From Near Death to a New Life

A non–Hodgkins lymphoma patients account of a treatment journey

By Ian Mallinson

Preamble

This is a real story. It is a positive one as without the skilled medical help I received I would not be alive today. Every persons journey will be different. Most will be relatively plain sailing without the initial complications that I had. I hope that this account will prepare others to plan strategies for coping and prepare them for some of the events that could take place.

Up to June 1998 Early Difficulties and Problems

I had a number of visits to my GP with symptoms of tiredness, lack of energy and swollen ankles. Blood tests indicated a problem with my liver and I was placed on the waiting list for a biopsy. Over a short period I became very ill and after practically collapsing at work I went home and asked if I could be placed on the top of the waiting list.

My condition worsened rapidly and I was admitted to hospital through casualty on the insistence of my GP. It was some time before the biopsy could be carried out, as it was found that I was also suffering from pneumonia, which had to be treated before the liver tests could be carried out.

On carrying out the biopsy it was found that the liver was having difficulty coping and was twice the normal size. There were problems with the ducts supplying essential nutriments to it. The diagnosis was then made that my primary condition was non–Hodgkins lymphoma, the cause of all these problems. The cancer was then found to be in an advanced state.

I was immediately rushed to the Haematology Unit at the Western General Hospital, Edinburgh to see the consultant specialising in my condition.

After a little thought it was decided that my condition was so serious that treatment would commence immediately (despite it being three oclock on a Friday afternoon on a bank holiday weekend). As I was so weak only a three–quarter dose of CHOP (a form of chemotherapy) was given. It was suggested that I would be able to lead a normal life and after treatment would be able to work. This was despite my scepticism about these issues as I already felt extremely rough and weak.

The dose had an immediate effect as the main symptoms of liver failure (such as jaundice and swelling of the ankles) miraculously went away.

Because of my condition a further full dose of CHOP was then given. This was found to have no effect on the advancement of the disease, and the lymphoma together with the side effects of the chemotherapy made me very weak.
June 1998  I was said to have a short life expectancy

The whole clinical team in a meeting with my wife present communicated to me the news that I had a short life expectancy as there was no further treatment that could be given. Blood tests had indicated that the chemotherapy had had no effect.

I remember feeling shock and disbelief largely because I had been led to believe that treatment would be effective. I bottled up my emotions and initially could not talk about them. Our contact became largely with the nursing station in order to discuss things in more depth. It was very beneficial to have nursing staff that were specialists in haematology.

My feelings were brought out into the open by friends who enabled me to focus on practical issues, as a means of coming to terms with the condition. Thus, I rewrote my will; I discussed my wife's pension position; I focused on enabling a colleague to finish off the work I was currently engaged in; I dictated to a friend an address to the annual meeting of the professional association of which I was president. I did not expect to be alive at the time of the annual meeting in January.

July 1998  Some eventual improvement

Initially I had experienced a worsening condition, here palliative issues were into the forefront and were used with varying success. I was still very weak from the chemotherapy and, although not in pain, existence was not very pleasant. I understand that at one stage I was not expected to last the night.

However, I then experienced a gradual improvement, although my disease profile had not changed. The clinical team talked about convalescence, but in view of the apparent finality of the illness I did not believe I would get better.

I was admitted to a hospice for convalescence.

August / September 1998 – Discharge home

I still did not believe I was improving as people went into hospices to die! However as I improved, I obtained clear goals of independence with the help of the hospice team. I was discharged after approx 6 weeks to home and took great pride and comfort from the fact that I was reasonably mobile and did not require any nursing care.

October 1998 to June 1999 – Remission

I dealt with unfinished business: I rewrote my will in a full and considered manner rather than the interim will that was all I could manage when I was so ill. I gave my own address to the professional association meeting; I made sure my affairs were in order and presented in a full and understandable way. I went through my list of assets with my wife and executors. I took out a funeral assurance policy and recorded my wishes for the funeral; I finished off some publications I had been involved in at work and sent them to the publisher; I finished off my doctorate and was awarded the degree of Doctor of Letters from Fairfax University, Louisiana, USA in June 1999.

I looked after my health and created a new lifestyle for myself. It was clear that I would not be able to work again. I looked to create a form of leisure that worked for me despite having periods of extreme tiredness and poor mobility.

I looked up friends many of whom I had not seen for fifteen years. By taking plenty of rest, and pacing myself through events, I was able to manage quite an active life. I found I could manage a three and half hour train journey before getting too tired to go any further (I had decided rightly, early on, that it would be unwise to
resume driving a car because of the stress involved). I therefore broke my train journey, if it was longer than the permitted time, and had lunch in one of the old railway hotels that proliferate on the network next to stations. There I could chill out for a couple of hours, recharging my batteries ready for the next leg of my journey.

As a result of my experiences I began making suggestions for disabled access in a variety of places with beneficial results and campaigned for some of the more thorny problems to be resolved to create a better deal for disabled people.

**July 1999  A relapse**

The symptoms of lymphoma, being aggressive, reappeared again. For example, I experienced heavy sweating for no apparent reason, particularly at night. I got more tired quickly and most importantly, now knowing what to look for, I could feel lymphoma nodules in my neck.

Something had to be done as a matter of urgency. I rang the consultants secretary and an appointment was arranged within twenty−four hours. My diagnosis was confirmed by examination and blood tests. It was clear now that having looked after myself carefully in the last 10 months had paid off. It was thought I might be able to withstand high−dose chemotherapy with stem cell support.

I was admitted into hospital within two hours, for tests to my heart and lungs and other vital organs, and a decision was made that the treatment was to go ahead. I undertook all this with some trepidation as I knew what would happen if it didn't have any effect. The choices were stark.

**August to November 1999  The treatment that saved my life**

I had three doses of chemotherapy over an extended period. This was administered through a Hickman Line, which is a tube that enters the vein above the upper chest and puts the mixture, in quantity, right into the heart for dispersal through the body. Before the final dose I had my stem cells from my blood supply harvested (after injections to boost the quantity of these). These stem cells were than fed back to me by transfusion so that they would replenish the bone marrow, which had been damaged by the chemotherapy.

I found that talking through treatment with a friend who had experienced similar issues to myself invaluable. She acted as a buddy to me, as I telephoned her on an almost daily basis at one stage. As I got used to the system I realised that I could make outgoing calls and charge them to my home telephone account by getting a BT charge card.

The period after the stem cell support, as is normal, was one where one had to be careful of diet and avoid infection until the bone marrow replenished itself.

Unfortunately the stem cell support was only partially successful, leaving me with a lower platelet count than normal. In practice this means that I can bruise more easily and if I have a cut it will bleed a little more profusely. This presents no problem in the general run of things. I am also more prone to getting infections as I found to my cost some two years later when I experienced a urinary tract problem, which had to be treated with an extensive course of antibiotics.

The only other gremlin that took place was unusual, in that the lymphoma itself caused varicose veins in my gullet. These have a tendency to occur on a recurrent basis and if not sealed, can bleed. This means that every six months I go into hospital for a morning and am given a routine endoscopy, where, under a local anaesthetic, a tube is inserted down my throat to inspect the varicoses and seal them with the laser if it is found necessary.
Conclusions: A new life: The present and the future

The future is uncertain, I have to pace myself carefully and take plenty of rest. I have created a new life style: visiting friends and relatives; going to concerts listening to music in order to relax; participating in research as a patient representative; I find the internet invaluable as I am able to do my shopping that way and arrange travel. I found the support group arranged under the auspices of the Lymphoma Association very helpful.

I am optimistic about what may happen. I am stable and in remission, and while there can be no guarantees, I am now at the milestone of five years on from my final active treatment and still going reasonably strong. If the lymphoma became aggressive again however, there is little that could be done for me. I have to thank the patience and perseverance of the medical staff that have cared for me for the quality of life that I now have and enjoy.

My situation has changed from near death to experiencing a new life. Each day is a real bonus. The difficulties of treatment have been worth it for the real benefits it has brought me.

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