

CHAPTER 1

The Patient Perspective

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OVERVIEW

- The family environment and the support it offers hugely influence how the patient deals with a diagnosis of colorectal cancer
- Surveys suggest that colorectal cancer patients seem generally grateful and satisfied with their treatment, including the quality and timeliness of the information they received, the quality of their healthcare, and their level of involvement in decision making
- Nevertheless, despite progress, individual coordination of care still needs addressing, particularly around long-term follow up
- Patients generally have a relatively positive outlook on their illness experience, although those with colostomies have some added difficulty and side effects of treatment often cause anxiety
- Patients need the whole team approach to manage overall care, and to act as a sounding board for ideas and treatment options – not only family and friends and cancer specialists, but GPs and allied healthcare professionals
- Clarity of communication, based on honesty and openness, is key

Coping with ill-health: family influences

Our views are not shaped through our isolated experience of life alone but also through our upbringing and family influences. The metaphysical poet John Donne said, 'no man is an island unto himself'. I therefore feel that it is appropriate to mention relative family influences which have obviously impacted on how I view the experience of dealing with colorectal cancer. This could be considered a different angle on personalised medicine, in which genetics are trumped by nurture.

My parents came to England from Ireland in the 1930s. My father was a maintenance electrician in a large machine tool manufacturer and my mother was a nursing Sister having qualified in both mental and general nursing. My mother's sister also became a nurse. My

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paternal grandmother was a midwife, as was my father's sister. I learned of the many advances made in medicine over their careers but also of its limitations and the gentle grace with which this was accepted.

My wife has specialised in elderly care and neuro-physiotherapy and for the past five years has been the physiotherapist at St Richards Hospice, Worcester. This makes life for her at the moment more rather than less difficult; she is more than well acquainted with the prognosis of my illness. Ignorance can sometimes have its blessings, if only in the short term.

Attitude matters!

I am an Incorporated Engineer and have been a director within several companies since 1976. The one thing I have found is that there is usually more than one view or resolution to any complex problem and there is normally a safe default attitude, bowing to the view of a glass being half empty. My gift lay with a logical appreciation of the technical argument, exploring and exposing possible alternatives and moving the argument and solution to one of a glass half full and getting more full! It is rare to find only one solution and for that solution to be perfect, without ongoing or unforeseen problems that have to be managed or mitigated. Therefore my expectations in expressing a patient's view are conditioned with a sense of reality. I am aware that NHS funds are not limitless and that there are others much worse off than me. This does not, however, stop me from exploring that which is or might still be possible and using every scrap of available information to empower this journey.

Signs and symptoms: get medical help as soon as possible

The first real noticeable symptoms of my illness manifested themselves in early 2007 and the regularity and severity of these increased as the year progressed. These included:

- increased flatulence
- feeling bloated
- feeling abdominal discomfort within an hour or so of eating
- having to repeatedly go to the toilet

- blood staining on toilet paper
- actually passing blood with stools
- having to go to the toilet during the night.

At first I was not too concerned as I had irritable bowel syndrome from time to time and had piles, and so to begin with had thought it was just a combination of these two. As the year progressed, my wife became more concerned and badgered me to see my GP but, typical of the male species, I put the matter off; after all, on occasions the symptoms would ease and almost disappear. Besides I had always been very fit and healthy (sporting injuries apart). I was never ill and hardly knew my way to the GP's surgery. Also, I was now in business with another colleague and I could not afford the time to be ill! My wife settled the matter and told me she had made an appointment for me with our GP (I had had the symptoms for 12 months by then) and my subsequent history can be summarised as follows:

- Late November 2007 – Initial consultation at GP surgery.
- Early December 2007 – Blood test appointment.
- January 2008 – Endoscopy appointment with consultant surgeon at Worcestershire Royal at which she informed me there were tumours and they were, from her experience unlikely to be benign. Appointments followed for MRI and CT scans.
- February 2008 – Consultation with surgeon to review results of scans which indicated the colon tumour had metastasised to the liver, then colon resection and referral to the liver unit in Birmingham for possible liver resection
- May to July 2008 – Referred to Cheltenham General Hospital for chemotherapy regime of six fortnightly sessions of Oxaliplatin and 5-Fluorouracil (5-FU)
- 2009 – Liver resection at St James's Hospital, Leeds
- 2010 – One further course of chemotherapy locally at Worcester-shire Royal Hospital.

Good communication throughout the care pathway is the golden key

So breaking bad news was done sensitively and in stages – after the endoscopy and scans with my wife present at each consultation. Although a massive shock, I was grateful for the frankness at each stage which meant there was no false expectation at any of the appointments, which had been in quick succession. I heard 'cancer' and 'secondaries' and little else and was grateful for my wife's attendance and the written, explanatory notes which we could take home to study.

Good to have a plan of action

I appreciated a plan of action to focus my mind. I became involved – saw the stoma nurse as a colostomy was a possibility at the time of surgery; saw a liver surgeon – to keep that in reserve for after chemotherapy. After my bowel resection (and thankfully, I didn't need a colostomy), I set about self-made plan to get fit for chemotherapy – to eat healthy food, to exercise avidly and to show patience and endurance throughout adversity.

Telling my sons, mother and three brothers

The worst bit about the diagnosis and pathway was telling my sons, mother and three brothers. As an ex-nurse, my mum was able to be rational and positive. I had to ask my elder son to come back from Iceland early and summon my younger son, who had just started university in Wales, to come home. We had never talked about cancer ever as a family but my son immediately told me that a friend of his had been diagnosed with testicular cancer, which made my problem seem small in comparison.

Rationalising having cancer

I didn't do the 'Why me?' question that fellow patients speak of, as that seems unresolvable and a waste of my energies. I had had a good life, travelled over the world and been fortunate to raise a lovely family – so felt fortunate. Emotionally, it's tough. I still contemplate all things that I thought I'd do, my dreams and expectations that, for various reasons, are out of reach now; we can no longer afford some of them, my earning capacity has been curtailed as I owned my own business. I have a different focus now, sadly taken up with treatment regimes ahead of me, and am unlikely to be fit enough to realise most of my dreams. So I keep it simple – what else is there other than a return to as reasonable a life as possible within one's own family?

As much as possible, I carry on with work; the stark reality is that the mortgage has to be paid, but we do need more information on what benefits the State might provide.

My colorectal cancer pathway

Due to the pattern of the care, my cancer pathway has had highs and lows, moments of high drama, low humour, encouragement and disappointment. As I write I find that, despite the best treatment that the NHS could offer and the indefatigable support of my wife and family, the cancer has recurred yet again and that there is no prospect now of cure. In some ways I am glad to be spared further chemotherapy at the moment, as the last session proved tough. My focus now is on keeping as fit and comfortable as possible, supported as I have been throughout by those constant companions, my family and GP. I know that I can access supportive and palliative care services if required, having already been introduced to my palliative care nurse.

I know that I have lived longer than if I had been diagnosed 10 years ago and that I may soon exhaust conventional medical approaches. I may consider complementary therapies but will avoid procedures that might make me feel worse.

Don't believe everything you read on the internet, but feel free to take control of your own life and travel hopefully. This I intend to do.

Acknowledgement

At a time when criticism of the National Health Service (NHS) still remains politically convenient, I can only report that once I was actively placed with the appropriate consultant, the care I received

for the three and a half years since November 2007 of my illness was generally first class. For the greater part, it would be hard to imagine that even the most expensive of private health care could offer very much more.

I do refer to certain criticisms of the NHS, but I would not want to appear to be churlish or ungrateful – far from it. The criticisms are to be constructive and serve to help others.

May I express my deepest gratitude to all the staff within Worcestershire Royal Hospital, Cheltenham General Hospital, St James' Hospital, Leeds and Queen Elizabeth Hospital, Birmingham, as well as my General Practitioner, Knightwick Surgery, Worcestershire and the Community Nurses for their professional skill and the kindness they have shown me.

Further reading

Useful websites for both patients and professionals:

American Cancer Society http://www.cancer.org/docroot/MLT/content/MLT_4_1x_Living_With_Uncertainty_-_The_Fear_of_Cancer_Recurrence.asp [accessed 10 April 2011].

Beating Bowel Cancer <http://www.beatingbowelcancer.org/> [accessed 10 April 2011].

Bowel Cancer UK <http://www.bowelcanceruk.org.uk> [accessed 10 April 2011].

The Lance Armstrong Foundation http://www.livestrong.org/site/c.khLXK1PxHmF/b.2660683/k.5BD8/Sadness_and_Depression.htm [accessed 10 April 2010].

MacmillanCancerBackup <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunication/Sexuality/Solutionstosexualproblems.aspx> [accessed 10 April 2010].