Lung Cancer – a patient’s journey

Nic Clews, Macmillan patient involvement
Notes from a diary kept online
31st January 2016
Where it began… A lump in the neck

• April to July 2008 Repeated GP visits to a new qualified doctor
  • “You are being paranoid”
  • Diagnosis – swollen glands, prescribed antibiotics
Margaret

- Larger than life
- “Talking was her hobby”
- Worked as auxiliary at Wrightington Hospital
- Even the occupational health said “lump needed investigation”
A different GP…

• 5th August 2008 referral to ENT
  • Chose to have a private referral through my company healthcare
• 18th August Monday Needle biopsy, camera, X-ray and ultrasound
• 22nd August Friday, nothing confirmed only arranged CT scan and open biopsy
  • Pre-op and operation on Tuesday 26th August
  • CT scan (fasting with barium) Saturday 30th August
• Wednesday 3rd September diagnosis, the lump was “squamous non small cell lung cancer”
  • Passed to Thoracic team at Bolton Royal
Private performance

• 5\textsuperscript{th} August to 18\textsuperscript{th} is 13 calendar days, 9 working days
  • Includes private healthcare authorizations
• Not being told the suspicions, if there were any, wasn’t good
• Progressed very quickly through diagnostics, appointments running concurrently
• 18\textsuperscript{th} August to 3\textsuperscript{rd} September is 16 calendar days, 11 working days (bank holiday)
• First NHS appointment in Bolton Royal Thoracic 5\textsuperscript{th} September, 31 calendar days from GP referral
Bolton to The Christie

• Attended Thoracic unit at Bolton Royal on Friday 5\textsuperscript{th} September
  • Felt somewhat more positive
• At Bolton Royal on Thursday 11\textsuperscript{th} of September met our Christie consultant
• Met the CNSs and given the mobile number of one
• Clearly described the diagnosis: small tumour in lung (and secondary)
• Details of chemotherapy and what would happen clearly explained
• We felt far more positive about things
• Our CNS visited our home to go through paperwork (Statutory Sick Pay) and see if we needed anything else
Treatment begins…

• Wednesday 17th September 1 PM: Baseline X-ray, bloods and a lot of waiting
  • 43 calendar days since GP referral
• Started late in the afternoon with anti sickness, Gemcitabine, saline, Cisplatin, then more saline
• A LOT of tablets to take home from the pharmacy (left 9 PM)
  • Initial confusion over taking so many
  • Margaret mostly out of it Friday to Sunday!
• Next Wednesday : repeat!
On the ward

• Chemotherapy care was evident from the outset, a nice atmosphere
Low immunity takes it’s toll…

• October 1\textsuperscript{st}, high temperature, day visit to Christie for IV antibiotics
  • 3\textsuperscript{rd} session delayed due to poor immunity (blood tests)
• October 8\textsuperscript{th} temperature above 38 C and admitted to Christie
  • 3rd session missed
  • Kept in for 2 weeks (hallucinating / Margaret unaware of where she was)
  • CT scan and lots of blood tests, allergy to a specific antibiotic
  • Outstanding care
• Back home and the district nurses took up the care
  • ECG at Bolton Royal to rule out heart valve disease
Personal impact

• Our 9 year old daughter still needs to get to and from school
  • “Best friends” mum helping out
  • Even teachers running her to and from school

• Friends and family rallied, past differences forgotten
  • “cyber knife miracle cure!”

• HR and line manager allowed home working
  • Remote access was possible and no loss of pay

• I was struggling with back pain (driving)
  • I had L4/5 spine operation mid December – no driving for 6 weeks
Change of plan - XRT

• November, Consultant gave us the results of the infection – it was fungal – and I was told treatment was palliative
  • Marg: “If the treatment is just palliative I don’t want it”

• Scan showed tumours had reduced
• Radiotherapy to be given to chest and neck
• Consultant somewhat reluctant to give more chemotherapy due to the reaction
  • We felt pretty disappointed
• Family had flu jabs
First XRT session – mid November

• Before and during (Children in need charity day 14 Nov 2008)
Further radiotherapy November-December

- Used Aloe vera gel on the burnt skin
- Christie “special stuff” liquid paracetamol very good
- Pain was sometimes difficult to control
  - Uneducated guesswork, running out of morphine
- GP only had access to paediatric liquid paracetamol (orange flavoured half strength by volume), but our CNS arranged a prescription of the “special stuff” from Christie (had to go to collect)
- Christmas was good - we made the most of it
  - I could not drive due to back operation
Radiotherapy effects

• Side effects quite evident (2 Dec 2008 – 9 Dec 2008)
New year, more chemotherapy

• January restarted the remaining chemotherapy cycles
  • Slightly reduced dosage and sessions with immunity booster
  • Quite used to the pills needed and sticking to the advice was working

• Started visits to the symptom (pain) control doctor at Bolton Royal
  • Trying (unsuccessfully) different pain relief Tramadol, now using MST
  • Morphine (oramorph) still proving most effective with MST
  • District nurses calling to administer (precautionary) antibiotics

• Next cycles (3rd and 4th) going well into March
  • More visits to the pain relief at Bolton Royal, Oxynorm / Oxycontin tried
  • Still difficult to judge the ‘ad hoc’ oramorph, still best
Daughter attends to see the mystery

• Waiting for the call up 30 Jan 2009
Final weeks

• Last of the cycles given mid March, plus a platelet transfusion
• Pain control under the control of a doctor based at the local hospice
• End of March awoke breathless and admitted to A and E via ambulance in the early hours
• I drove in with our daughter
  • Resuscitation doctor said nothing could be done other than to make her comfortable. Margaret agreed (midazolam)
  • The whole family turned up
• Gradually improved and wanted to be at home
Final week

• Hospice arranged delivery of a special bed installed in the living room
• Electric oxygen machines installed, backup cylinders
• Family care rota
  • Offered but declined Macmillan (we already have us and district nurses), though there were some family tensions caused over care
• District nurses charging pump driver
  • Regular visits from pain relief
  • Many friends and family visitors
• Passed peacefully
At home

• In good spirits
Reflections and questions

• High standard of care perceived as we walked this unknown pathway
• Private diagnosis into NHS introduced minor issues of the transfer of data
• High level of integration between Bolton Royal and The Christie
• Almost always left with another appointment scheduled
• Contactable and proactive CNSs giving a lot of support and reassurance
• Local hospice supporting the end of life process, GP support good
• But no initial information about what palliative care was, or what Macmillan could do for us…
I just am a bit fed up when lan
in this bloody rain'.

Marg