

Presentation by Kenneth Muller

OOSO Quarterly meeting, Churchill Hospital, Saturday 11th June, 2016

Presentation by Kenneth Muller, Former Upper GI Patient

Introduction

Kenneth Muller aged 65 and married to Sheila Muller. We are both retired and live in Marlow, Buckinghamshire. We have two adult daughters and two teenage grandchildren.

I had an oesophagectomy in February 2015.

Past health background

During the last 15 years, I had become increasingly overweight and until 2011, when I retired, my lifestyle was not particularly healthy, especially in diet and irregular exercise. Before my diagnosis, I had reached almost 16 stones in weight. I had only had two previous occasions of being admitted to hospital for surgery.

- 2006 A hip resurfacing procedure.
- 2009 A broken tibia and fibula involving two successive operations

Diagnosis

During August 2014, I became increasingly easily fatigued. In early September 2014, after a routine blood test, I was found to be extremely anaemic. I was prescribed a strong course

of iron tablets and referred to a colon cancer consultant for investigation. Following a dual endoscopy and colonoscopy at Stoke Mandeville hospital, I was diagnosed as having a cancerous tumour in my oesophagus. Initially, it was viewed as, possibly, being too close to my aorta for surgery. Fortunately, several subsequent exploratory procedures confirmed that surgery could be possible, but only after a combined course of chemotherapy and radiotherapy, comprising 5 x Monday sessions of chemotherapy and 25 x separate daily sessions, Monday to Friday of radiotherapy, throughout December and into the first week of January 2015. On the 17th February, I underwent a 12-hour operation at the Churchill Hospital, followed by 11 days of recuperation.

There are three topics in particular that I would like to explore:

- Care and support
- The biggest challenge
- Two top tips to share



Care and support

Being referred to the highly modern Cancer and Haematology Centre at the Churchill Hospital, immediately after formal confirmation of my diagnosis, has proved to be, literally, a life-saver, both for myself and for Sheila. From the first time we met Anne Phillips and Anita Joyce, the Advanced Nurse Practitioners, and Bruno Sgromo, my consultant, we realized that we could not be in any better or in any more reassuring hands. Despite several weeks of nerve racking uncertainty, as to whether I was only going to receive palliative care or, more positively, to be prescribed a suitable course of pre-operative treatment, the Churchill team ensured that we both received a combination of highly positive ongoing encouragement alongside a regularly delivered candid assessment of the varying challenges ahead, dependent upon which eventual prognosis would be finally confirmed.

The regular phone contact with Anita Joyce, always aimed at both myself and Sheila, covered a most critical phase of time, prior to us discovering the eventual prognosis. It enabled us to deal with and respond objectively and rationally to the differing challenges that kept appearing before us, especially during the ultra-strained months of October and November. It also equipped us to keep our family and

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close friends, more authoritatively informed about the developing situation. The continuous focused care and support from the Churchill Team was always with us, as was the amazing level of support and encouragement from our family and friends. Sheila and I never felt remotely alone in the long fight that lay ahead. Post-surgery, OOSO has, of course, significantly reinforced this support.

The biggest challenge

For both myself and Sheila, it is without doubt the entire subject of a new dietary regime and all that entails. Within weeks of returning home, I became increasingly unable to maintain the recommended regime of half a dozen snacks or small meals, evenly spread throughout the day. I became repeatedly nauseous at even the very thought of the next snack after such a relatively short interval since the previous one. However ingeniously varied was that day's devised menu, my overall appetite for eating radically diminished. In those first six months, following surgery, the entire subject of eating had become my worst nightmare, since the actual diagnosis and the ensuing period of pre-operative treatment and then the surgery, itself. That nightmare was shared by Sheila, who was valiantly, but frustratingly, always searching for more amenable eating solutions that might, hopefully, suit me better. Additionally, I had become repulsed by almost all red meats and by numerous cooking smells. Since then, I have gradually returned to eating three times per day. I do start with two or three cups of tea between 07:30 and 08:30. Mid-morning. I will generally have a bowl of mixed fresh fruit, followed by a couple of slices of toast and jam. Between 13:00 and 15:00, I will make a couple of sandwiches and eat them during that two-hour period, sometimes with a little more fruit or some cake. I rarely drink any fluids during the afternoon. At about 18:00, Sheila and I will wind down our daily activities. I will usually drink a couple of gin and tonics until 19:30. Then between 20:00 and 21:00, we will sit up at the table to have dinner, usually comprising a main dish, cooked or salads, and then some type of light desert. My plate volume is, of course, much reduced than before my surgery. I never experience any reflux after dinner nor throughout the night. I do, though, take a 30mg Lanzaoprazole tablet every morning with my tea. However, I did experience fairly frequent early or late dumping for the ensuing few months, especially when I forgot to limit my volume intake per meal session.

This situation is very prevalent whenever we now go away on holiday, such as our two weeks holiday last

February on the island of Zanzibar. Breakfast offerings were sumptuous. My eyes were so much bigger than my now much reduced stomach capacity. Encouragingly, during these last three months, I have rarely experienced any dumping. Since my surgery, I have maintained a steady weight of around 12 stones. However, only one month after surgery, I developed a growing intolerance to milk, especially when mixed with hot beverages, such as tea and coffee. I also refrained from having cold milk and cereals. I did try a variety of other recommended milk products, but all of them reacted in me, to one degree or another. I used to love milk at any time of the day.

At my last 6 monthly consultation with Bruno Sgromo, mid-May, we discussed this challenging issue. He recommended a daily lactase enzyme tablet, first thing each morning. This recommendation is already beginning to work to good effect.

Just returning briefly to the subject of my daily evening gin and tonics, I feel that I should clarify and justify their inclusion in my weekly diet. At the first OOSO quarterly meeting that Sheila and I attended after my discharge from hospital, we received a superb presentation on dietary issues and on the changed operational nature of what remained of one's oesophagus and/or stomach, post-surgery, from two of the leading members of the Churchill's dietician team. We were advised to limit our consumption of carbonated drinks. A couple of brave ex-patients proffered their liking for drinking tonic water and, additionally, diluting it regularly with gin.

After a short stony silence, Nick Maynard gave us his qualified approval, but cautioned us with the ever repeated mantra, "in moderation". Naturally, I followed such welcome endorsement enthusiastically and gratefully. Actually, I do believe that I do benefit from these evening's libations, but I do ensure that a suitable time interval is observed before starting to eat my dinner. Cheers!

Two top tips to share

Tip one

At no time, did I ever want to become an expert on oesophageal cancer. The amount of informative literature that we were given on various matters of importance, during those initial five months, before surgery, could have pushed me in that direction, entirely against my base instincts.

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Notwithstanding, I always studiously ingested the informative and, often essential, array of verbal and written advice and explanatory data that the Churchill team and, particularly Anita Joyce, would specifically recommend for our close attention, ahead of any impending major next stage of my pre- and post-operative treatment. Being faced with the necessity to select one out of two very different oncology options on offer, is an important case in point.

Tip two

On being discharged from hospital at the end of February 2015, Sheila and I immediately discovered that we would have to work determinedly to get suitable levels of care support and local monitoring through our GP's surgery and by the District Nurses. We experienced several anxious and frustrating disconnects. After only a couple of weeks back home, I was compelled to request a transfer of registration to another GP within the Practice, who would provide a more empathetic and holistic approach to my needs for post-operative follow up treatment locally.

Before my first three months post-op consultation at the Churchill, I had to push very hard to get the GP's surgery to authorise regular full blood count tests. My immune system, since chemotherapy, radiotherapy and surgery had taken a real bashing, particularly relating to neutraflis and white blood cells results. I had been critically neutropenic between chemotherapy and surgery and I still remain at the very bottom of both of those listed ranges to this day.

During recent months, we know of other acquaintances and friends who have been going through similar periods of ordeals, following Upper GI surgery. My firm advice is to push relentlessly from the outset at your local GP's surgery for them to seamlessly complement the excellent effort expended by the Churchill Team, on our behalf.

Conclusion

I want to conclude this presentation on a hopefully beneficial positive note. It is now almost 21 months since my diagnosis and about 16 months since my surgery. The long-term prognosis for me from the Churchill Team is encouraging. I have had several holidays, since my surgery, some of them abroad, including sailing across the Channel to France during the last ten days.

I have done a lot of walking, including several Marlow

to Henley Thames Path treks, each comprising a distance of about 9 miles.

Increasingly, I can do more outside to assist Sheila with our two acres of garden and woodland. I do have to take care of myself by not physically overdoing it. All that said, I have my life back under my control, almost back to normal routines, but with a few obviously necessary lifestyle changes. And finally, whilst concluding this presentation with an upbeat tone, it is beholden of me to set some sort of balance in outlining the respective levels of progress that each of us individually experience before and after our pre- and post-operative treatment.

We all tread the same road of utter shock, bewilderment or abject helplessness, on learning of our specific diagnosis. Subsequently, our individual journey entailing either palliative care,

pre- and post-operative treatment, as well as a wide variance in the actual extent of each surgical procedure, leaves us with a myriad array of fervently optimistic expectations, wildly frustrating unknowns and sometimes shattering disappointment. The common bonding factor this morning for this OOSO quarterly meeting is that we are able and willing to convene together to support one another in order to keep progressing positively forward. Of course, this common bond which we share would not be possible to realise if there was not such a dedicated team based at the Churchill, constantly delivering the most proficient level of professional medical care and support.

Kenneth Muller
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