivacy
- **I**nforming yourself
- **N**etworking
- **G**rieving

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

Confronting the issues

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.

Openness to feelings

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. It can be helpful to write down your experience of cancer – either what happened from diagnosis to the end of treatment and/ or the feelings that have surfaced since being in this world. The popularity of blogs and social media shows how helpful the process of writing and making sense of your experience can be for both the writer and reader.

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.

Privacy

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 your 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.

Informing yourself

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 choose 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.

Networking

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 Moving Forward 17: Being Positive and Thinking Positively); 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”.

Grieving

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 Moving Forward 3: Beginning to Recover & Recuperation) 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. Plus remember how you would treat a friend who was grieving…all that kindness needs to be offered to yourself at this stage!

Dr Jane Clark, Consultant Clinical Psychologist

Next 9: Dealing with a Changed Body

June 2021

Moving Forward: 9. Dealing With a Changed body

tickingoffbreastcancer.com/life-after-cancer/moving-forward-9-dealing-with-a-changed-body/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

One of the many possible consequences of treatment for breast 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 scar hidden under clothing, or essentially hidden – and internal – removal of a woman’s reproductive organs (for those of you who discover that you carry the BRCA gene and decide to have preventative surgery to minimise the chances of other cancers).

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.

It’s not mere vanity

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 look on Instagram or 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.

How you feel

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.

Part of your body not being yours

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. The changes in sensation may make it even harder to accept that this is part of the body now. 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.

> "*When I first had my breast reconstruction using an ADM and implant, it felt like I had a beanbag stuck on my chest. I felt like I'd never get used to it. But slowly, without me noticing, my brain seemed to incorporate it into my sense of body. It doesn't feel like my old breast, but it does feel like part of me now*."

Additional issues…

An unwillingness to talk about feeling unhappy with your changed body 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.

You can see the process of adapting to a changed body as similar to the process of bereavement. There's a period of loss and sadness about the change. There may also be anger and other strong feelings. The stages won't be linear but over time, people generally find that they come to some kind of acceptance of their changed body.

Dr Jane Clark, Consultant Clinical Psychologist

Next 10: Dealing with Fatigue

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June 2021

Moving Forward: 10. Dealing with Fatigue

tickingoffbreastcancer.com/life-after-cancer/moving-forward-10-dealing-with-fatigue/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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.

Cancer fatigue: it takes more than a few early nights to get over

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.

> "*It's like hitting a brick wall. And it's not just a physical tiredness. I found that the mental and emotional fatigue hit me harder than my body just feeling tired. It knocked me for six and I had to strip life back to the essentials to get through each day, just as everyone's expecting you to be full of positivity because you've finished treatment.*"

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 suggests that up to 90% of patients report some degree of it during their treatment – particularly chemotherapy.

Post cancer fatigue: it can affects a lot of us

After the treatment has finished, it is suggested that about a third of people report some degree of continuing fatigue. A 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.

How to deal with post-cancer fatigue?

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.

Start with small steps, literally

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 metres. Then set yourself the target of walking 50 metres (which, of course makes 100 metres 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.

How would an athlete come back after an injury?

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.

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 (pre-pandemic anyway!).

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.

Take it slow, step-by-step

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.

Dr Jane Clark, Consultant Clinical Psychologist

Next 11: Dealing with Chemo Brain

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June 2021

Moving Forward: 11. Dealing with ‘Chemobrain’

tickingoffbreastcancer.com/life-after-cancer/moving-forward-11-dealing-with-chemobrain/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

A number of people report that their brain doesn’t seem to work as well during chemotherapy – a phenomenon that may last well beyond the duration of the treatment for some. Researchers have termed this cancer-related cognitive impairment.

What does ‘chemobrain’ feel like?

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, these can include:

- feeling that your memory is not working as well as you remember
- finding it more difficult to concentrate or think clearly
- feeling that it is more difficult to find the right words when talking
- finding it more difficult to plan or put thoughts into action

> *“I remember literally forgetting the simplest of words in the middle of a conversation. But I think I found it really hard to make decisions, to work out how and when to do things. Trying to keep on top of things at home, children, school, food shopping. It all just felt overwhelming. I leant on my husband a lot to keep everything going at home.*“

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.

Stress and worry can have a profound effect on your thought process

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 and 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.

Hormone therapy plays its part too

Alongside chemotherapy that may cause changes in your cognition, research has suggested that hormone therapy may also play a role in causing cognitive problems. In addition, fatigue and menopausal sympyoms are also a contributing factor in changes in cognition.

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.

Worry and anxiety about fatigue don’t help

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 may fear that not only will it not get better but may actually 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 scientific evidence on this problem, but like the phenomenon itself is does not give a clear or straightforward answer.

The challenges involved in understanding fatigue better

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. That does not mean that they are not frustrating or debilitating to live with every day. The research also suggests that the cognitive changes improve as the time from chemotherapy increases (but if you are still taking hormone therapies then you may not notice these improvements).

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. Some research has suggested that post-menopausal women may experience greater cognitive impairment after treatment with chemotherapy and/or hormone therapy. But again, this needs further investigation.

What can you do?

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.

Try not to worry

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 you 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.

Dr Jane Clark, Consultant Clinical Psychologist

Next 12: Regaining Trust in Yourself

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June 2021

Moving forward: 12. Regaining Trust in Yourself

tickingoffbreastcancer.com/life-after-cancer/moving-forward-12-regaining-trus-in-yourself/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

Many people, from all walks of life, say that one of the most difficult consequences of cancer 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.

> “*I think my lack of confidence wasn’t obvious at first. But looking carefully, I definitely doubted myself and my body. I felt like I was just waiting for the rug to be pulled from beneath me. I didn’t look too far ahead, and it took a lot of ‘one day at a time’ to move on from those feelings.*“

You can’t get confidence on prescription

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 immobilising loop from which there seems to be no escape. Exactly why this should happen is not entirely clear.

Feelings powerless and not in control

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 anymore – 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 (pre-pandemic!). 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.

Making plans become fraught with worry and difficulty

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 step at a time is the way to go

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.

Set yourself easy, achievable goals you know you can achieve

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 Moving Forward 10: Dealing with Fatigue).

It's easy to forget how complex and difficult life can be

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.

Build your life back up gently

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.

Dr Jane Clark, *Consultant Clinical Psychologist*

Next 13: Regaining Trust in the System

Moving Forward: 13. Regaining Trust in the ‘System’

tickingoffbreastcancer.com/life-after-cancer/moving-forward-13-regaining-trust-in-the-system/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

It is an unfortunate truth that some people have very bad experiences at the hands of the healthcare 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.

When things go wrong

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 (particularly during the pandemic).

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.

How a negative experience might affect your self-confidence

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 Moving Forward 12: Regaining Trust in Yourself) and trust in your own ability to monitor your health (see Moving Forward 6: 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.

What can you do to regain trust in the system?

You may be able to request to see 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.

Finding someone you trust who will listen to you

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.

Dr Jane Clark, *Consultant Clinical Psychologist*

Next 14: Regaining Trust in Other People

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Moving Forward: 14. Regaining Trust in Other People

tickingoffbreastcancer.com/life-after-cancer/moving-forward-14-regaining-trust-in-other-people/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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 Moving Forward 5: Getting Back to Normal and Other Unhelpful Phrases).

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.

Your mask

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 Moving Forward 17: On Being Positive and Thinking Positively); or those who completely ignore you, saying that they thought that you probably had enough on your plate or 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.

> "I felt that one friend seemed to be desperate to know the outcome of each appointment or my results at every stage. I think her intention was to be supportive and there for me but, at times, it felt like she was almost enjoying the drama of it all. I feel terrible saying that about my friend, but I experienced her calls and texts as too intrusive. I needed time to digest things before I was ready to share"

Re-instating your social network

Re-instating your 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? If you think back to the boat analogy – who do you want on your crew and who do you need to lose overboard?!

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? In this digital age, the supportive cancer community is more accessible than ever before with things like Facebook groups and networks via Twitter. These communities come with huge benefits as the knowledge and true understanding from women who have been through breast cancer is unparalleled. You can also share your experience and help others who are just starting out on their cancer experience.

But they can also have their drawbacks. They expose you to all the potentials and possibilities, such as an online friend, who was in a similar situation to you but who then dies can be devastating and rock your sense of stability. They can also keep you hooked into the world of cancer when you might be ready to move away from cancer and everything related to it.

There is no easy answer but think about the pros and cons for you personally of remaining part of the cancer community. I have had women say to me that they find themselves following the stories of women whose cancer has recurred and becoming compelled to check on them every day. But whilst they do these checks, they are overwhelmed with anxiety and fear about their own future. At this point, I encourage them to balance out the urge to know what’s happening with the cost to their anxiety every day.

Over-helpful people

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.

Moving forward

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 has 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.

Dr Jane Clark, Consultant Clinical Psychologist

Next 15: Getting Back into the Ordinary World

The information and content provided in this page is intended for information and educational purposes only and is not intended to substitute for professional medical advice.

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Moving Forward: 15. Getting Back Into the ‘Ordinary’ World

tickingoffbreastcancer.com/life-after-cancer/moving-forward-15-getting-back-into-the-ordinary-world/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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.

‘Getting back to normal’ might not be 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 Moving Forward 5: ‘Getting Back to Normal’ and Other Unhelpful Phrases). There may be some specific issues that confront you in this process.

One is about identity. It’s all very well for people to say you have to put it all behind you when they still see you as someone 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 compassion and understanding for what you have been through, but you do not always want to be seen simply as that person who had cancer.

Choosing how much or how little you want to talk about 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 in Moving Forward 8: Coping after Cancer where we talk about protecting your privacy). 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.

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.

Going back to work can signal a return to 'normality'

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 Moving Forward 10: Dealing with Fatigue) taking things in a step-by-step fashion is a helpful approach.

How to work out what is and isn't possible

The first stage, of course, is to 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 our Useful Resources page for life after cancer).

Do you go back to your old job, make a career change or stop work completely

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.

> “Having taken an extended leave of absence from work during my cancer treatment, I found the decision to go back to work quite difficult. I wanted to get a better work/life balance and to do this I knew I was going to have make some changes.”

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.

Managing your return to work

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

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 to settle 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 Moving Forward 6: 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.

A gradual return

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.

Managing work relationships

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.

Starting a new job

If you are 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. It is worth really considering the issue of 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.

Your time out from work might alternatively give you renewed passion for a job that you truly believe in and that allows you to express your values. So, you might find the return to work energising and feel more committed to your role.

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.

Dr Jane Clark, Consultant Clinical Psychologist

Next **16: It’s Not Always All Bad**

June 2021

Moving Forward: 16. It’s Not Always All Bad

tickingoffbreastcancer.com/life-after-cancer/moving-forward-16-its-not-always-all-bad/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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 you 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.

A DIAGNOSIS IS NOT A LIBERATOR

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 choose 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’). This 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.

PERSONAL MATTERS

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.

Dr Jane Clarke, Consultant Clinical Psychologist

Next 17: On Being Positive and Thinking Positively

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June 2021

Moving Forward: 17. On Being Positive and Thinking Positively

tickingoffbreastcancer.com/life-after-cancer/moving-forward-16-on-being-positive-and-thinking-positive/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

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.

Does being positive always mean being cheerful?

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.

Why do people encourage you to be positive?

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 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.

Does 'being positive' close down open and honest conversations?

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.”

What does the research tell us?

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 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.

How do thoughts and feelings effect outcomes?

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 is a strong evidence-base undermining the idea that psychological intervention prolongs survival. 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.

Optimism and hopefulness

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. Many people find real benefit in having a medical team who keen their sense of hope (realistic hope) alive.

Dr Jane Clark, Consultant Clinical Psychologist

Next 18: Do I Need Therapy

June 2021

Moving Forward: 18. Do I Need Therapy?

tickingoffbreastcancer.com/life-after-cancer/moving-forward-18-do-i-need-therapy/

This article is adapted by Dr Jane Clark from an article originally written by Jane and Dr Peter Harvey. See our introduction for a background on this series of articles.

Everything getting on top of you

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.

Basic principles of seeking professional help

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.

What do you want out of therapy?

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.

What can therapy help with?

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.

How to find someone

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.

There are also centres such as Maggie's where you can access psychology or counselling sessions. 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.

Dr Jane Clark, Consultant Clinical Psychologist

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