



**CYNGOR IECHYD CYMUNED
COMMUNITY HEALTH COUNCIL**

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Chairman: Mrs Delcie Davies

17 July 2006

Jane Westlake
Clerk to the Health and Social Services Committee
Room B4.07
National Assembly for Wales
Cardiff Bay
Cardiff
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Dear Ms Westlake

CANCER SERVICES FOR THE PEOPLE OF WALES

Please find attached response to the above consultation by a member of the Brecknock and Radnor Community Health Council.

Yours sincerely

Bryn Williams
Chief Officer

REVIEW OF CANCER SERVICES FOR THE PEOPLE OF WALES.

Over the years Velindre Hospital in Cardiff has provided an invaluable service to the people of South and Mid Wales. Over the last few years it has become a centre of excellence. It has always sought to encourage the views and comments of patients and carers and continues to do so in the form of the patient liaison group, which holds a regular meeting once a month to discuss issues arising, representatives from the group attend in house meetings such as outpatient clinics and the beyond good group looking to improve patient care.

Today information technology has become invaluable. The idea of tracking a patient's cancer journey has to be way forward with information being readily available where ever the patient is e.g. a patient who has received treatment in Velindre and then goes to stay with a relative in North Wales a record of that treatment should be available in the area the person is staying. I also think G.P. practices should have some form of computer information on the patient. Although patients have a record of their treatment and their own doctor will receive a letter to say what is happening the first place everyone looks to is the computer so a summary in the surgery would be quicker to access.

Research is vital to the delivery of care for patients. Without research new forms of treatment, regimes of treatment, and new drug treatment would not be available. I am slightly concerned that newly diagnosed patients, sometimes very shocked are asked to take part in drug trials etc. I have heard comments that they don't like to say no in case it would affect their care or "I had better do it for myself perhaps it will help someone else". I had been under the impression that the cancer networks were to be the driver of all the cancer services but there does not seem to be any information or details as to what these networks are doing! I feel very sorry that a hospital like Velindre has to go to every health board to negotiate a service agreement, go to WAG for funding, go to Health commission Wales for contracts surely everyone knows that Cancer is disease that is increasing in number surely it would be better to cut out all these tiers of beurocracy have one body to regulate all these thins cut down on all the administration, less time attending meetings and provide the necessary equipment and staff to give treatment to patients.

It is obvious that the breast screening has saved the lives of many women

and wouldn't it be advantageous to screen women for ovarian cancer and man for prostate cancer. I appreciate there are psychological issues to screening but I would have thought the benefits would outway the cost. I think one of the barriers to developing technologies is cost and funding. Why aren't the drug firms more involved in funding. Why should the government of the day or donations from grateful families have to provide all the new equipment required. I am sure a lot firms should contribute to this.

I would like to see a lot more closer working between the voluntary sector and the NHS. The voluntary sector provide an invaluable contribution to care especially local care and support. The voluntary sector should be working along side the NHS but not be expected to be a "cheap option" of care.

In Powys we are very fortunate to have the small community hospitals which are often GP led. This is a good support for patient and carer but it should be used in conjunction to the patients needs. Often times patients have to come into hospital because it is impossible to provide a 24hr nursing care at home. A data base on the terminally ill patient and their needs could be kept to see how services could be better delivered.

It is quite common that when you are prescribed a drug you can be on it for life! A better use of the care pathway for the last days of life would prevent unnecessary drugs being given. A lot of work went into the care pathway so I feel it should be more widely used in hospital and especially the community.

Why should patients have to pay for their drugs at all? Enough has been said by the government that the NHS is free at the point of delivery. Patients with cancer will clutch at anything to have their treatment sometimes putting themselves into debt to pay for these drugs surely if the Consultant looking after the patient says that person needs a drug it should be available. I think Doctors pharmacists and specialist nurses do have better access to information and guidance on prescribing than they did and I also think there is a better communication system between professionals to discuss treatment options plus there are research documents available .

I think Velindre is excellent at involving patients in treatment options and care as I mentioned the patient liason group. I think the presence of a consultant and senior nursing staff at the meetings also help where free discussion can take place.