



Paul Middleton

I've
been
there

50 Tips on
coping with lymphoma

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Introduction

My name is Paul. I am nearly 73 and I have had cancer. Three times. I am writing this Introduction whilst waiting for the result of my latest PET scan, but for now I know that I have had follicular lymphoma (Non-Hodgkin) also known as lymphatic cancer. To date I have had 15 days of pill chemotherapy, 30 sessions of intravenous chemotherapy, 2 CAT scans and 7 PET scans. I was diagnosed with the disease on 3 March 2011 and today's date is 12 November 2014. Phew! Got the medical details out of the way.

I became ill quite dramatically in January 2011 when I completely lost my appetite and started to feel nausea most of the time. My weight loss was dramatic and substantial. For about a year I had suffered from occasional bouts of heartburn but I put this down to lapses of diet, greed or just part of the ageing process.

With the loss of appetite and weight loss, I sort medical advice and thus put into place an on-going process of blood tests, PET and CAT scans, exploratory biopsies and endoscopies. I am not in remission at the moment. During these many months I had time to think and time to come to terms with my illness.

Before retirement, I spent 30 years in publishing, so it only seemed natural to turn to the written word, to try and help myself come to terms with my illness. I found it a great therapy so I had the idea to spread the word beyond my family. I do hope you can use this short guide to help steer you through your tough times ahead.

The Tips are completely random and I have made no attempt to place them in any order, so pick and choose as you will.

Paul Middleton November 2014

For the uninitiated, PET stands for Positron emission tomography, and CAT, Computed axial tomography (TAC in Spanish).

Special Thanks

Above all, I would like to thank my wife Pippa. What a source of strength and perseverance. I have been an absolute pain at times (despite my best efforts!) and so it has not been easy for her to lead a 'normal' life. I have tried so hard to live up to my own Tips but when I have failed, Pippa has been there helping and cajoling, and trying to force both of us into a calm and 'ordinary' existence. What a wife.

Special Thanks too, to our dear daughters Kate and Jess, and their partners, and to our friends Jenny and Paul, who have all accepted the burdens placed upon them by my illness and have simply been there, uncomplaining, understanding and supporting.

Tip 1

Switch over to the Stoic mood

One dictionary defines this as ‘... free from passion, unmoved by joy or grief, and submit without complaint to unavoidable necessity’. The key words here for me are ‘unavoidable necessity’. Do you agree that ‘what is, is’ and ‘what happens, happens’? If so, then it’s not so far along the path to belief in unavoidable necessity. The strange thing is, that today, when I write this first Tip (Monday 25 November 2013), is the first day of ‘Live Like a Stoic for a Week’, which ends on Sunday 1 December. I only noticed this when I read today’s paper, that a team of philosophers and psychotherapists are testing whether living by the true principles of Stoicism can help us improve our lives. Their Handbook at <http://blogs.exeter.ac.uk/stoicismtoday/stoic-week-2013/> is well worth a read as it outlines the philosophies of the Stoics, their ideas and suggestions for a Plan for Living. I have also found that Kare Anderson, a Contributor to *Forbes Magazine*, wrote a great article on stoicism. Here are some excerpts:

‘The Stoic creed didn’t promise material security or a peace in the afterlife; but it did promise an unshakable happiness in this life.’

‘Stoicism tells us that no happiness can be secure if it’s rooted in changeable, destructible things.’

‘Stoicism tells us that we all have a fortress on the inside.’

Yes, that fortress on the inside is precisely what I have tried to build over the last three and a half years. Not a forbidding place full of doom and gloom but a strong, light and airy place where I can invite my friends to stay for a while. While it’s natural to cry out at illness and pain, the Stoic in one can stay indifferent to everything that happens on the outside, to stay equally happy in the difficult ride along the switchback of disease and cure. It’s a difficult way of life, but the reward it gives me is freedom from some of the emotions

that so often seem to control us, when we could control them. Emotions like self pity or even self loathing. I think a real Stoic isn't unfeeling. But he or she does have a mastery over these emotions, because Stoicism recognizes that fear or grief only enter our minds when we willingly let them in.

Tip 2

Use the benefits of stoicism

My stoicism manifests itself in a feeling of calmness where my stress levels are low, my relationships with my spouse, family and friends are open, friendly and loving. All bitterness at my condition has been swept away. That destructive force has no place in my environment. The benefits are at first hard to achieve as a lot of thinking is involved! But when you first embark on the journey through your illness, take some time out, some 'thinking time'. Go for a walk initially on your own. Think a little about yourself and a lot about others, particularly those who will be most affected. Think how your illness may affect them, Try and think of ways in which you can make their burden easier. Then think a little about yourself, but do NOT fall into the trap of self-pity. Then a little while later go for another walk to talk through your feelings with the person closest to you. Tell them exactly how you feel and ask them what they want from the new 'relationship'. Because, brother and sister, your relationship has indeed been transformed. Just make sure it's for the better!

Tip 3

Expect the unexpected

That's not so difficult a concept either. Life always has and always will, throw things at us both horrid and nice. The nice things are just that, so it's coping with the horrid that's more difficult. But the unexpected will ALWAYS pop up so be mentally ready for that demon looking over your shoulder, and deal with it by following some of my Tips.

Tip 4**Treat Side Effects as friends to be managed**

As I have said before, they will come along to upset our lives. Now my method of dealing with them is to put them into separate boxes and deal with them one at a time. Don't EVER try and deal with them all at the same time. Treat them as naughty friends and they might start being nice back. If you read the medical notes attached to all your cancer literature, you will be aware that there is a multiplicity of side effects. And they really do crop up at any time and sometimes do not appear to be related to your present condition. Here is a small example. At the moment of writing this paragraph I am in remission and my last chemotherapy treatment was 3 months ago. But for the last 2 nights I have suffered from interminable sensitivity on areas of my skin. We all know how intensely difficult it is to avoid scratching an insect bite!

How did I try and manage this? First, I applied a soothing dermo skin cream, and then I tried the usual well-known technique of going through in my mind all the muscle groups and trying to relax them one at a time. Meanwhile I had shut away the bad side effects in another place. And as a follow up I tried to remember the names of all the England rugby team and the reserves. Why don't you try it? No, maybe not the rugby bit!

Tip 5**Try not to panic when you get bad or good news**

Panic or excitement are not too good for you. When you get news about your condition, count to ten or a hundred, and believe what they tell you, but don't ask endless questions - you will never remember the answers. So write down what they say and only then question what you have written down. Then write down their answers. In that way you should be less confused, and you will be ready for the next piece of news!

Tip 6

Avoid the WHY ME syndrome - at all costs.

It isn't healthy to think like that. I have known people with less serious diseases or conditions who are constantly looking for someone or something to blame. But don't let it grip you – please don't. This is so negative when you desperately need to feel positive. There really is no-one to blame. It is all too easy to start blaming the world, or God, or your own Prime Mover. But stop and think again. Why NOT Me would be my answer. And oh Brother or Sister, you are not alone. Never forget that.

My wife Pippa has an unusual mantra. She says that all events and decisions are always 50/50. By that she means that things either happen or they don't, and you either do things or you don't. Not statistically valid, but I do see a great deal of merit in this simple and clear attitude to life.

Tip 7

Face the word cancer

I think it so important to be able to use the word cancer. In a strange way I have found it liberating to be able to look people in the eye and say that I have cancer. Now I have found that some people find it incredibly difficult to talk to your face about 'cancer' - they simply do not know what to say. Don't let them hang in there embarrassed - encourage them by saying how much you value their attitude to your illness. I am sure that most of us at some time have had to speak to the recently bereaved, so you should understand how hard it is for some. We've all been there.

There are also some who actually avoid contact with you for the same reason - embarrassment. Don't let them get away with that! Their avoidance makes their lives a misery - they will have an increasing feeling of guilt. They would like to face you but now cannot as they have avoided you now more than once. Break their circle as it will make them feel a great deal better.