

After the Treatment Finishes - Then What?

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Imagine a roller-coaster. Some of you will find this an exciting and thrilling image: others of you - like me - will find it terrifying and beyond belief that anyone in their right mind would willingly subject themselves to the torment of being transported at high speed and with great discomfort in this manner. However, I have chosen this image to represent the process of the diagnosis and treatment of cancer. On a roller-coaster, you will be strapped in and sent off into the terror, knowing that there is nothing you can do about it until you emerge, wobbly and battered at the other end. You manage by getting your head down and dealing with it as best you can at the time. It is only afterwards, when you are on solid ground again, that you can look back with amazement and view what you have experienced and marvel at your courage.

This seems to be an analogy for what happens after diagnosis and during treatment. The end of the ride is equivalent to the end of treatment. And this is where I want to start - after the treatment has finished and at the point where you can begin, bit by bit, to deal with all that you have been through and all that is to come. You may have had to endure months of treatment by knife, chemicals or radiation until you are probably sick of the whole business, both literally and metaphorically. Now is the time to heal both body and mind. What I hope to do is to look in more detail at this process and make a plea that this critical stage is given more attention than it has had in the past.

I want to set out a framework in which to develop an understanding of what is happening. The first part of this framework is the recovery process that has to be gone through. For me this happens in three stages: recuperation, convalescence and rehabilitation. I make this distinction to represent the different stages that have to be passed through and completed before moving onto the next one - each builds upon the other, although there will not necessarily be a clear dividing line between them.

Let's look at each of these in turn, beginning with 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 - we cut and possibly mutilate, inject you with poisonous and powerful chemicals, subject you 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 of course, but this very power takes its toll in other ways. These interventions place enormous physical strains on the body. There is often little time to recover from one treatment before the next one starts. The treatments themselves may make it difficult for you to sleep and eat properly - two important 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 - the dealing with the impact and implications of the diagnosis, the uncertainty, the upheaval, the additional burden that you feel that you are imposing on family and friends, the loss of so many aspects of your routine. Emotional stress can be as energy consuming as any physical activity. After all that, is it any wonder that you feel wrung out and exhausted, without resources or reserves?

All too often I meet people who, for quite understandable reasons, 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. In my view, however smoothly your treatment has progressed and however well you have tolerated the various indignities to which we subject you, some time 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. Take however long you feel you need. Recuperating is the very first step in a process of rebuilding.

The next stage is convalescence. This is a rather old-fashioned term, and I am sorry it has fallen into disuse, despite its association with bath chairs, rugs, the seaside and strengthening broth. The word has a Latin root meaning 'to grow strong' - rather apt under the circumstances. Once you have recharged your batteries, then you can begin to build up your physical and emotional strength. Again, there are no set rules or guidelines for how long this can take, but I firmly believe that to miss out this stage builds up problems later on.

Once you have recuperated and convalesced, then you have the foundation and the energy to start doing those things that you want to do - and, perhaps, to stop doing those things that you don't want to do. I remember the patient of a colleague of mine 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, she had decided to change both job and husband. Now your rehabilitation may not be as dramatic or as quick as that, but behind that rather clinical term lays a whole raft of important issues. Perhaps one of the most critical of these concerns the phrase 'Getting back to normal'. I will argue that, if taken too literally, it can be more of a hindrance than a help and may become a burden which impedes progress. My reason for taking this stand is based on the observation that once heard, the diagnosis of cancer can never be forgotten. Whatever your prognosis, whatever your hopes, whatever your personality, the second that you know that you have cancer your life changes irrevocably. For many people, their sense of security and safety is undermined, their hopes for the future compromised, their trust in their world denied.

I will return to the process of dealing with that threat later on, but for now I simply want to acknowledge that to 'get back to normal' as if nothing has happened is an unlikely hope. But of course, within that phrase lie a number of other aspirations and messages. 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 some thing 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. Rehabilitation, therefore, is a process of regaining and refreshing old skills, learning and refining new ones to enable you to live the sort of life you want.

So what are the tasks that have to be completed in order to get through the process that I have outlined?

Regaining trust in your body

For many of you, your cancer will have been discovered whilst you were feeling 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 (I know this is not true for all, but it is a common experience nonetheless). And then you hear the diagnosis, that word that will be forever etched in your memory. 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 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 recognise when something is wrong with your body. After all, you may not have been able to tell that you had cancer in the first place and your body is now significantly changed so that there is a whole set of new and unusual sensations to experience. This is most marked in the period after treatment when the anxieties are still high and the uncertainty at a peak. Is this lump the cancer coming back? What does that pain mean? Should I go back to the clinic, just in case? Such anxieties are perfectly understandable under the circumstances.

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. You will be on the lookout for them in a way that you were not before. This is a combination of doing what you have probably been told to do by the 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 so guidelines to manage your fears. For example, if the pain lasts for more than a couple of days or gets worse, if there are symptoms associated with the site of your surgery for more than a certain length of time, only then might you need to call your doctor. Your consultant and specialist nurse will be able to give you guidance as to what they think will be important. Whilst many people quite naturally, and over time, learn to manage this unpleasant and frightening experience, some will not, especially if you have always been a 'bit of a worrier' about your health. In this case, I think it 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.

Regaining trust in yourself

I cannot tell you how many people, from all walks of life, have told me that one of the most difficult consequences of their illness and its treatment is their loss of confidence. It seems to make no difference if you are a woman or a man, old or young, have a high-powered demanding job or are retired.

Cancer is a great leveller in this (as in many other) respects. Of course one of the great problems with confidence is that no-one else can give it to you: you cannot get your doctor to write a prescription or buy it in a bottle from Sainsbury's. 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. Part of it is probably due to the sense of uncontrollability and the experience of powerlessness that cancer and its treatment engenders.

Another factor that will undoubtedly contribute is the sense that the world is not a safe place any more - that you are vulnerable and at risk is brought home to you with a terrible certainty. This can manifest itself in a number of ways, but one that seems very potent concerns holidays. Many people have the idea that what would be really nice at the end of treatment is a real holiday. You or your relatives may plan to have a break very soon after treatment ends. But when it comes to it, when you have finished, perhaps the prospect doesn't seem so attractive after all. For many people, the period immediately after treatment is marked by real feelings of vulnerability and of not wanting to stray too far from home or from the easy reach of medical and nursing care. Apart from the tiredness and fatigue, the feeling of not being entirely safe is powerful - powerful enough to spoil a holiday or break.

There is also the sense that you cannot afford to look too far into the future, that planning too far ahead brings its own worries and fears. Your time horizon has been understandably limited to the next treatment, the next clinic appointment. You may have been living one day at a time. To switch suddenly to planning six months ahead seems to be a task too much. I must say that I regard the point at which someone can look forward to and plan a holiday is key sign of recovery. It doesn't always happen quickly, and often not as quickly as people might like, but happen it does.

One of the things that I will advise people to do is to plan for short trips away - perhaps a couple of hours - to places they know and with which they are familiar. Once they 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. And that model is the key to many aspects of the rehabilitation programme that 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.

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 realise this.

Sometimes I think that living is like competing in an Olympic event - but because we take it so much for granted we forget how demanding and tiring it can be, even at an ordinary, everyday level. Let's take this analogy further and pretend that we are all Olympic sprinters - a rather far-fetched concept in my case, I should add - who have had a serious injury.

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.

Of course one of the other factors contributing to lack of confidence is the uncertainty that living with cancer brings.

Living with uncertainty

This is one of the most difficult aspects of living with the aftermath of cancer. You will note that I have deliberately avoided using the phrase 'coming to terms with 'uncertainty, because the reality is that this is something to be lived with and managed, not 'come to terms with'. For those of us not living with this threat, this Sword of Damocles, truly understanding what it feels like is almost impossible. The nearest that I can get to it is to think about that phrase so often used lightly and as banter - ' See you tomorrow unless I get run over by a bus.' The difference between those living with the threat of cancer returning and those free from it is that you have seen the bus coming and don't know whether it will stop in time. Until you can be given a 100% cast-iron, gold-plated, rock solid guarantee that your cancer is completely gone, never to return, then you will have that nagging worry gnawing away at you.

Again, immediately after treatment finishes, these fears may be at their worst, compounded by the lack of trust in your body and the lack of confidence that you may be feeling. It makes sense that you would feel that way and the reality and power of your feelings need to be acknowledged by all around you, both lay and professional. As time goes on, you may well find that the terrors inspired by the uncertainty reduce and are sent to the back of your mind rather than residing in its forefront. However, it may not take much to restore them - clinic visits, milestones and anniversaries, high profile celebrities with cancer - can all serve as potent reminders of what you have been through and may bring everything flooding back with a vengeance. It would be surprising if this were not the case. Your experiences cannot be expunged or erased from your memory banks - they can be made less accessible, less easily revisited, but there they will be. It would be impossible to simply 'Put all that behind you and forget about it' as some of you may have been exhorted to do. If only it were as easy as that.

What is often helpful, to balance your understandable pessimistic and frightening thoughts, is to remind yourself of any helpful comments that your doctors and nurses have made. These are constructive alternatives that are not about naively 'looking on the bright side' but are real counters to equally real fears.

This brings me on to the next task.

Dealing with the world

You won't need me to tell you just how helpful a kindly word or supportive act can be. Likewise, you will need no reminders as how hurtful and insensitive can be other words and comments. I have already quoted one phrase which I would class as not only impossible but unhelpful and insensitive to boot - trying to 'forget all about it and put it all behind you'.

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, that doesn't make them any easier to bear or tolerate. It is quite probable that you will already have developed a mask that you put on in some situations in order to hide some of your real feelings. Most people need to defend themselves against the unwittingly hurtful or the crudely insensitive remark. Many of you will have learned to smile sweetly as someone says brightly to you 'My, you look really well' when you actually feel terrible. There will be times you will need to keep this defence going because people will still say unhelpful things.

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 complex than this simplistic analysis. As I said to you last time, you have a right to privacy (so you don't have to tell people everything) and you have a right to tell people what is helpful and what is hurtful. This can be a very difficult task with some people who will take offence very easily, but for your own protection I think that it's worth it - because, in the words of the advert, you are worth it.

Regaining mastery and control

This is the final task which builds on all those tasks that I have outlined before. It is the alternative to getting back to normal, a place which I said could not be rediscovered. You are in a new and sometimes frightening place where the old certainties and structures are gone and where you have to look at the world afresh. This doesn't mean that you have to change everything; it may mean that you change nothing. One way of thinking about this is to use yet another analogy. Most of us have a sort of life plan, more or less worked out. For some people this is a highly detailed route identifying what we will be doing and by when. For others of us it is a rather vague amble with the odd aspiration sketched in. But once you meet a life threat, somehow the map becomes less clear, sometimes even a blank. This is a terrifying experience - where do you go from here when you can't see the future? For some people this is a chance to review and reshape their life.

The realisation that life is too short gives an opportunity to decide what you want your life to be about. And there is nothing stopping you saying that you want it to be about what it was about before or it can be about wanting to stop doing what you did and become the world bungee-jumping champion.

Everyone will find their own route and their own path and it is for people like me to provide support and help during that process.

To summarise thus far, what I have tried to do is suggest that the end of treatment is the beginning of something else - a rebuilding process that needs to be managed and directed. Paradoxically, in psychological terms, this may be the most challenging and difficult time of all. It is a time of immense psychological vulnerability when people may feel that they have gone to pieces and simply cannot cope any more. So a word here about coping - a term as misused and burdensome as any. During treatment you deal with life as best you can because you have to.

You may not be comfortable or find it easy, but manage you do. During this time, there is often a good deal of support - both formal and informal - available. You are also dealing with very obvious and tangible stresses. Then, all of a sudden, you are on your own with just as many threats but these threats are much less obvious and immediate. And very commonly, people find that when they can relax their guard a bit, let go of the reins, that's when they feel they can't cope, that they are going mad, not managing things. All this at a time when they - apparently - should be able to cope better because the stresses are less. I have already argued that, in fact, the stresses are no less, but different. And because you may be exhausted and washed-out, your ability to mobilise yet more energy is compromised. And what makes it worse is that you may be allowing yourself to think more deeply about some of the things that you have been pushing to the back of your mind - particularly about the future and about trying to make some sense of what has happened to you. So there is often a sense of turmoil, a lack of coherence in your understanding of yourself and the world. In my view, this is the point at which the need for some sort of support and space in which to talk through some of these issues is at its peak. You may need some time to sit down with someone - it doesn't have to be someone like me although it can be - someone you trust - to reflect of what you have been through and to begin to put it in its rightful place in your personal life history.

I have not spoken much about mood yet and how this is linked up with all the other factors. There is, as you might imagine, a complex relationship between mood and all the issues that I have referred to. If you are feeling low you won't find it easy to do things, your self-confidence will be low and your level of self-criticism high. If you are unable to do things this in turn will make you low, so you can easily get trapped in a downward spiralling vicious circle. But there are two sets of feelings that commonly arise at the time of treatment finishing which we need to talk about. The first of these is a sense of abandonment. This makes sense. After all, for many weeks - if not months - you will have been cared for by a large number of people, all of whom have your welfare and well-being at heart. You may have met other patients and relatives with whom you have been able to swap stories and get powerful support from someone who really understands. There has always been someone there to check out that little niggling pain or troublesome symptom. There has been a routine, a structure for you to trust in. Then all of a sudden, it goes.

One of my patients described it like this:

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

Such feelings of aloneness and abandonment are not in any way a criticism of the people who have been caring for you.

It is simply a reflection of the fact that they now have to focus on those who are starting out on the process that you have completed. The second set of feelings that some people experience is a sense of disappointment that they don't feel more joy and happiness at the end of treatment, but rather a sense of let down, anticlimax almost. This can be in marked contrast to what they might have expected. How is it that expected 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.

And I have already referred to the uncertainty and sense of threat that may continue well beyond the actual end of treatment. There is also the fact that you may be completely de-energised - plain exhausted - which does not leave much spare capacity for unrestrained ecstasy. In addition, you will have been looking forward to the absence of something unpleasant rather than the eager anticipation of the arrival of something pleasant. So I am not surprised at patient's surprise at their lack of elation as treatment finishes.

It isn't all doom and gloom and there will be times when you wake up feeling better than you did the day before and this slow process will gradually change until one day you wake up feeling so well that you realise just how awful it has been. Remember that for months you may have been having to live one day at a time under the most difficult and challenging circumstances. You may well have been unable to enjoy those things you usually like - your sense of taste and smell may have been affected, your desire for food undermined by nausea, your ability to go out limited by your lack of energy. But now you are freed up from the routine of treatment, from the more immediate and restrictive side-effects of that treatment you can begin to move away into a different space. Again, I would emphasise the principle of one step at a time. It is important to build up gradually and by maximising your chances of success. Small, easily achievable targets and goals will be the building bricks of your success.

In closing, I want to try and bring some of these strands and themes together in a coherent framework. What I have tried to do is give a sense that the end of treatment can be as challenging a time as any that you experience. It is made more difficult by the profound physical and emotional assaults to which you have been subjected. And it is the time when the obvious sources of support are unavailable. I have argued that there is every reason for feeling frightened and out of control at this time. But what I have also tried to do is give a sense in which you can manage this process in a way that may avoid some of the pitfalls. Regaining and rebuilding your strength - both physical and emotional - is a task that I cannot emphasise enough.

That is your foundation. And taking the time to reflect, either with someone or on your own, about where you want to go from here, can begin to give you the sense of mastery and control that you may have been denied during the treatment itself.

One part of this is the process of putting the experience of cancer in its right place in your life. For months, it has dominated, been in control.

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

The reflective process may face you with choices about where to go from here. The exact path you choose (or the one that you have already chosen) is entirely a matter of personal choice and circumstance. Some of you will become stalwarts in the voluntary sector, helping others by running and managing support groups and becoming activists in cancer care and cancer politics - others will want to leave that part of their lives in a separate compartment and distance themselves for that experience.

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

Dr Peter Harvey

This is an edited version of a talk originally given by Dr Harvey at the annual conference of the Cancer Self Help Groups