

National Assembly for Wales  
Health and Social Care Committee  
Inquiry into the progress made to date on implementing the Welsh Government's  
Cancer Delivery Plan  
Evidence from an individual – CDP 22

I live within the Aneurin Bevan health board (ABHB) area and was diagnosed with oesophageal cancer (OC) 1 Feb 2013. I welcome the opportunity to share my experiences in order to try and improve services surrounding this dreadful disease.

I would like to start by saying that staff involved throughout my treatment have been wonderful, however, I strongly feel that cancer care is under-resourced in Wales. I would like to challenge Mark Drakeford to utilise tax-making powers to raise more funds for cancer care, on the back of a pledge that they go directly to cancer care. Considering that one in three of us will get cancer at some time in our lives, when you consider the network of family, friends and colleagues affected by our cancer, that means we will be affected by cancer a number of times in our lives.

I would also like to ask that information re cancer services be made clearer and kept up to date on the internet. I really struggled to find advisory treatment times - eventually found the 31 days/61 days to treatment, only recently found the 10 working day diagnosis target. Found a South Wales Cancer network and followed through to ABHB and found documents and promises dating back to 2005 and not the latest Welsh Government targets. In comparison, charity sites such as Macmillan are tremendous, however, our reliance on charities during these times of austerity is alarming.

Based on my summary below, I am and have been concerned with delays in my diagnosis and treatment, being:

- 10 weeks from GP to diagnosis.
- Almost 8 weeks from diagnosis to start of treatment
- 11 weeks from surgery to post-op chemo (12 weeks is limit for effectiveness)

Delays are particularly critical with a hard to diagnose and aggressive cancer such as OC and also cause unnecessary worry and stress to the sufferer and their families. Had I known about the 2 week diagnosis target and the likelihood of my having cancer based on my

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dysphagia I would have chased the diagnostic appointment much harder, but we really shouldn't have to fight for treatment whilst fighting the disease itself.

Another thought - is that for those of working age and in work, the quicker we are treated the quicker we return to work and return to contributing to the economy.

Whilst the Velindre Cancer Centre does wonderful work, my observation as an in-patient and out-patient there is that it is at breaking point - some outpatient visits there has barely been a free seat, and due to its being busy it is quite a stressful environment to be in - often for 2 - 3 hours. It must be stressful for the staff there too.

From discussions on the Macmillan community:

- as a generalisation, patients get seen much more quickly in England, sometimes within days.
- most OC patients seem to be tested for HER2 positivity and if positive offered Herceptin - whereas Wales doesn't routinely test for HER2 (i should add that they did test me when requested)

I fully support the "centre of excellence" model for complex illnesses such as cancer and firmly believe that it leads to much better outcomes for patients and as side effect is much more efficient for the NHS .

Should you wish to discuss any of my comments further I would be happy to engage.

A brief summary of my experience is as follows:

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Difficulty swallowing mid Oct 12

Visited GP 23/11/12 - urgent referral made to Royal Gwent Hospital - (suspected cancer)

Chased appointment during December with RGH and told 10-16 weeks average waiting time (at this stage I didn't realise how clear an option cancer was)

Revisited GP 31/12/12 who re-referred me to RGH

Chased appointment with RGH 04/01/13

Appointmment with consultant 14/01/13 and referred for gastroscopy

Gastroscopy 01/02/13 - cancer diagnosed

CT scan required but not forthcoming via ABHB thus went privately 11/02/13

MDT meeting 15/02/13 cancelled

21/02/13 post MDT meeting appointment and treatment plan advised, from here things progressed more quickly (involvement of specialist team from University Hospital of Wales, Cardiff)

Week of 25 Feb 13 PET scan, EUS scan

07/03/13 saw Oncologist to discuss neo-adjuvant chemotherapy

Commenced chemo 28 Mar 13

Chemo induced seizure 22/04/13, mobile paramedic arrived within 10 minutes but 45 minute wait for ambulance, resulted in emergency admission to RGH and 6 hours on trolley in corridor in A & E.

Surgery at UHW 01/06/13 - brilliant treatment there, all staff fantastic, caring, knowledgeable and efficient.

27/06/13 post surgery appointment - previously undetected lymph node involvement thus post-op chemo required.

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Returned to work 7 weeks after surgery on phased return.

date for post-operative chemo offered of 15/08/13, rang 23/07/13 to request earlier chemo but advised no earlier dates available.

3 cycles post-op chemo 15/08/13 to 15/10/13 and even then had to travel to Merthyr for first treatment.

Returned to work 21/10/13.