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7 July 2016

Dear Chairman,

P-04-668 Support Yearly Screening for Ovarian Cancer (CA125 blood test)

Once again thank you for the opportunity to send in my views on the contents of the letter you received from Mark Drakeford dated 20 March 2016.

Ovarian cancer is certainly a distressing disease but I fail to see how the "research has helped to make welcome advances in diagnosis and treatment." There's no screening to effect an early diagnosis and according to a friend, who was a chemotherapy nurse in Velindre, more than fifteen years ago, the treatment has not changed in all that time. She should know because a couple of years ago she was diagnosed with stage 3 ovarian cancer and she has been receiving the same treatment as she was giving to her patients at that time.

Mark Drakeford also mentioned that "Early diagnosis of ovarian cancer is both desirable and needed" but "the evidence recently published from the large UKC TOCS trial indicates that the data to date are not sufficient to recommend a national population screening programme in women with no symptoms or relevant family history". Surely he is aware that ovarian cancer is a silent killer and that when the symptoms become obvious it is usually diagnosed at a late stage. It is certainly true in the cases of the women I have met - several of whom have died in the past year. In other words if a woman still has her ovaries in situ after the age of 50 she is at risk.

He also mentions that the "UK NSC requires the highest quality evidence about population benefits before a new programme can be recommended" to "ensure screening programmes do more good than harm."

Question: What possible harm can a simple CA125 test do? It may not be a perfect test but surely it is better than nothing - which unfortunately is what we have at present.

Mark Drakeford stated that he had asked Velindre NHS Trust to develop an "awareness campaign for ovarian cancer" and that it was launched on 9 March to coincide with ovarian cancer month. It includes "the dissemination of symptoms awareness leaflets and posters to all G.P. surgeries in Wales".

Question: Is he aware that when, and if, women visit their G.P. surgeries that they do not always see leaflets and posters? so how will that help raise awareness?

Perhaps if a leaflet was sent to all women over 50 then the message might get through to them. Even that is questionable. Whereas if women were sent a letter inviting them for screening the message might be more effective.

I have spoken to female friends, over 50 years of age, to see if they know about ovarian cancer and an awareness campaign - they don't.

Question: How is this message getting through to the general public?

I am well aware that GPs may only see a few cases of ovarian cancer - possibly in their lifetime. Invariably most cases are diagnosed in A and E departments - as is well known. By that time it is usually too late to get an early diagnosis because the disease has spread to other organs.

Wales does not have a Cancer Drug Fund so some people have resorted to going over the border to England for treatment. Annie Hulshand, who died recently of ovarian cancer did just that. She stayed at her daughter's address in London and was treated at the Royal Marsden where she received Avastin (denied to Welsh women) and was able to be included in trials of drugs that never came to Wales. She did a lot to champion the cause for women to have the opportunity to have better medication and treatment. It has been said that we in Wales have the poorest outcomes for both cancer and heart disease in Europe.

Question: Why is that?

Since Devolution we have our fifth Health Minister and apart from two, one who was a social worker and the other who was a probation officer, the other three do not seem to have had any experience of health or social care.

Mark Drakeford mentions "the Cancer Implementation Group has prioritised better access to diagnostics."

Question: What does he mean by that? Obviously not screening.

He says "The UK NSC is currently reviewing its recommendations about ovarian cancer screening and is still considering the latest research"

Question: How long is this going to take? And what is the outcome likely to be?

He says "The recommendation remains for no population screening at this stage, although as with all emerging research evidence the UK NSC will continue to monitor all emerging evidence."

Question: Why is it that so much research points to the fact that early diagnosis can make a difference to outcomes but that findings are rarely implemented?

He states "The UK NSC is recognised as a world leader in its field and provides an advisory function that informs the advice of the Wales Screening Committee".

Question: Why can we not decide our own screening priorities?

YOUR MOTHER'S GOT TO DIE OF SOMETHING

A dear friend, another retired nurse, was diagnosed aged 69 in July 2015 with stage 3 advanced ovarian cancer. Her daughter, in her

late 40s went to her GP and asked if she could have a CA125 blood test, in view of her mother's diagnosis. The GP then stated that "Your mother has to die of something." She was denied the test and advised to pay privately to have it done. The GP did not make it easy for her to do by not giving her a letter of referral.

Her other daughter, in her early 40s went to her own GP but was given the test. The result was 55, the cut off being 35 - she was then given an ultrasound scan. What a difference in G.P attitudes!!

Private Health Care

Ash Tree Private Medical Centre offers a ROCA test (CA125) and says "It's clinical trial involved over 200,000 women from across the UK, 16,500 of whom were from Wales, (the Cardiff area)" and the conclusion was the same as that from Ovarian Cancer Action. It appears to have been the same trial. I had never heard of it which suggests to me that the awareness message is not getting across to all Welsh women.

They offer the CA125 blood test for £200 (the NHS one costs between £20 - £25 I believe). The BRCA1 test is offered at £600 (the cost to the NHS is £300 I believe). Consultation is by telephone. It does give women a choice, if they can afford it - but I came across the article, in a magazine, by chance. It raises the question of how many women can afford private health care?

Women are dying due to the consequences of the decisions made by our politicians and their advisors and it all comes down to money. Perhaps if money was better spent in the NHS the cost of screening would not be such a problem.

"Gynaecological cancers are among the most common cancers to affect women, but collectively attract less attention than they deserve from the public and policymakers" and it needs "a more positive message developed to improve the prevention, screening, treatment and care so that women throughout Europe have the best chance of survival and quality of life".

Gynaecological cancers in Europe / Facts and figures 2015.

Yours sincerely

Margaret Hatcher