

Mike Lambert's

Cancer Diary

On Tuesday 16th August 2011, I was diagnosed with multiple cancers. On Thursday 25th August 2011, my diagnosis was changed to offer me a realistic hope of a cure. I felt the need to capture my thoughts in a blog. Although primarily for me, this may prove to be helpful to other people who find themselves in a similar situation. Some of these entries will be very boring, little more than a diary of activities. I would like to think that others will have more significant content.

These blog entries unashamedly reflect my Christian Faith and trust in God.

Preface

Following my diagnosis with cancer on 16th August, I decided to maintain a blog recording my feelings and what happens. This document represents a collection of those blog entries.

On 14th August, I had no inkling of my likely diagnosis. I knew that I had a lot of pain from my back. The assumption was that this relates to an old injury.

I was waiting for an MRI scan and I was having problems with my digestive system.

A cancer screen a few months ago was clear, so I was not unduly worried. I had two attempts at colonoscopies, both of which failed, so I am also waiting for a CT scan.

We made it to church today. I needed a cushion and several people commented how ill I looked.

The blog is just a stream of thoughts. Some days have pretty deep thoughts, others are simply be a record of what happened.

I hope that two things shine through:

- 1. My dependence on God to carry me through the whole experience**
- 2. The love and support of those around me**

If there are lots of references to Center Parcs, that is because I spent the first week of August with all my children and grandchildren at Center Parcs in Elvedon Forest, Norwich.

As these events unfolded, my youngest daughter and her family were in New Zealand, visiting friends.

Tuesday August 16th

Initial Diagnosis

Not the greatest day of my life!

On Monday evening, I was referred to the hospital by my GP. My right leg had started to swell up quite badly.

At the start of Tuesday morning, I was looking forward to more definitive answers about what is causing me so many problems. By the end of the day, I had more information and all of the news was bad.

I had the CT scan at midday and I don't think I had any idea of the outcome. The afternoon passed slowly, but I didn't really imagine what the outcome would be.

We had given up on getting any information until Wednesday. Sue was just about to go home when we were approached by a posse of doctors!

The scan did produce some results.

1. A mass on the right side of my large intestine .. probably bowel cancer
2. A lump on the liver .. probably liver cancer.
3. Degeneration to the bones of my right pelvis.

Overall, prognosis is very bad.

Sue was devastated. I felt as if someone had kicked me in the goolies.

I forced Sue to phone Chris, who came immediately into the ward. Sharing the news with a 3rd party was helpful and we started to make plans for when to tell others. I have consciously decided to be positive and upbeat.

- Maybe it isn't cancer.
- Maybe it hasn't spread anywhere else.
- I will cooperate with all the treatments.
- Whatever range of dates they give me, I will beat the longest one!
- There are no absolute rules.

I WILL TRUST IN GOD AND LEAN ON THOSE WHO ARE SUPPORTING ME IN PRAYER!

Midnight and sleep is a long way off. I felt the need to share my problems with others and yet, logic tells me that I need to have more confirmed details before talking to anyone else.

Strangely, I now felt better than I have all day.

Fear was now being replaced by a sense of anticipation and a desire to find out once and for all what is going on.

Hospital is not a great place to sleep. The ward was very hot. The guy next to me was snoring. Two of the others are talking quite loudly. In the corridor, there are the normal sounds of a hospital, with phone negotiations over beds and alarms.

Wednesday August 17th

The Shock Starts to Wear Off

What a difference a day makes.

Yesterday morning, I was full of hope, only to have those hopes crushed by the scan results.

I went to sleep, thinking about the possible upsides and way forward. I woke up focussing on everything that is negative. I need to focus on some element of normality and start to think about up sides again -- weetabix maybe!

Not that sleep consumed a great of the night. I spent a long time in the half-light of the hospital ward, trying to doze, trying to read but mostly thinking.

The most important thing that we needed to plan our future, is some idea of timescales. I needed time "to put my affairs in order". Apart from that I needed to keep things as normal as possible for as long as possible. On the other hand it is not fair to ignore everything and leave others to pick up the pieces.

Building a personal "bucket list" and trying to knock the items off is simply not going to be fair to Sue and the rest of the family.

Early ward round was encouraging. The doctor seemed quite upbeat, talking about the various options and explaining what would be happening at the oncologists' case conference tomorrow.

There was lots of focus on normality rather than details of treatment outside of normality.

Sue came in the morning .. not in the rules but wonderfully reassuring.

A cancer nurse came round and Sue was there. She did a good job of explaining what is going on and support services that would be available. I am not really sure how that left me feeling.

The hospital chaplain then followed and that was very helpful.

EVERYTIME THAT I THOUGHT ABOUT THE NUMBER OF PEOPLE EXPRESSING SUPPORT AND PRAYING FOR ME I GET REALLY EMOTIONAL. WE GOT A WONDERFUL E-MAIL FROM BEN AND CHERYL CALLONI, A COMMITTED CHRISTIAN COUPLE WHOSE LOVE FOR JESUS AND OTHERS SHINES BRIGHTLY.

Sue agreed about ideas of keeping as close as possible to normality. We started to develop a communication plan - what we were going to tell who and when. In particular what we were going to say to Jenny and my dad.

The nurse was helpful. She explained that Jenny as a doctor will already have a very good idea after seeing me at Center Parks. I sent an E-mail to Jenny based on this assumption, but leaving out the liver part.



The Jacksons in New Zealand

Later, Sue and I phoned Cathy. She confirmed that she and Jenny spent time talking at Center Parcs and that Jenny had a pretty good idea. That meant that Cathy also was somewhat prepared. It didn't, make things any better for her; she was still very upset. (Look, I used a semi-COLON, I am not frightened of the word!).

Cathy said that she would visit at the weekend .. so the first element of our plan to ensure that she didn't drop everything and come immediately worked well.

I managed to give Achitecting-the-Enterprise a hint without being too specific and processed a couple of workbooks to show some link to reality.

In the evening, I uploaded some Center Parcs photos to Smugmug (more reality) and watched a couple of episodes off Eggheads on iPlayer.

I had an intravenous steroid, which immediately sent my blood suger sky high. That meant careful monitoring and quite a lot of insulin.

I spent 30 minutes reading Job and saying a prayer. Then I slept for 8 hours, only getting up twice.

Thursday August 18th

Confirmation of Diagnosis – Reality Sets In

I was woken at 6.15 for an injection of steroids and then went back to sleep. I woke again at 7.45, got up and had a shower. I felt better than for a long time.

I was cheered up by the mess that the hospital made over my breakfast. They delivered a small dish of Rice Crispies with a splash of milk. The prunes and croissant that I ordered were missing.

With a constriction in my intestine, diet rules have changed. Low fibre takes over from high fibre. **I am not allowed to eat broccoli!**

Ward round came at around 9am and an upbeat session with the doctor. He explained that the nurse would come around to tell me what was going on immediately after the 1pm review meeting. That would be "crunch time", when I got a better idea of long-term prospects, which at least would allow us to set some targets. There was lots of promise of being able to go home today.

I got the first feedback from the "case conference" and it was not good.

Currently, the tumours are inoperable. The first stage of treatment would be a biopsy to confirm assumptions, that will happen at 2.30 tomorrow. The sense of urgency is gratifying.

I was allowed go home for the night and come back in the morning at 9am for the biopsy.

Then the plan entailed a combination of chemo and radiotherapy to try to reduce the size of the tumours. If that works, surgery may become an option. There is still hope, but maybe less than before.

Nevertheless, I have a worldwide community of people praying for me.

I spent the night at home. What a wonderful uplifting experience. Chris came round. I spoke to Cathy and Jenny on the phone. It is wonderful to have a relatively close family at a time like this. What a motivation to fight!

I sent relatively honest messages to my colleagues at ATE and a few people in The Open Group.

Writing the emails proved to be therapeutic and some of the responses were very moving. It is amazing how many "closet Christians" I have encountered. One message from Lydia in particular was very moving and uplifting:

Just remember God is your fortress. And through him anything is possible.

Walking up to the house from the car seemed to be really difficult, but as the new drug regime kicked in, my mobility improved dramatically and I

was moving around the house, including the stairs relatively freely. I started to use Sue's stick and that helped.

Overall relative normality kicked in and I got a good night's sleep!

Friday August 19th

39th Wedding Anniversary

Our 39th Wedding Anniversary and clearly we had mixed emotions.

I got out of bed at 7:45am and had a very refreshing shower. My mobility was better than for a couple of weeks. I was able to enjoy a nice breakfast with brewed coffee.

Despite the fact that I had to go back to hospital, I felt really upbeat.

For the first time all week, I started to think about life other than just moving from chair to chair and chair to bed.

Life is going to be different, but will go on. I just needed to work out how to make the best of it.

I was starting to think about things that we could do. I got a message from American Airlines confirming that our flights to Fort Lauderdale in December have been upgraded. We have a Panama Canal Cruise booked. Normality!

Back in hospital I had a biopsy of the tumour on my hip at around 2:30pm and then went back home until treatment starts.

I managed to walk to the car with relative ease. In the ward, I was able to collect E-mail including a lot more supportive messages.

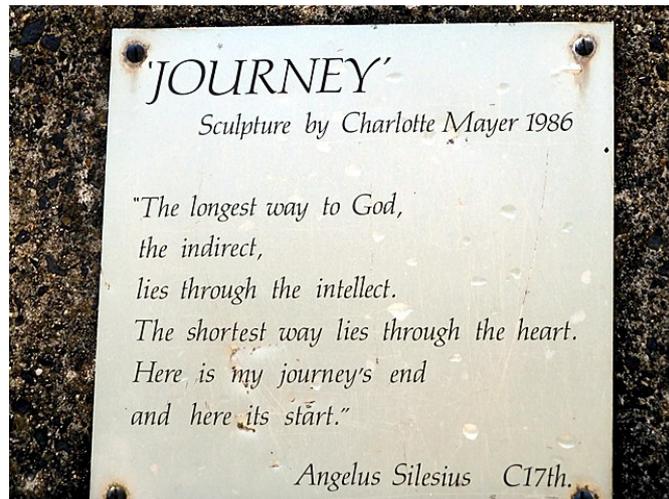
By the end of the week, I realised how important keeping contact with people is and in particular, how much value I have been getting from this tablet computer, which is much more practical than a full PC, and the motivating impact of being able to receive E-mail. The combination of my Xoom and the 3 Mifi kept me occupied wonderfully.

The weather looked beautiful from my chair in the ward, so I decided to go for a walk to the IBM garden.



Fountain in the IBM Garden

This proved to be a bit of a challenge, with stiff muscles, but the stick helped. It was wonderful to sit out in the sun with my book for 15 minutes.



The IBM garden at Basingstoke Hospital

I was very tired when I got back to my bed, but it only took a few minutes to recover .. another encouraging sign.

Sue returned after a counselling session with Caroline West at St. Mary's. It was very comforting for me to know that Sue has got the support of St. Mary's surrounding her. They looked at Psalm 5 with a focus on prayer.

I found the same psalm valuable later in the day.

The main reason for being in hospital was an extended scan to check whether the cancer has

spread upwards into the chest region and a biopsy to take some tissue from the growth on my pelvis.

Although not comfortable, lying on my stomach for 15 minutes, this was not painful. In fact the doctor seemed to take an immense amount of care. Nothing would now happen until next week, when the tissue samples have been analysed, so I was hopeful that I would be released shortly, but that depended on getting drugs ready.

Eventually we got home. I had a whole tray of drugs, that I needed to keep them under control.

Sitting down watching TV, I had probably the lowest moment of the week. The reality of what is happening to me started to bear down very heavily.

I shared it with Sue (why have I just taken her for granted for so long). A few minutes chat and holding hands was enough to pull me back up.

I finished the evening by processing some photos from Center Parcs, handling a couple of emails and reading the bible.

I got to bed around 12:45 and got a great night's sleep.

Saturday August 20th

A Magical Saturday

Saturday morning .. so what would be normal for today? Cathy was coming – I knew that was bound to be emotional.

One of my first thoughts was how unreal the last few days have been. I went to hospital on Monday feeling really ill and hardly able to move. This morning, apart from some low grade pain in my leg, I felt so much better.

I have now had 3 good nights in a row and don't feel very tired. As I sat at home, the pain killers are kicking in and I am virtually pain free.

Sue needed to go to the postbox. I decided to go with her. It was slow going and I didn't make it all the way. Camrose Way is hard going; the pavements are in a very poor state.

We met Sally Tyler on the way back, walking her ageing collie. This was the first time that we had actually spoken to someone face-to-face who did not already know the extent of my problems. It was a much easier conversation than I expected. That gave me more confidence about facing people at church on Sunday.

Now for some light relief. Sue was about to go to the garage to get some bread and it started to rain. We both went into the garden to get the washing in and I managed to strain a muscle in my left groin!

Cathy arrived. It was wonderful to see her, and very reassuring at how naturally we were able to talk about my condition. It was nowhere near as emotional as I expected. We planned to go out, but it was throwing it down with rain.

However later in the afternoon, the rain stopped. We got in the car and ended up with coffee and dessert in the garden of the Gamekeepers in Mapledurwell.



The green countryside around Mapledurwell

What a splendid idea. The sun was very hot, the garden quiet and we were able to talk in a relaxed way for about 45 minutes.



A rare picture of me with Cathy

I finally managed to pluck up courage to phone my dad and my sister. These were very difficult calls to make! Deciding to make the calls was a very important decision, but I felt a lot better when I had finished.

I decided that I am not interested in dates or probabilities. They don't apply to me. I am stubborn and determined .. inherited from my father **and I HAVE GOD ON MY SIDE.**

We had a very pleasant trip to the Hatch for dinner and planned our trip to church for Sunday.

We have given Caroline West the go ahead to tell people and include me in the prayers.

Finally, we received another wonderful and uplifting E-Mail from Cheryl Calloni.

At bed time I was in a lot of discomfort from my LEFT groin .. how silly!

Sunday August 21st
St. Mary's and A&E

Not quite so good this morning. I had a good night's sleep but on getting up have a lot of pain from my left groin when I try to move.

Initially I thought that it might be something that would loosen up as I moved around a bit more.

Getting socks and trainers on was a surprising ordeal. It took me a long time to get ready for church.

Our morning service could have been aimed straight at me.

Come to think of it, it probably was. Clive Hawkins confirmed that the text was selected weeks before and he wrote his sermon at least 4 weeks in advance, but God has a plan for everything.

John Saunders mentioned us in the prayers in a wonderfully sensitive way, after which everyone knew that I have a serious problem. The feeling of love and support moved both Sue and I to tears.

There were lots of people talking to us at the end of the service, which is just what we wanted.

The focus of the sermon was spot on .. from James chapter 5 verses 13 to 16, entitled "The prayer of Faith."

Is any one of you in trouble? He should pray.

Is any one happy? Let him sing songs of praise.

Is any one of you sick? He should call on the elders of the church to pray over him and anoint him with oil in the name of the Lord.

And the prayer offered in faith will make the sick person well; the Lord will raise him up. If he has sinned, he will be forgiven.

The music included very moving and relevant lyrics.

From Susi Hare (who used to be director of music at St. Mary's):

I will come with open hands to receive what you have planned.

I will lay ambition down all for You, all for You. Lord,

I surrender all that I am, all that I'll be; Lord, I surrender to your work in me.

An old hymn from Stuart Kyne:

When through the woods and forest glades I
wander and hear the birds sing sweetly in the trees;

When I look down from lofty mountain grandeur,
and hear the brook, and feel the gentle breeze;

Then sings my soul my Saviour God to Thee. How
great Thou art; how great Thou art.

Finally a newer song from Stuart Townend (just after
the prayers):

In Christ alone, my hope is found, he is my light, my
strength, my song; my cornerstone, this solid
ground.

After lunch at the Hatch, I had a problem! I could
hardly walk, my left groin is so painful.

When Cathy had gone home, I went upstairs to the
loo. I could hardly make it, so at 4pm and we were
back at the hospital in A&E trying to get some relief
so that I could walk around.

At 5pm it is clear that none of the other pain relief
has had any impact on the groin.

And now a real low point. Birmingham lost 3-1 to
Middlesborough .. it is going to be a long season.

A&E is depressing. We had been here for 2 hours and very little had happened. There are people who were there long before we arrived.

The estimated wait time gradually extended. When we arrived, it was about 2½ hours. By 6pm it was 3½ hours. More urgent cases must have arrived by ambulance elsewhere.

Sue headed off in search of coffee and a snack. The coffee and panini were very good and consumed time. It was frustrating not to know what was happening. After 3¼ hours, apart from triage, we have just been sitting here.

Finally at 7:25 there was some progress .. I was moved into a cubicle. After another wait while doctors attend to a more urgent need, I was pretty thoroughly examined and then referred for an X-Ray.

It still looked like being a long evening still. 4¼ hours and counting.

But everything seemed to be speeding up now. There was very little wait for the X- Ray. By 8:30, I was back in A&E for assessment, but beginning to feel the need for painkillers. The X-Ray pushed my back into some strange uncomfortable positions.

Sue was wonderful this afternoon and evening, pushing me around the hospital in a wheelchair. I don't know what I would do without her. The X-Ray showed no bone damage and no link to the cancer on my right hip. Good news!

I left with a dose of heavy duty pain killer and crutches. The many hours waiting ended on a positive note. I entered A&E in a wheelchair and left on my feet!

When we got home, I realised what a difference the crutches made. I walked up the path, not exactly pain free, but comfortably and then got up and down the stairs at home with little problem.

‡ A very brief theological note. This does not mean that all a Christian has to do is ask and they will be healed. "Well" in this context has other meanings.

Monday August 22nd

Back to Work

John came round in the morning .. so now all the family knows everything they need to know. He coped with the news very well.

He was still planning to move back in around a week. I really thought that there is a chance that this will be the catalyst we need to start to repair the relationship between John and Sue.

Sue was very motivated to make sure that family relationships are right and John could see that there are things he can contribute to the family, even if it is only emptying bins in the short term.

The night started badly. I was in a lot of pain in my right hip and could not get comfortable in bed. Sue with infinite patience, tried lots of things and eventually thought of the ice pack, which worked wonderfully.

It was a disturbed night, but I did get quite a lot of sleep. I decided to try whisky in the evening.

The hospital offered me a morphine based pain killer .. for the time being, I would like to put that off.

The weather was wonderful, so getting out of the house was a priority. We needed some small items of shopping, so our exciting excursion, was Sainsbury's!

I sat in the cafe with a cup of tea, while Sue did the shopping.

I rather bullied Sue into getting something for lunch in Sainsbury's (rather than going home). I was comfortable and didn't want to move yet!! So we had a Panini for lunch and a real meal later.

Waiting for paninis in Sainsbury's was almost as bad as waiting at A&E. At least, the seat was more comfortable than a wheelchair. Sainsbury's has a large new cafe, but the service still resembled a WVS charity cafe!

While I was waiting, Chris Barton came over to talk to me. There seemed to be a reason behind every decision we took.

Judith Jones phoned and said she would call later when I am home. For the first time in my life, I used a disabled loo, feeling like a cheat.

I walked comfortably out to the car, with crutches, and discovered that I can use a normal walking motion, rather than a "dot and carry" approach. There was some pain in the hip, but that was only to be expected and it calmed down as I relaxed in the car.

More work for Sue now.

- Fill up with diesel (only 137.9, so that has to be good).
- Collect my prescription
- Buy another ice pack or two.

I joined the ATE (Architecting the Enterprise) Knowledge Pool teleconference (work!). I found this to be very encouraging, getting back to discussion about work matters and talking to my colleagues for the first time in several weeks. I even agreed a work program for the week.

Judith phoned later in the afternoon. She confirmed that I would remain on full salary until the end of the year and I should do whatever I feel capable of. This is much more than I expected and represents a tremendous statement of support.

I spent until 6:30 working .. my longest stint since before Center Parcs.

I completed another phase of my home music server project, that I started before I went into hospital. Earlier in the week, I connected a PC to our home hi-fi system. This afternoon, I connected a PC and speakers in my room. The next step is to set up music in Sue's room.

I had some discomfort in my right leg late in the evening, then I realised that painkillers were overdue.

Tuesday August 23rd

A New Web Site

The weather today was rather wet and depressing.

After a reasonably good night, breakfast was cheered with some photos from the Jacksons in New Zealand. They would be coming home next week; their NZ trip seemed to have gone very quickly.

That plus an E-mail from Ben Calloni started the day on a high note.

Straight after breakfast, I spent the morning at my PC, and started to load my blog to my website.

I had lots more encouraging conversations, including Chris Blake and Colin Godfrey.

I contacted Clive Hawkins, rector of St. Mary's, my local church. We arranged that he would come round to see me later in the afternoon.

I sat at my PC for more than 3 hours. Apart from swelling in my legs, I encountered no problems.

Clive came around at 3pm. I found it really helpful. He carefully explained some of the theology around healing. It is not an automatic entitlement. We need to be very practical and realistic about what we ask for. We had a general chat and Clive prayed for me, for the medical staff and for Sue and the family.

At 4pm it was time for second lunch (to accompany my next round of pain killers). After sitting for a couple of hours, I actually had very little pain.



A Cocktail of Drugs

With a doctor's appointment scheduled for the following day, which could entail quite a lot of walking, at around 6pm, I decided to "test" my legs.

Getting trainers on was ****very**** painful, but I did walk to the far end of our garages and back, around 200m in all. Yes there was pain, but recovery time was good, so all systems go for the doctor.

My major achievement for the day was transferring my blog notes to a web site. Eventually, I decided to overwrite my mglweb.com website completely.

There was nothing really important on there anyway.

Almost immediately, I got requests for permission to pass on the link to other people.

Wednesday August 24th

Planning Treatment

I was hoping for a relatively uneventful day.

I was still waiting for notification of start of radio therapy, and now getting more pain from my hip, so it looks like that is needed.

The first task of the day was to return to my GP, to register all the drugs I have been prescribed, so that I can get repeat prescriptions of some nasty combinations that would not normally be allowed.

The visit to the GP was been successfully completed.

He did tell me that I have a fracture to my hip, so it is allowed to hurt.

I was been advised to keep walking to reduce the risk of blood clots. The doctor did encourage me to have a bottle of morphine sulphate in the fridge, especially for bed times. I started to think that I need a bigger tray for all my medication!

Sue has some shopping that she needed to do, so I got comfortably established in Starbucks for an hour or so. A nice cup of coffee; what more could I ask for? Actually free Wi-Fi would be good, so I signed up for a Starbucks card which gives me just that.

Progress. When we got home, there was some progress in my treatment. I was given the first appointment in Southampton to plan my radio-therapy session at 3:30 today.

Things were beginning to move. We were a bit concerned about finding the right place, so we left plenty of time. In the event the directions we were given were very good and we found the oncology department by 3pm, with half an hour to spare.



The Southampton General Oncology Department Clock

Now that treatment was starting, things did seem to be more real. But there was a real problem, no Vodafone or 3 signal in the waiting area!

After another CT scan, I was tattooed with targets for the radiation machine, with one mega blast of radiation planned for Friday.

I don't know ... I waited 4 months for a CT scan and then 3 came along together.

The Hitachi scanner in Southampton was very much bigger than the one in Basingstoke, where I had to be carefully positioned to get my shoulders through the scanner.

We just escaped from Southampton before the real traffic build up.

More progress. I now had an appointment in Basingstoke at 9:30 am on the following day at the haematology department, presumably to plan and possibly initiate my chemo therapy sessions.

Earlier in the week I was concerned about having to wait. It seems that the medical team delivered on the plan they outlined last week, which gave me a great deal of confidence.

All of a sudden, however, everything was getting real. Part of me wanted to put off treatment and pretend that everything was fine. However, untreated, these tumours were continuing to grow, so realistically the quicker we could start treatment, the better.

Judith Jones, the CEO of Architecting the Enterprise, came round to see me bearing flowers and gifts, more than a 2 hour round trip. I haven't

spoken to her face-to-face since May. In common with everyone else she was the bearer of upbeat wishes. Thank you, Judith.



Flowers from Judith

Back to the mundane. We went to Pizza Hut for dinner. During dinner, we got good news. Our son, Chris, is trying to buy a house. Today he was told that his offer had been accepted.

Back home and for the first time today, my hip is pain free. A good end to the day.

Best Wishes from Staff at Architecting the Enterprise

SORRY TO HEAR THAT YOU ARE UNWELL
 ALL THE BEST
 Cathy

Get well soon Mike!
 Take care.
 Linda Yu xxx

I hope you get well soon Mike.
 All the best
 Kris

Let's see a full recovery shortly!
 Best wishes,
 Rob

Get well soon Mike!
 Sorry to hear that you will push it through!
 Love, Sue xx

Thoughts are with you Mike at this testing time.
 Delma

Get well soon Mike!
 Take care.
 Linda Yu xxx

Get well soon Mike!
 Sorry to hear that you will push it through!
 Love, Sue xx

My thoughts are with you. I hope you get better, Mike.

Thinking of you
 Chris

Get well soon Mike!
 My thoughts are with you!
 Chris

Mike, I am praying for a speedy and full recovery. Get well soon - George!

Get well soon Mike. Be strong. I know you can do this. Thinking of you + your family. I will be praying for you.
 Love: Jacqui

Get well soon Mike. You seem to be a fantastic guy. I really hope you can get well soon. Wonder.

Mike, you still need to do your fair share of TMA's! With very best wishes.

Pills are best. Take a little. A good whiskey. Dr. Sober. Good luck.

Great luck and all the best. My thoughts are with you.

Best Wishes
 Steve

Communication and the role of IT

The ability to communicate with people and in particular access to the internet played an important role in helping me remain positive.

Of course, I have a good PC set up at home, but mobile communication is particularly important, because I was spending such a lot of time away from home.

It seems that lots of IT capabilities had come together to provide me with everything I could ask for.

1. A primary tool is my tablet computer (a Motorola/Google Xoom). This gives me full E-mail and internet access, via public hotspots and two 3G enabled mini wifi devices on different networks. The combination of light weight and long battery life are ideal.
2. I used a very simple app .. Inkpad .. to maintain my blog.
3. I have thousands of photos loaded to a site called Smugmug, in the cloud, available on demand. It was great to be able to look at pictures of my kids when they were young and now my three grandchildren, together with some of the wonderful places I have been lucky enough to visit. I really ought to be more selective in the photos I upload, but that takes a long time and internet bandwidth is good enough to search with thumbnail sheets.

Thursday August 25th

An Answer to Prayer

I did not have a good night. At 4:30am I hadn't yet slept. I started off twisting my hip getting into bed and then developed cramp. I hoped that moving around a little and then a tot of whisky would help me settle for a couple of hours.

Meanwhile, the weather outside sounded foul, with torrential rain. I was filled with important questions like "Will I get my feet wet on my hospital appointment today, if I still can't get my trainers on?"

Meanwhile, the news had just broken that Steve Jobs is standing down as CEO of Apple because of ill health.

I went back to bed to try to get a little sleep, and I did sleep for about an hour, but by 6:45, it was clear that I was not going to sleep any more, so I got up and had a refreshing shower.

There had to be a bad night sometime. Maybe, that means that I'll sleep a lot better tonight.

By now, I was used to arriving for hospital appointments and nobody actually expecting me. Everything was moving so quickly that arrangements were made by phone and didn't always seem to make it onto the computer systems.

The same happened today. I was actually registered on the computer, but no one seemed to know who I was to see.

WOW WOW WOW WOW!

The reason for this appointment was to transfer me to the haematology department.

It seems that the original diagnosis was ****wrong****.

The biopsy I had last Friday, showed that the source of my cancer is Lymphoma, not my bowel.

This was still not good .. I have a fight on my hands, but unlike the combination they thought I had, it is curable!

The initial plan was for me to still have the planned radio-therapy to reduce the pain on my hip. The good news was that this kind of cancer responds better to radio therapy.

The not so good news was that it will do nothing to sort out the fracture in my hip. I have to live with that and it will cause pain. **I'll take that!**

More not so good news is that the chemo therapy they use for Lymphoma is much more aggressive than the stuff they were planning to use. I will potentially have worse side effects. **I'll take that!**

I take this as a wonderful answer to all of the prayers for me over the last week. As Lydia from

Architcting the Enterprise said "**In God everything is possible**".

I found it really difficult to control or even describe my emotions at that moment. Obviously there were periods of total euphoria. I have now been given a great chance of seeing my grandchildren grow up! Then there were reality checks when I realised that I am still seriously ill and I still had a real fight on my hands.

A change of plan. I am not having radio therapy. There is an urgent need to start the chemo therapy and it should reduce the pain in my hip, so they decided to start tomorrow. It looked as if I would be in hospital over the weekend.

Last week, I was in a ward. Today, I was in a private side room, with en-suite facilities. I decided that I would be able to cope!

It was a busy afternoon. I had to have a bone marrow aspiration and an echo cardiogram before the chemo could be administered.

I have to be monitored for side effects over the weekend, especially impaired kidney function. I signed up for a clinical trial of a new experimental drug.

The first real down-side. We were told that we would have to cancel our Panama Canal cruise in December. The chemo therapy will not be complete. **I'll take that!**

We were covered by insurance, so we will be able to book something when the treatment is complete and I feel up to it.

I settled in my room, with a working internet connection via my 3 MiFi device.

The first test of the afternoon was taking bone marrow samples; not the most pleasant of procedures. However because of the fracture in my hip, the doctor decided to give me liquid morphine to allow me to lie in the correct position. That left me in a very relaxed state, which I am sure reduced the pain of the bone marrow procedure.

The next test was an echo cardiogram to make sure that my heart is up to the treatment. This was very uncomfortable because of my hip, but my heart seemed to be fine. So now it was all systems go for the chemo tomorrow. The machine they used for the echo cardiogram is just like the machine they use to scan developing babies. Sue observed that I seemed to be developing aliens!

Now to more mundane problems. I may have had en suite facilities, but the toilet had to be switched off, so I had to change rooms. (There was already the sound of a cow trapped in the pipes and then the toilet flush started to run continuously).

Oh dear. Late evening and I had severe pain from my fractured hip. The nurse gave me liquid morphine sulphate, but that made no difference at all. Eventually, the on-call doctor prescribed injected morphine.

I do believe that the pain was diminished, but not enough to allow me to sleep. I think the main problem was the impact on my fractured hip of the man handling involved in the bone marrow aspiration and echo cardiogram.

I have been thanking God for his gift of hope and everyone who has been moved to pray for me. That seems to be bringing me some peace and relief from pain this evening.

This still promised to be a long and disturbed night. At 11pm I was still awake and uncomfortable, and in 2 hours the nurse was going to have to change the saline drip into my arm. It was important I get fully hydrated before the chemo therapy starts in the morning.

Even this late at night, I was still receiving messages of support from very unexpected sources. That gave me the strength to cope with a night of pain.

At 1am I was still awake. There was no way that I could actually lie in the bed. The emails continued to come in and I had just finished reading Mark's Gospel from end-to-end, something that all Christians should try to do at least once.

I thought I heard approval for another morphine injection. That should help damp down the pain again, but I decided to stay in the chair, rather than trying to get into bed. I could keep the weight off the area that hurt. The time taken to get doctor's approval did at least consume some of the night hours.

I was sure that things would feel a lot better in daylight. But this time there was no doctor's approval, just the liquid oramorph this time. Another litre of saline was plumbed in, which would take 8 hours to transfuse.

3am. Time was passing, but every time that I dozed off, the saline drip managed to kink and the machine buzzed demanding attention. I was still not able to lie down and put any weight on the back of the hip bone.

Friday August 26th

Treatment Begins

By 6:45 am. I had managed to doze in the chair for about an hour. I had a ****lot**** of pain in my hip. There was no way that I could lie down. Still, I did sit in the chair most of the night. I had about 3 hours of saline drip left.

Looking down, I needed to charge my tablet before I got immobilised for the day with another drip.

I was greatly cheered up by the performance of Birmingham City last night in progressing to the group stage of the Europa Cup. This is their first foray into European football for more than half a century. I can still remember the last time, I was there!

It was time for some more pain relief and another morphine injection. I decided to get a shave to try to feel a little bit more human. I wouldn't actually be able to change my pyjamas for a shirt for another 2 hrs and 21 minutes, because I was connected to the saline drip.

At 8am two more phials of blood were taken. There was just around 2 hours of the saline drip left.

At this stage, I was not sure whether I would be on the bed for the chemo today. With virtually no sleep for 2 nights, I was likely to want to doze, if I could get comfortable.

So last night was difficult. Yesterday, I said I would take the pain from the fractured hip and I will! I found E-mail communication and my bible to be helpful in the middle of the night. A simple breakfast, prunes, porridge and a croissant, helped me wake up and feel slightly more human.

At 9am, I still have one hour left of the saline drip. Then I would be able to finish getting up and change my shirt.

9:30 and it seemed that we are getting ready to start the treatment. It looked like I would be able to sit in the chair, rather than having to get into bed. Instructions were given to make sure I get enough pain relief so that I am comfortable. Based on the explanation given by the nurse, I realised that I would be getting a variety of treatment, not just 1 long drip.

At 10:00am I got some pre-medications, anti histamine, steroids etc. The next stage would start in around 30 minutes.

At 10:53, the first medication was started, Rituximab, by IV drip, through the existing cannula. First time round, this was administered very slowly with my blood pressure tested at regular intervals to ensure that I was tolerating it



Blood Pressure Monitoring Machine

At 11:32, the second dose of Rituximab was started at a slightly higher flow rate. So far, so good.

At 11:57, I was on the third dose of Rituximab. Again there were no problems, so far. Time seemed to be going relatively quickly.

By 13:00, the fourth dose was complete with no problems. The diabetic nurse came round with goodies, including a new insulin injection pen and shorter needles. Lunch came and went. (Fish and chips, pretty good really).

By 13:30, the fifth dose was complete. The machine gets very insistent if you ignore it and there is nobody to do anything about it. One of the nurses reset the alarm, but it still beeped.



IV Drip Machine

At 14:39, I was nearing the end of another 30 minute period. There couldn't be many left.

At 15:00, another session approached the end. It looked like there was just one more dose of Rituximab to go (about 35 minutes).

Because the upcoming weekend is a bank holiday, the doctors were planning to discharge me on Saturday evening or Sunday morning. Good news!

The nurses were now planning for the next stage of treatment. I needed another cannula for the other drugs. I was also given mouth wash to protect against fungal infections.



The "octopus" cannula

At 15:45. I was finally finished with the Rituximab and just needed a few minutes of saline to flush the residual drug from the drip tubes.

Now I had to wait for a specialist nurse to be available to administer the next stage. By 16:45 we were ready to start.

By 18:00 the first phase of chemo was in my system. This involved about half a dozen enormous syringes of chemicals pushed my vein via the cannula. This was all done with incredible care. I didn't know what to expect, but there was no discomfort at all.

Just before Sue left the hospital to go home, we spent a few minutes in prayer, thanking God for progress so far.

I finished with a simple request for a good night's sleep. "One more thing, Father, please help me to get comfortable so that I can sleep. If it is your will that I should spend another night in prayer and reading the Bible, so be it, but personally I would prefer a good night's sleep. Amen."

Saturday August 27th

Super Saturday

After everything that has gone on in the last 2 weeks, there is only one possible title for today's blog - "Super Saturday".

I had a great night's sleep.

The business for today was to check whether my body has tolerated yesterday's chemo and in particular to monitor my kidney function.

Meanwhile, I now felt able to talk about an important aspect of the original diagnosis.

When I got that original diagnosis, I knew that the combination was terminal, the only variable was time, and I was thinking in terms of months, not years. Sue also realised that. Yet, we behaved as if that was not the case.

The oncologists were 99+% sure that they had the right diagnosis. So why was this a no go area in talking?

Maybe we didn't want to face up to reality?
I like to think that we had Faith that God could do anything.

Certainly, I didn't want to talk to others about the end, especially the family.

If things don't go well in the treatment of the lymphoma, I hope that I will remember the first few days and there will be no areas at all that Sue and I will not talk about.

That was now in the future, hopefully the long term future. We could focus on fighting the lymphoma and at that moment, I felt good and confident that I was going to win.

Late on Friday night I had an E-mail conversation with an old friend from The Open Group days, Dennis Busch. It was great to be getting in touch with people like this for the first time in a decade.



Flowers in the IBM Garden

It was a beautiful day. This is where the blog starts to get boring and repetitive. I left the ward and walked down to the elephant and IBM gardens. It was lovely to sit in the sun and get a breath of fresh air. By the time I got back to the ward, my right shin was aching and my hip was uncomfortable.

I did need to drink more to avoid being tethered to a rehydrating drip again.

The consultant came round late morning. Everything seemed to be going well, so she released me for "home leave" for the afternoon, complete with lots of dire warnings about things that could go wrong and when I absolutely ****must**** contact the hospital.

In the event, the trip home was useful. At home, our loo is upstairs. Reaction to the chemo generated the need to visit the loo at regular intervals, which proved to be too much for the pain relief I had been given for my hip. When I was ready for discharge from hospital (hopefully the following day) I needed to make sure that additional pain relief is prescribed.

Life seemed to be peppered with numerous incidents. One of the gating items to be able to go home is to have "opened my bowels" (what a horrible term). Sue was just mixing up the laxative I had been given, when I had to rush away. A few minutes later, I called down from the loo "Don't bother", as one of yesterday's drugs did the work for me.

Half-hourly visits to urinate prove that my kidneys were currently doing their job and getting rid of the casualties from the cell wars going on inside me.

Eventually, we returned to the hospital room, where I only have to walk a few yards to the ensuite loo. I could sit upstairs at home near the loo, but that would be a rather pointless activity.

We have been talking about getting a downstairs loo installed for quite a while. Now seemed to be the time to do something about it.

We made plans for the following day. As long as blood tests are OK in the morning, they would let me go home. Sue and Chris planned to come in late morning.

More goodies today. Sue has bought some nice thick pillows to raise chairs to a point where I could have my legs at the right angle to minimise the pressure on my hip.

The consultant warned me that I have a have a high tolerance to pain and that I needed to be very sensitive to any new pain, especially in my abdomen. I have never thought that, but then Sue reminded me that I have been walking round with a "significant" fracture of my hip for months. So, I need to be watchful.

I have lost my private room! Someone with more need of isolation is being admitted, so I had to be moved into a small ward with one other person. I should look on this as something positive. At this

stage of my treatment, there ere people in much more need than me.

Bad news, the "cow" (see Thursday) is in the plumbing in this room. There was lots to think about and so much going on.

On Saturday evening. I was promised some strong pain medication to help me sleep. Meanwhile, I decided to relax and do not a lot for the rest of the evening.