


# Improving access to post-treatment support for patients with cancer – thinking outside the box: A patient perspective

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## Abstract

Aggressive cancers such as mantle cell lymphoma are life-changing diseases, affecting all aspects in the life of a patient. Not only affecting a patient physically due to the disease itself and potential treatments but also mentally, socially and economically as well. The aim of this article is to describe the journey of a patient from a clinical and personal perspective, highlighting the importance of a collaborative approach to patients' post-treatment care from clinicians, allied health professionals and patient advocacy groups/charities. The case presented the journey of a 51-year-old male with stage IV mantle cell lymphoma presented from his own perspective. The clinical case highlights a number of key issues on post-treatment support and the need for improvement to ensure cancer survivors have the best quality of life once treatment has ended. It is essential that cancer survivors receive the support and information they require to adjust to lifestyle changes arising from their disease and treatment. Improving communication and access to care and providing additional emotional support may assist survivors in adapting to these changes. Increased collaboration among physicians, researchers, allied health professionals, patient groups and charities and patients will continue to improve quality of life for cancer patients after treatment has ceased.

## Keywords

Quality of life, mantle cell lymphoma, supportive care, survivorship, patient satisfaction, cancer

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## Introduction

Every year, 250,000 people in England are diagnosed with cancer. An estimated 130,000 will die of the disease, although 1.8 million people are living with or beyond a cancer diagnosis.<sup>1</sup> Health policy measures have focused on improvement of the organisation and delivery of services for the prevention, diagnosis and treatment of cancer, leading to substantial increases in both short-term and long-term net survival from all cancers.<sup>2</sup> Mantle cell lymphoma (MCL) is a cancer associated with rapid progression, only temporary responses to chemotherapy, and a high recurrence rate, resulting in a poor long-term prognosis with reported median survival time of only approximately 3 to 4 years.<sup>3–6</sup> With an incidence of about 0.4 per 100,000 per year, MCL is a relatively rare entity and accounts for roughly 7% of all lymphoma subtypes.<sup>7,8</sup> That said, median overall survival of

advanced-stage nonblastoid MCL patients has increased by almost twofold within the past three decades, even though MCL therapy is still noncurative.<sup>9</sup> As the improvement in survival rates through use of enhanced treatment regimens has led to a growing number of cancer survivors, the importance of work ability, (re-)employment and social reintegration has gradually emerged as critical topics within psycho-oncological and cancer survivorship research.<sup>10</sup>

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## Case presentation

In 2007, I was a 51-year-old healthy male with no past medical history of serious illness or cancer; I began to feel extremely tired and was persuaded to visit a doctor by my wife. I underwent a routine check-up and had a series of blood tests. The following day, I was referred to the hospital ear, nose and throat (ENT) clinic, to see a specialist. During this time, my tonsils had swollen and I was not sleeping properly.

## Hospital treatment

I underwent surgery to remove my tonsils and adenoids and following surgery felt much better; however, they informed me that they had done a biopsy on my tonsils and discovered that I had MCL stage IV. I was told that there was no cure but they could give me chemotherapy, to shrink the tumours, and then a stem cell transplant, which might give me some more time.

I had six regimens of R-Chop which successfully shrunk the tumours and put me into remission. Unfortunately, I had no sibling donor but a stem cell donor was found, through The Anthony Nolan Trust.<sup>11</sup> I received the stem cell transplant on 19 December 2007 and after 6 months of fantastic care by my wife and doctors, I was back on my feet, feeling positive and living my new life.

## Post-treatment complications

Unfortunately, this new life did not include going back to work, as following my transplant; I suffered various infections and viruses and became seriously ill with graft versus host disease (GVHD) on numerous occasions. In 2011, when I felt I might be over the worst, I started to think about a return to work, but then got shingles on the back of my head, followed by GVHD of my skin and muscles. I was treated at St Thomas' Hospital in London with a process called photopheresis, over a period of 3 years.

## Post-treatment support

I felt that I was becoming a prisoner to the disease as many patients do; I was always at the hospital or resting at home and in a downwards emotional spiral. What did success look like for the hospital? I believe that getting me into remission and giving me a successful stem cell transplant was the most that we could expect. Just getting me home living a life was also success for me. I felt that living beyond the initially predicted 6 months was incredible! However, as my life progressed, I found I needed a lot more help to make adjustments in my life.

Cancer has a lot of money and resource given to it, involving large pharmaceutical companies, politicians, the National Health Service (NHS) and national and international charities, generating many jobs. Unfortunately, the

communication is poor between all sectors, resulting in very slow progress for people affected by cancer and time is not something many cancer patients have. For a cancer survivor, their struggle might only just be starting, when they leave hospital after treatment.

Once you are affected by cancer, it can become very difficult to overcome the mental and emotional scars that still remain after treatment. It is the unseen fallout following a cancer diagnosis that I refer to. Unfortunately, society is quite heavily discriminating against people with long-term or chronic illness. Cancer patients may encounter issues with work, insurance, banks and so on, as well as trying to deal with physical, mental and psychosocial changes.<sup>12–17</sup>

I experienced this first-hand and found there was no practical help for me outside the hospital regarding money, returning to work or psychological support for my wife and myself. Working for myself for so many years had enabled me to find my own solutions to problems and this situation was no different but some people are not equipped to deal with these complicated situations and need additional support. I found that charities were very slow to reply to my emails and then had nothing solid to offer. I was entitled to very little money from the Government as I had always supported myself and I had my own house. Trying to find any work was impossible, literally anyone I spoke to about even the most basic work, could not see past my incurable cancer. Even my bank did not want to extend my mortgage because of my cancer diagnosis.

## Charities and online material

In today's digital age, cancer survivors often look to the Internet and charities as their first port of call when struggling with these issues that arise in day-to-day life. There are many charities in this sector, but unfortunately the large ones seem happy to duplicate work in the name of their brand. Most focusing on fundraising with little thought for collaboration.<sup>18</sup> The accuracy and the quality of information found on the Internet are varied and can sometimes lead people in the wrong direction. One study, which looked at bladder and kidney cancer information presented online, found that in most websites, there were deficiencies in the clarity of aims, presenting symptoms, investigations and treatment options.<sup>19</sup> So it's no surprise that many cancer survivors find themselves feeling confused and overwhelmed.

## Helplines

Helplines can be another key resource for cancer survivors across the United Kingdom. Although cancer helplines in the United Kingdom offer reasonably broad coverage across the country, one study found that there are still a number of potential barriers to accessibility.<sup>20</sup> The study concluded there is a lack of out-of-hours service provision,

free-of-charge services, provision for non-English speakers and little or no specialist provisions in place for callers with hearing impairments, speech impairments, communication difficulties, visual or other physical impairment or learning difficulties. In addition to this, the authors found very few helplines provided welfare, benefits or legal advice, which are issues many cancer survivors may encounter. Some of the helpline staff found that callers were worried by information from online sources, which were inaccurate or provided poor-quality information, which is additional evidence of the challenge above brought about by lack of collaboration and the duplication of information online.

### **Taking action, Chris' Cancer Community and beyond**

Initially I started my own charity, I wanted to raise money for specialist equipment in the ward that looks after me, I raised funds through various activities and an online portal ([www.justgiving.com/chrislewis2](http://www.justgiving.com/chrislewis2)) raising £25,744 for St. George's Hospital. I then started volunteering, to find out more about cancer and its impact, which gave me something positive to focus my time on when my health allowed.

As a very independent person before my diagnosis, I was used to working on my own, but my thoughts turned to all those vulnerable people that were not. I was lucky as I had a fantastic support network of family and friends, but what about the people who don't? I still found it very tough going so want to help improve the system for others.

One idea I came up with is to create a position as a discharge coordinator for anyone affected by cancer, someone who specialises in access to the appropriate support and resources available outside of the hospital. For example, benefits, local support groups and services. Someone you could liaise with on a regular basis for non-medical issues. I believe this would take a lot of pressure away from primary and secondary care professionals. It would also help connect those people with others who have a similar issue and they can help support each other and learn from their different experiences. This will help remove some of the isolation felt by many people affected by cancer and reduce the pressure on General Practitioners and hospitals. Once you have cancer, it is hard to know what is 'normal' or not. Someone on the end of the phone who is an expert in post-treatment issues would really be reassuring for all.

As my personal experience showed me that these support services were lacking for people after their treatment and that discharge coordinators are not yet a reality, I decided to start Chris's Cancer Community<sup>21</sup> as a safe place to bring cancer patients together and allow them to express their feelings. I thought at first it might only be me who felt this way but through the website many people connected, to share their own stories and issues and it was apparent that wasn't the case.

I now work with many of the national cancer charities getting involved in numerous projects that enable me to use my business and personal skills and help them improve the services they provide to cancer patients and survivors. I also work to raise cancer awareness in the community and have started my own charity, simPal,<sup>22</sup> helping support people affected by cancer with the cost of mobile phones to encourage communication.

Frequently, I am invited to talk at health conferences and I am constantly looking at ways to improve the lives of people affected by cancer. I am very much aware that this is not only the patient themselves but also the family, friends and so on. Everyone's life changes with a cancer diagnosis, and since it comes with no rule book, a lot of people struggle to make sense of things. I find that most people just want to communicate their situation to someone who has time for them and who had maybe encountered some of the situations they were facing.

### **Conclusion**

Cancer may not be life-ending, but it usually is life-changing. A cancer diagnosis instantaneously turns life upside down for patients and their families. While accurate diagnosis and effective treatment are paramount, cancer survivors may experience long-term treatment complications, must live with the risk of cancer recurrence and often experience practical, mental and psychosocial complications that require supportive care services. Increased access to appropriate, concise online information for patients and their families is becoming increasingly important in this new digital. National and international charities should strive to collaborate more to alleviate the duplication of important information and develop their services, such as websites and helplines, with patients and the difficulties they face in mind.

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