

## ***I THINK WE HAVE A PROBLEM.....***

*(An interview with Wayne Osler who has lived with cancer since mid 2004. During this time, he has had 40 chemotherapy treatments, been to hospital for various lengths of time on 43 occasions, and received a bone marrow transplant which required 3 months hospitalisation. Although the bone marrow transplant provided a remission period of only 18 months before cancer returned, he is in remission again after another year of chemotherapy and remains hopeful).*

**How and when did you think that you might have had some problem?**

*Very early in 2004 I was experiencing substantial lower back pain and sought physiotherapy treatment over a few months. The pain was usually at night and no amount of stretching/exercise could relieve it. I also noticed that I was 'thickening up' a bit around the waist. I started to go on a diet with no result. Tiredness was also a factor. I put this down to poor sleep as a result of back pain. We went to China in June to pay our respects to (friend) Julia's brother in law who was seriously ill with cancer, and in fact died as we were en route. I struggled with the back pain and tiredness to the point that I decided that I just had to go to a hospital. I was hoping that it was the traveling around, bumpy roads etc. that was the problem. Deep down I was a bit worried when all of the stretching and exercises couldn't give me any relief. The weight was also still increasing around my stomach. We underwent some examination, had acupuncture, cups and massage. In the end, the doctor who spoke no English said to Julia that I should go home ASAP and get treatment. By this time the only bit of pain relief I could get was by laying down and I really had concerns about the trip home. Fortunately Julia was able to arrange for me to have four seats so that I could lay down all the way home. Having been a very active person and used to a few aches and pains, I knew that what was happening was a bit different.*

**What is your background in terms of your health and lifestyle?**

*Up until I turned 50, I was fairly fit and healthy. I was a non smoker, consumed alcohol sparingly and exercised regularly. Since age 30 I had competed in some 12 competitive marathon races, ran thousands of kilometers in training, cycled, swam, competed in triathlons and played competitive tennis all year round. It is fair to say that I could be a bit obsessive in many aspects of my life and in particular, my work. From age 50 my health started falling apart while the pressures of work and personal life increased substantially. I had developed sleep apnoea, had my gall bladder removed, ruptured an Achilles tendon, developed a heart condition which required insertion of two stents, and suffered a stroke requiring an operation to clear a carotid artery leaving me with some residual problems. My work load increased considerably, my marriage collapsed and I reached a point whereby I*

*could not continue. I left work with stress and anxiety related problems in 2003. I was classified as totally and permanently disabled after 6 months and my employment was terminated. The following year cancer turned up.*

**What was happening in your life at the time of the cancer diagnosis.**

*Julia and I had been good friends for some time and we decided that she might move to Heathmont in May 2004. I had been having difficulties with anxiety and depression but was living quite happily with my dog Eddie in Heathmont. My golf game was coming along nicely and my fitness seemed by and large pretty good. My children were settled and going along well. My mother who passed away earlier this year (2009) was starting to have some difficulties living by herself and the family knew that this was a growing problem which we later helped mum address. With a few exceptions life was pretty good. I was happy to keep to myself and lead pretty much a solitary life. Morning coffee with some other regulars was my social life.*

**What treatment did you seek over what period of time?**

*When we arrived home from China I made an appointment to see the doctor. As I was showering I noticed a large swelling protruding from the side of my stomach-about grapefruit size. I decided straight away to go to emergency at MaroonDAH Hospital – this swelling had suddenly become very significant. After sitting around for a few hours with substantial pain, I had to lay on the floor for another couple of hours before I was attended to. From there I was put in bed, had blood taken and later sent for a scan. The doctor told me that the results would be through in a few minutes. It was several hours of waiting that followed. I remember asking the nurse about the delay and she told me that the doctor had to check a few things out. We were already concerned that the problem could be a big one, and the delays weren't helping us to change our thoughts..*

**How was the news that you had cancer relayed to you?**

*A doctor came in, pulled the curtain around and asked Julia to take a seat. I'll never forget his first words .. 'Now we can't be absolutely sure...I think we have a problem' He went on about lymph nodes, spleen and so on. We were just waiting until he finished, and just before he did, he said that he believed that I had cancer and that at that moment an oncologist was looking at the scan results. He was a bit emotional about the situation.*

**Do you remember your first reaction to the news?**

*Yes, it was a bit emotional for a couple of minutes, and then I asked the doctor about what was going to happen next. It wasn't a real shock to find out. It was*

*more a confirmation for me. Now that we knew that there was a problem and that it was a bit on the serious side, I really wanted to get on with what had to be done in terms of treatment, and in terms of getting my affairs in order. I was starting to think about how I would tell my family and decided to tell them that the diagnosis didn't mean the end of anything, rather the start of something which would be completely different. Don't know if it helped, but I went with that.*

**What happened then in terms of treatment?**

*After some paperwork, and they established that I had private health cover, I was transferred to Ringwood Private Hospital. It was great news because I had thought I might have gone to a city hospital. Being just down the road from home was a relief. The memory is a bit hazy about it, but I did have a long conversation with oncologist Michael Leyden who recommended a course of chemotherapy treatment and that this would be starting the next day. I found him to be a pleasure to deal with initially and my respect for him grew every time I had anything to do with him.*

**Was there any counseling provided or made available to you at this time?**

*No. While there is counseling available, and I understand that they do a first rate job, it wasn't made available to me largely because of the time frame involved. Normally there is a period of time after diagnosis and start of treatment when all of these things are put in place. My case sort of fell through the cracks, and I was too busy thinking of other things to ask. For some reason I regarded my problem as deeply personal, and that it was going to be up to me to quickly sort out how I was going to behave and what example I could set for my children and those around me. I started this process pretty well straight away and relied on humor and good spirits to get me through dealing with both the cancer and visitors. I just wanted people to walk away thinking that I was on top of it all. Others will judge how well I did this at a time when I was pretty frightened and feeling vulnerable.*

**Did you undergo any operations initially?**

*Yes, I remember having lymph nodes removed from under my arms, and a bone marrow biopsy which I have to say isn't something you would voluntarily line up to have. There have been four of these over the journey I think. There were other bits and pieces but nothing major.*

**Did you investigate alternative forms of treatment at that time?**

*No, everything was happening very quickly and we were comfortable with the explanations given at the time. There was of course the opportunity to reject the chemotherapy treatment, but I opted to go with it and asked that they didn't 'hold back'. As I said before, this was very personal for me, and other than a very few people who I believed had a strong history with me, I took it on by myself. There was no shortage of advice ranging from turning to god, consuming all sorts of*

*strange concoctions, seminars, meditation, microwave treatment in WA and so on. I am still getting advice to this day. The decision to not seriously investigate alternative treatment had a bit to do with treasuring my time. Rather than spend my energy and time running up dead end streets, I wanted to devote it to the very moment in which I found myself. Thanks to oncologist Michael Leyden, I was able to discuss many of these alternatives with him and will always be grateful for how he managed the information he gave me.*

**You had been off work for some time, and now facing considerably more time off. How much stress were you under financially?**

*Thankfully none. The earlier marriage breakup and subsequent property settlement meant that I was still paying off my house. Many years earlier I had taken out income protection insurance, having sold many of these policies and training many advisers in how to sell it. I was and am still passionate about the benefits of having such security, and believe, as does the oncologist, that being able to avoid all financially related stress was very instrumental in my ongoing well being. Over the time, I saw many who were in dire trouble as a result of loss of income..businesses lost, houses having to be sold etc. Every day, I feel pleased that I made the decisions to have both private health cover and income protection insurance both of which had to be taken out when they weren't required so that the cover would be in place for a situation like this. It is highly unlikely that the bone marrow transplant in 2005 would have been available to me without private health insurance, and at the time, I was pretty well finished.*

**When did you tell your family and what was your thinking in those first few days after diagnosis?**

*I called the kids and told them that I was in hospital and that I could be in a bit of strife. They came in to see me and I just told them the basics. I assured them that I was going ok and just wanted them to get on with their lives. Julia seemed to be committed to looking after me for the duration. I called my mum and promised her that I would outlast her. Certainly I didn't want her thinking that she might have to come to my funeral. My brother came in, and I phoned my sister in Sydney who offered to come down to Melbourne. I told her to stay put and that I would tell her when I really needed her to be with me. She understood and has been my closest confidante. I was pleased to see her and her family a little later when it was becoming clear that the situation wasn't going to improve any time soon. The thinking was to try to get a bit organized and not get too far ahead of myself by becoming an 'expert' and panicking about what might happen. As we know, many of the things we worry about haven't yet happened and probably won't. There was no point getting too concerned about what had already happened either. I didn't want to waste my time on much other than the present day.*

**How were you doing mentally. Did you have feelings that this was a bit unfair and ask 'why me'?**

*No. I am not the only one living with cancer, and like anything else, a quick glance over the shoulder will tell you that others are doing it tougher. Thinking about luck, fairness etc. would have been too self indulgent and certainly no help. I recall thinking about what would be the worst possible outcome, accepting that this could very well happen and what could I do to improve on that. On one of the few occasions I voiced the view that I was a bit stiff given my pretty healthy former lifestyle, only to be told by a medico that if I hadn't lead that lifestyle, I would have most likely died three times already. From that time on, I never complained about being unlucky, indeed the opposite was the case. There were definitely emotional times and tearful times, but I tried not to let many people see that. In the end there was no 'what if' 'why me' etc. , rather understanding and working with 'what is.'*

**Having been a very active person, how did you cope with being confined in hospital?**

*It's a bit different than having a broken leg. I actually felt pretty crook and was happy to be looked after in such a nice hospital by such caring and understanding people I was pretty vulnerable and a bit apprehensive, so being in hospital gave me the security I really needed. I was hooked up to a monitor all of the time and every time I wanted to move, I had to take it with me. I was keen to take the monitor for laps around the ward as often as possible. Calling in on other patients occasionally, making myself a cup of tea etc. helped fill in the day, so it was really a pretty good place to be. I slept a lot, listened to the radio and watched DVDs reminding me of how good my life had been to this point. I made a conscious effort every morning to look at myself in the mirror and promise to be a happy bloke, make no complaints, and make no criticisms. This became a bit of a challenge when vomiting in the hand basin at the time. Humor is so important at any time and the hospital staff helped enormously in this regard. I would need as many people as possible wanting to help me and decided that this would be the best way to go about it. Nurses, cleaners, kitchen staff etc. tell me that there is no shortage of whingers in hospitals and I never ever wanted to be classed as being one. I took the view that as long as I was in the right place for me at the time, then I'd be happy about it. If I was home, then that's good. In hospital, well that's good too. Looking back I'm happy with that strategy and will stick with it. Certainly being a regular patient tells you that it is wise to have some coping strategies in place.*

*During my life, I have been in control and had others depending on me to be in control and on top of everything. This was going to be difficult because so many things were out of my control. I decided early on that no one else could control what I thought or how I behaved and so I became determined to be on top of those two areas for a start and as treatment progressed other things would become apparent where I could be an influence.*

**Did you contemplate the possibility of death, and if so, what was your thinking?**

*Absolutely. The initial thinking was to immediately organize whatever I could to get everything in order. I planned to see a solicitor as soon as I could get out of hospital and get my will sorted, go through my files and put them in order and take the family through the house and possessions to explain my wishes. I thought about this quite a bit so that I could do it quickly. This was my responsibility and I felt that I needed to get this over and done with while I had the capacity. Several people thought that I was being negative, but what I wanted to do was to address the death question, organize myself ASAP to handle it, then put it right out of my mind to focus on the problem at hand. I really never got caught up dwelling on my demise after everything got sorted. Even later during the bone marrow treatment when I overheard several people express their doubt that I would ever get out of the hospital alive, I never thought about death. The other really important decision was to get a portable DVD player so that I could look at the 'Life Story' Julia had put together and remind myself about what a great life I had enjoyed. I was able to believe that if this was to be my time, then I could be well satisfied about my contribution. Right from the beginning, that DVD was one of the first things packed when I was heading to hospital. While I might have appeared to be in control and on top of things, I was frightened and apprehensive a lot of the time.*

**How did family and friends react initially?**

*Thankfully my children are well adjusted mature people, and while there was some emotion, they were very supportive of my views on how I was going to address the issue. Likewise my brother and sister. Some of my friends didn't know how to react and found it difficult to speak with me. Others, even to this day advise me to 'keep the chin up', 'stay positive' and 'hang in there', and while no doubt well intended, these comments are unhelpful. I guess that they could at least feel as if they were seeming to do something with these words and I never let them know that these words were neither comforting nor helpful to me. Endless stories about other people suffering with their illnesses didn't comfort me then or now either. We have to adjust and live with this thing, and those kind of comments served to drag me down when I really needed more positive input. Some people had many questions to which I had no answers and had no real interest in thinking much past the first chemotherapy treatment and taking it from there. There were many times when people visited and I sort of drifted off. When they thought I was asleep or not paying attention some of their conversations made it clear that even if I wasn't expecting to die right away, they weren't very confident about my chances. That told me that most people were putting on their brave faces around me which meant that maybe I should just go along with that. It was difficult for everyone, and I'm sure that everyone sincerely wished me well.*

**Do you remember your first chemo treatment?**

*Certainly. I had been briefed on what I was going to be given, how it would be given over what period of time and was aware of some of the after effects. The oncologist was keen for me to monitor what was actually happening and faithfully*

*report it to him rather than sweat on the possibilities, most of which wouldn't happen. I was all hooked up by Renae who was resplendent in mask, goggles, gown and overshoes. The first program was called PACE BOM which is an acronym for the chemicals making up the chemotherapy cocktail. I remember messing about and feeling pretty good for the few hours I had to wait, but when the tubes were in and the taps turned on, the gravity of the situation hit and it was pretty emotional for me. Even now after around 40 chemotherapy treatments, the reality of the situation seems to hit home at that time. Having chemotherapy is still the big reality check for me. The rate at which chemo is given depends on the capacity of the individual to receive it and has to be modified should there be fluctuations in blood pressure, temperature etc. I can recall getting severe shakes which scared the family a bit and frightened me. After you experience that and understand what is going on it just slips away into relative insignificance just like other aspects of the treatment. I am so thankful that my daughter Shelley was with me that day.*

**What were some of the after effects?**

*There are many many after effects, but the ones I experienced were largely confined to nausea, diarrhea, vomiting, ulcers, headaches, vision impairment, infections, skin rashes and overwhelming fatigue. The smell of food would bring on the vomiting consistently, but it could happen any time. There were drugs for all these things which of course had their own side effects. Vomiting while sitting on the toilet hooked up to the monitor and drugs took some getting used to. Again the hospital staff were great. I was always concerned about how I would cope with this at home. Later, it was to become much more difficult.*

**Did you spend much time thinking about the possibilities that lay ahead for you?**

*Not really. Often friends and family would ask me about it and what was ahead. I never asked the oncologist about it largely because he couldn't tell me. I did ask him to promise to tell me if in his professional opinion, he believed that I was terminally ill. It was important that I know this because it would mean that I could access my life insurance cover to take care of my financial commitments and make certain provisions for a few people. He made me that promise. My main interest was to monitor any reactions to medication and report it. Thinking about tomorrow was something I tried not to do.*

**When you were allowed to go home, how different was your life and how did you adjust?**

*As everyone living with cancer will know, chemotherapy kills off both good and bad blood cells severely compromising your immune system. Keeping away from places where someone may have a cold for instance, limits your movements. No shopping centres, trains, picture theatres etc. Vomiting and frequency of toilet visits also*

*limits you. The food situation must have frustrated Julia considerably. She was doing her best and while I would suggest something for dinner, the smell of it cooking would send me outside. Thank heavens for Sustagen, fruit and toast. Despite this my weight was ballooning as a consequence of the chemicals, and I was very susceptible to skin, bladder and chest infections. My temperature had to be checked consistently as it fluctuated rapidly, and it was back to hospital straight away if there were infections or the temp approached 40 degrees. I felt a bit insecure and was happy that help was very close at hand. I could phone the oncologist any time 24 hours a day, and he would phone back about 10 minutes later to tell me that they were waiting for me at the hospital and for me to get there ASAP. Things could get out of hand very very quickly and so I never ventured far from home, hospital or a toilet. Thankfully I was happy to spend time at home. Never felt much like going anywhere.*

*I did however resume playing golf whenever I could albeit only 9 holes and in a golf cart. Kevin would drive me there and bring me home. It took extreme planning with toilet, food etc. and of course I was threatened with eviction if caught urinating behind a tree for fear that I would poison the flora. I was the butt of humor at our golf Friday mornings, especially when occasionally I had to zip back to the toilet during the game.. No one was going to give me mouth to mouth, carry me on their back, or make any allowances. I was playing drug assisted in their view and was never going to get any other help. It was the highlight of the week and remains a huge motivator for me now and the future.*

*It was all very good training for what was to come. While it was all a bit tough at first, the situation was to become just part of everyday life and nothing special. Little did I know that this was just a walk in the park compared to what was to come.*

### **How supportive were your family, friends and neighbours?**

*Interesting to reflect on this. Many people visited me while in hospital, but very few visited me when I spent periods of time confined to home. It seemed like a 'duty' thing to some. Others would tell me to give them a call if I wanted them to do anything. I was never ever comfortable with doing this. Julia and I coped pretty well. One family we knew, and who have become very close to us over the four years, said that they would commit to walking my dog Eddie every night. Peter and his family have lived up to this commitment over the years to this day, and they have provided excellent support. Other neighbours offered to drive me anywhere I needed to go, cut my lawn and generally keep an eye on the place especially when I was in hospital. My family pretty well always visited when I was in hospital. I couldn't spend consistent time with my grandson due to regular childhood illnesses which would create havoc with me. Everyone soon sorted themselves out as to who would really help as distinct from those ringing occasionally to tell me to stay positive and keep my chin up which still makes me cringe. At all times, I tried to be self sufficient and not lean on anyone for support.*

**How important was it that the oncologist was happy for you to keep your dog Eddie, and in fact encouraged you to have Eddie visit you in hospital?**

*Dr Leyden explained that I was more likely to create an infection problem for Eddie rather than the other way around. To this day, Eddie is a very important part of my life. His visits to the hospital not only gave me a huge boost, he was welcomed by other patients and the staff. His photos are still on notice boards in the hospital. Eddie received his accreditation as a cancer patient visitor and I have taken him to the hospital to visit patients on many occasions. Eddie is very well known around Heathmont.*

**Once you became relatively acclimatized to chemotherapy and the routine of scans, blood tests medication to relieve after effects, did your thinking turn to the future and what you might do?**

*I never thought too far ahead. It was more of a day to day thing. Most people think that if you are in hospital, then you must be sick, and if you are at home, then you must be ok. This was not the case. There were some good mornings when I could go for a walk, and some when I actually played some golf. There were frequent infections, fluctuating temperatures and all of the other side effects mentioned earlier. I hoped at some point that there might be a positive scan, but sadly this didn't happen in that first year, so there were no real thoughts of the future other than accepting that things may not change, and could well get much worse. While some mornings were pretty good, things fell apart during the afternoon and evening.*

**The chemotherapy 'cocktail' as you put it earlier would have involved a number of drugs. Do you remember what you were given?**

*Yes, and I have kept a record of what was prescribed in that first year. It's interesting for me to go back over it, check out the information on the internet and get some perspective. Looking back over this information, it's no surprise that I felt less than my best a lot of the time. The bone marrow transplant included six consecutive days of intensive chemotherapy, and there was to be another year of chemotherapy when the cancer returned. Contrary to some advice I get, I don't want to forget any aspect of the experience...I may need to draw on it again at any moment.*

**You spent considerable time in hospital in those first six months..how were you coping with the uncertainty surrounding this?**

*I was just happy to be in the right place at the right time. The staff at the hospital were exceptional. They provided the security for me, and while of course everything was uncertain, the peace of mind they gave me was all important. It was pretty basic....what's working, what's not? What can I do today? The situation pretty much demanded that I react appropriately to what was actually*

*happening rather than think about what I might prefer. There was just no point in wasting energy kidding myself.*

**How long did you enjoy your period of remission?**

*There was one clear scan, then it bounced back within weeks.. You don't exactly come off chemo one week and resume your normal life the next. There are still the drugs and a lot of recovery required and all of this takes time. There was certainly relief that there was no chemo and that I might be able to start reducing the drugs, but I still felt weak, tired. I never thought past the next scan which was never more than a month away. There was no time to get too excited about having the good scan.*

**What was your reaction when you found out that the lymphoma had returned and was a lot more aggressive than expected?**

*Disappointment for a couple of days, but it wasn't totally unexpected. My main thoughts were concerned with what we might do now, and how soon. Certainly it wasn't as if it was a great shock. My main concern was that I didn't know how much more treatment I could take without my body starting to break down. There is a limit to how much chemotherapy a person can handle, and after a year of constant treatment, I was in pretty ordinary shape.*

**When did the subject of the possibility of a bone marrow transplant come up?**

*The oncologist raised this immediately as the best hope for me, and I went with it knowing that it would be a serious exercise with life threatening risks attached. A make or break effort if you like. There was no real choice to be made.*

**How did you feel about that?**

*My only thoughts were to understand what my role was in all of this and to do whatever it was to get myself into a position to have the best chance of getting through the process. I never thought past what was expected of me from one oncologist appointment to the next.*

**Can you take us through your initial understanding of what was to happen?**

*I was to have a course of injections at home to boost my cell counts, then go into the Alfred Hospital to have stem cells collected over a number of consecutive days until they had sufficient to transplant. They would then prepare the blood which would be given back to me at Box Hill Hospital shortly after. I can remember clearly*

*Julia hovering over me with the syringe every four hours, both of us laughing while I encouraged her to put it into my stomach promising her that it wouldn't hurt.*

**How difficult was the stem cell collection process for you**

*It was ok. Blood was taken from one arm, passed through a machine to extract the stem cells, then back in the other arm. There was no pain associated with it, just a bit uncomfortable being strapped down for around 4 hours on your back. Getting to and from The Alfred was the biggest problem because I couldn't drive myself but friends helped me out. Compared to the previous year, and the upcoming one, it was largely a non event.*

**Were you apprehensive of what might occur in the transplant process?**

*Definitely. The risk of death was high, and having had a heart attack and a stroke previously, my chances weren't all that flash. This was not going to be a picnic. The husband of a cousin had recently died in the process but like all statistics, they don't matter unless they happen to you. I thought of it like getting on a train...I was there for the journey for however long it took and couldn't get off until I got to the end of the line, and no one could tell me where and when that might be. I knew that I would be given substantial chemotherapy treatment for six consecutive days to kill off all of my good and bad blood cells. I knew that this would be pretty hard going and that the consequences wouldn't be pleasant.*

**Did you undergo any surgical procedures leading up to the actual transplant?**

*Yes, they gave me a Hickmans catheter – a device which connected three lumens directly into the main artery. This was great because blood was taken and drugs administered through this which reduced the number of injections etc. required. My veins had taken a hammering so I was happy to give them a bit of a break. This catheter stayed in place for about 6 months. While infection around the site was an issue it was preferable to having injections all of the time and being woken up every couple of hours. Staff could access the catheter to administer drugs, take and give blood without waking me up – a real plus!*

**Did this delay your later return to golf?**

*No. Shortly after my 3 month stay in hospital was over, I resumed Friday golf irregularly albeit rather gingerly and with the aid of a golf cart. I was a bit restricted, but so happy to be out there. I didn't expect much and it helped take my mind off everything else.*

**Can you tell us of some of your more difficult experiences?**

*The unrelenting nausea and bowel issues. The challenge was keeping everything in the bed and not let anything escape onto furniture or floor. The staff appreciated just rolling up the bedding and sending it to laundry, then cleaning me up.. This happened most days for months. The situation demanded that I return to my early childhood and have a napkin strapped on. Privacy, dignity, control etc. was all out the window. Given the blood counts, dormant childhood diseases were likely to flare up, and so chicken pox duly arrived which was a bit irritating. I suffered a minor stroke which was a bit difficult for a few days. This wasn't unexpected, but then again, neither was death. Most other patients were struggling just like me, so my situation was nothing special. The actual bone marrow transplant wasn't difficult in itself. It was a bit emotional and the gravity of the situation was brought home when I saw the staff standing next to the bed saying a prayer for me. There were single rooms and some 4 person rooms. If you were moved out of the single room, it meant that someone was in more strife than you were, and while it was good to get moved into a single room, it meant that you were not travelling so well. I recall being moved out of the single room on one occasion and a lady being moved in there..she died the next day and that was sad for everyone. I was pretty well drugged up and out of it a lot of the time and am a bit vague. There were blood tests done all of the time, drugs administered and blood transfusions from time to time so you weren't left alone for long. And of course there was the ever present monitor with the bags of drugs hooked up to keep me company during the lonely times.*

**How did you manage your days in hospital?**

*Having spent considerable time in hospital, I understood that I had little control over anything and had to do as I was told. My only responsibility was to faithfully report any changes in my condition as and when they occurred. Things get out of hand extremely quickly in that situation and the quicker they get onto it the more chance you have.*

*The whole situation was too much to contemplate so I broke every day up into 4 hour blocks. 6am until 10am, 10am until 2pm, 2pm to 6pm, 6pm until 10pm. When the time ticked over into the next block, I tried to forget everything that happened in the previous block, and refused to contemplate what could happen in the next block. My life was lived 4 hours at a time, and sometimes when it became really hard, it got down to hour by hour. Lance Armstrong of Tour de France fame was an inspiration to me. My only goal outside of the 4 hour blocks in which I tried to live was to somehow get to the communal lounge to watch the SBS highlights of the Tour to check on how Lance was going. At other times, and at least once every other day, I played 9 holes of golf at Ivanhoe in my mind. I played every shot and in my mind, I played pretty well. I never had three putts in the three months that I was in hospital! Nurses used to laugh at me and kindly ask if I had finished putting before attending to me. While so many things were out of my control, I kept up with what medication I was having, and took absolute control over how I behaved, and what I was thinking about.*

*There were many times when the situation became pretty difficult and I had serious thoughts as to whether the battle was worth it. Fortunately I could draw on some*

*experiences in my past to help at these times. When I was in my mid 30's I was part of a group who ran from the Melbourne city square to Portsea and back. I can recall that it was a long and tough day. I would compare how I was feeling with how I felt that day and told myself that if I could get through that, I could certainly get through this. I am so grateful that I had been well outside my comfort zone many times and could draw on these experiences.*

**Do you remember your first bit of good news?**

*Definitely. After my blood cells were killed off and I had the bone marrow transplant, I was given a chart showing all of my blood counts. The plan was that the counts would start to rise as the transplant took hold. While nothing happened for a while, the counts started to rise which gave me huge optimism. I still have those charts. Every time the blood test was done I would pester staff for the results to record on my chart. This was tangible proof to me that I was in with some chance. The charts were a life raft for me. I have kept the originals showing what the blood count ranges are supposed to be, what they actually were day by day. I look at these from time to time to remind myself of just how fortunate I was to sneak through. When I feel a bit low, I remember these times clearly, and it helps to give me the confidence that I can get past difficult times.*

**Do you remember your initial feeling about going home?**

*I felt very insecure and vulnerable. I was very weak, barely able to walk more than a few steps unassisted and suddenly I was outside getting into the car to go home. No monitor attached, no one to check me every few hours, and I was a bit frightened. Certainly I was pleased to go home, but I was very tentative and cautious. It had been three months and I wasn't in great shape. I still had to return every couple of days for checks, and had 24 hour phone access.*

**What did you do to improve your general condition?**

*I had been given nutritional advice, and was still on a considerable amount of drugs which would take time to reduce. Getting from 100 mg of cortisone daily to zero would take a long time for example. As the cortisone levels were reduced, I discovered that rheumatoid arthritis had set in. This is an immune deficiency disease and wasn't unexpected – it was on the list of things more than likely to occur apparently. I had the grips on my golf clubs enlarged so that I could actually hold them, and as one medication was reduced, complications arose in other ways which required other medication. This was all a bit depressing, so I became involved with a natural therapist. Over a 12 month period I was able to drop most of the drugs other than cortisone which I had reduced from 100 mg daily to 5mg. Unfortunately this didn't last too long as the rheumatism got worse and the*

*cortisone was lifted to 15mg to keep it under some control. My plan was to get myself into the best possible shape so that should cancer return, then I would be in a position to be able to cope with being loaded up with chemotherapy again.*

**You were in remission after the transplant, how long did this last, and what were your circumstances when it returned?**

*Well, things were going ok and my stamina was returning. I was still taking some drugs and my confidence about living for a while was growing. The period of remission lasted just on 18 months. My golf game was in reasonable shape and with a few exceptions life was going along pretty well.*

**I understand that in the space of a week, your mother died, your cancer returned, there was the funeral, and chemotherapy treatment recommenced... that's a fairly big week - how did you work your way through that period?**

*Well, I just took enormous comfort knowing that mum died believing that I was in good shape. It was a bit disappointing knowing that the best chance of survival was now gone and it was a whole new game now. The week was about mum, so other than a couple of people very close to me, I didn't say anything to anyone until after the funeral. The oncologist told me that he would start 'with a tap of a hammer' for a few weeks before introducing the 'axe'. We were pleased with my overall capacity to cope with large doses of chemotherapy. My joy in having normal bowel and eating habits for over a year was to end.*

**Was the subject of another bone marrow transplant raised? What was the thought process at this time? How supportive was your oncologist?**

*Yes. There was no chance of a repeat Autologous transplant, but the oncologist believed that my only chance might be an Allogeneic transplant. To this end, I had family members tested for compatibility with no luck, and an international search was conducted for suitable donors. Two matches were found on the German register. They were located and retested and their compatibility was confirmed. The process would involve up to two years in hospital with the probability that I would not live through the process. If I did live, then there was a 15% chance of being cured. In these circumstances, 'cured' doesn't mean what most of us think. There would still be the drugs and other problems. There was very little chance of ever getting back to anything resembling a life as I knew it. We decided to put the idea on hold for a while to see how the chemotherapy would go and revisit later.*

**What was your life expectancy prognosis at this time?**

*In October 2008, the oncologist gave me a chance of 5 years if he could get me into remission. Possibly less, and hopefully more. The process was to be chemotherapy in the hope that remission could be achieved. I was told that given I only had 18 months remission after the bone marrow transplant, it would be very unlikely that if we could achieve remission, the period would exceed half of that time. There was also a probability that remission would not be achieved and this would result in a steady breakdown of my health and resistance ending in a relatively quick demise. This demise could be as a result of stroke, heart attack, pneumonia, kidney or liver failure. I knew that there was a limit to how much chemotherapy the body could take before falling apart. It was a race between achieving remission and the body failing as a result of the chemotherapy loads. Of course, another bone marrow transplant couldn't be contemplated unless I was in pretty good condition. It was a 'Catch 22' situation. While it was a long year of chemotherapy, the body thankfully held up pretty well. The waiting for scan results was a bit stressful, and it was hard work maintaining an outwardly confident manner knowing that my condition was sliding downhill.*

**During this time there were problems with your relationship with Julia and you separated. What effect did this have on your general well being and how did you cope with that?**

*It's fair to say that the recurrence of cancer changed a few things. There were decisions made which were very unfortunate. Stress is not a good partner to cancer, so it's fair to say that the situation wasn't helpful. The stress was drawn out for a fair period but that is all now behind me. I am disappointed, but not bitter or angry about it. People do what they do for their own reasons and all the worry and anger in the world won't change anything other than affect your health.*

**You were later in remission. Were you expecting that? Did this affect your thinking about another bone marrow transplant?**

*In Feb 2009 I had a clear scan and I stopped chemotherapy. The oncologist was a bit surprised, and I remembered that the prognosis was at best nine months with no chance of exceeding that. Well, it's now over 14 months. While I'm not getting ahead of myself, I'm confident enough to iron three shirts at a time !!*

**Against all odds you are now more than a year in remission. How is it all going for you at present?**

*I'm having regular scans, blood tests etc. Still on cortisone and a few other drugs. By and large going ok. The rheumatoid arthritis is becoming increasingly restrictive but is presently being controlled pretty well with daily cortisone and other drugs. The stress of the past year brought on angina attacks, and I believe that I'm on top of that now. I took a chance and had a holiday cruise in Norway by myself, and have taken up photography as 'brain food'. The Norway experience*

*was a good one in that I am more confident to travel by myself, and I met some people from Holland with whom I have become very close. There are no complaints. My next scan is in two months, so I'll enjoy myself and see what happens then.*

**How might you summarise your experience ?**

*It's either a death sentence which is all consuming, or a huge opportunity to set an example to your children and others as to how to conduct yourself with dignity and cope with adversity. You always get to choose how you behave and how you think, so make that choice carefully and wisely. Do you succumb or not? I have had to ask myself that question regularly and it is for others to judge how successful I have been in coming up with the right answer. It is deeply personal and private and you have to search within for the answers.*

*Over the years we have heard many motivational people urging us to 'seize the day' etc. I have to confess that while there have been times in my life when I lived my life that way, I now let the occasional day slide by without a great deal of interference from me.*

*My current remission is exceeding all expectations. Can it last? Will it last? No one knows. I woke up this morning feeling pretty good so I'll achieve a bit today in case it is different tomorrow morning.*

*Certainly, I am a much better and wiser person for the experience.*