

South Wales East Regional Committee

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Venue:Oasis Christian Community Centre, Cefn Forest, Blackwood

Title:Evidence from Macmillan Cancer Support in relation to the Health and Social Services Committee's Review of Cancer Services

Introduction

Macmillan Cancer Support improves the lives of people affected by cancer, providing practical, medical, emotional and financial support. Working alongside people affected by cancer, Macmillan paves the way to better care and support for everyone affected by cancer, by acting as a source of support and a force for change.

Here in Wales, cancer is a major public health issue. Indeed, cancer is the second most common cause of death in Wales, with over 16,000 people diagnosed with it in 2003. Today there are three times as many people in Great Britain living with cancer than there were 30 years ago, with 1.2 million people living with it across the United Kingdom. Currently, one in three of us will eventually develop cancer before the age of 75, with recent reports in the Western Mail listing an increase to one in two.

Inevitably, with the incidence of cancer increasing, the Welsh Assembly Government is under increasing pressure to provide better and more appropriate service delivery, treatment and care to cancer patients. As more and more people face the future living with cancer, their needs will certainly change requiring more emotional, social and financial, as well as medical, support.

We have learnt that this can only be done in partnership with people affected by cancer, and placing their wants and needs at the very heart of everything we do. Macmillan health and social care professionals are keen to develop care of the whole person, rather than the treatment of the disease only. Consequently, we welcome the South Wales East Committee's investigation into cancer services in their area and the opportunity afforded to the public to share their views about cancer services in this particular area.

This paper has been based on our initial response to the Health and Social Services Committee's preliminary thoughts on the subject and terms of reference of the Review into Cancer Services. As a result, this paper has been divided into four sections, namely service delivery, resources, treatment and care, and the cost of cancer. We refer to examples in the South East Wales area, where appropriate.

1. Service delivery

- Problems relating to this area stem from a lack of an adequately resourced strategic framework – known as a Cancer Plan in England – for developing cancer services in Wales, including an emphasis on broader quality of life issues, ring-fenced money, together with performance targets, and arrangements for developing the workforce to ensure that the people of Wales have equitable access to the most appropriate services. Improvements also need to be made in tracking cancer money to ensure that any new cancer money really benefits patients. The NHS Cancer Plan for England has been instrumental in accelerating the modernisation process and reducing delays in accessing treatment. Macmillan would like to see a similar strategic plan for Wales.
- Ensuring user involvement at all stages of service delivery to ensure a people-centred approach to good quality cancer care. User involvement should promote inclusiveness and reflect the diverse sectors of Welsh society. Macmillan has funded three Cancer Network user involvement facilitators over the last three years, funding for all of which will come to an end over the next twelve months. Efforts are currently being made to seek statutory funding to sustain these posts. User involvement is crucial and failure to commit ongoing funding will undo the good work already funded by Macmillan.
- As well as a cancer plan, the views and experiences of people affected by cancer are essential to ensure that services are meeting need in the most appropriate ways. Mechanisms for gathering the cancer patient and carer experience in Wales (including that which happens beyond the hospital), akin to the Department of Health and National Audit Office surveys in England, are essential. These surveys need to cover the cancer patient and carer experience at all stages of their cancer experience.
- The recent Health Inspectorate Wales review of the three Cancer Networks found weaknesses in the role that the Networks have to play in the delivery and monitoring of cancer services and standards. It is essential that the review takes on board the report's recommendations including consideration of the benefits of increasing the cancer networks' powers to influence planning and commissioning of services.
- While we welcome the reshaping of health services on a regional basis in response to changing needs among the population, the financial impact of service centralisation on people affected by cancer, particularly those in rural areas should be recognised. Centralisation and specialisation leads to better clinical outcomes, but it also means patients have no choice but to travel long distances for treatment, which in turn exposes the weaknesses of patient transport services and lack of overnight stay provision.
- The needs of minority ethnic groups should be better met. Monitoring of patient ethnicity and action plans for addressing needs are yet to be fully implemented. Macmillan is investing in a regional initiative with the SE Cancer Network to contribute into this wider health needs issue.

- There is a need for greater joint working between Health and Social Care at all levels. The anticipated Social Care Strategy will hopefully highlight the need for a central role for local authorities in delivering the new pattern of cancer services. At the local level, more effective joint working is required between health and social services departments to ensure that people affected by cancer are able to live at home and to die at home when they wish.

2. Resources

- Funding for Linear Accelerators, (LINACS), in Wales, and particularly the SE Wales region does not allow for adequate levels of treatment capacity. The UK standard of one LINAC per 1 million of population is not currently met. In the South East one LINAC is in need of replacement and an additional one is required to meet the standard. The current situation creates longer waiting lists and inevitably impacts upon outcomes for patients.
- Similarly, PET scanners are not available in Wales. PET scanners have been proven to reduce the necessity and frequency of invasive and major surgery for patients.

Treatment and care

- Macmillan recommends that the relationship between the National Institute for Clinical Evidence, (NICE) and NHS Wales and the Welsh Assembly Government should be clarified in order to more efficiently and effectively manage the delivery of new treatments to people in Wales.
- Adequate information and support for people affected by cancer should be central to a quality cancer service. Macmillan is pleased to announce that we are investing in a national information coordinator who will work with the networks to develop an information strategy. This work will be integrated into the service infrastructure and will require ongoing resources from year four onwards.
- A shortcoming of 'Designed for Life' is that it does not outline measures in relation to supportive and palliative care for those with advanced illness. If it is agreed that standards or measures ought to be developed for supportive and palliative care, certainly it should also be recommended that money be attached to these.
- Of equal importance is the need for a strategy to deal comprehensively with the needs of carers. As Cancer patients often cross several organisational and geographical boundaries to receive treatment, the coordination of care and navigation to help them find their way is particularly relevant, such as good out-of-hours care and good end-of-life care. Access to out-of-hours support and pharmaceutical services in the SE Wales region are currently poor with difficulties in accessing appropriate advice. The SE Wales Cancer Network recently conducted a review of out-of-hours support in the region and found that 24 hour nursing is not available across the whole of

the region. This is a problem not just for local people in need of Out of Hours support. At the strategic level, NICE guidelines are predicated upon the presence of 24 hour nursing services. In Wales, therefore, it is currently not possible to implement NICE guidelines.

- The development of greater levels of community and home treatment brings with it the need to ensure consistent quality standards and the cascading of new and innovative treatment practices. For example, training in syringe driver use must reach all nursing staff in a range of settings, and the drive for efficiency and value for money should not restrict efforts by trusts to deliver innovative services to minority ethnic groups.

Cost of Cancer

- Nearly all people with cancer suffer some form of financial hardship. Macmillan's research shows that cancer patients, particularly those of working age, frequently experience both a drop in income and at the same time incur extra costs (e.g. travel, parking, prescription charges, special diets, wigs and clothing, higher heating bills, etc). However, our evidence also shows that patients are not receiving advice about existing welfare benefits. For example, 55% of Welsh cancer patients in a recent Macmillan survey said they received no advice about welfare benefits while 64% of UK patients who incurred travel costs had not been informed about the Hospital Travel Costs Scheme (HTCS).
- Macmillan wants all cancer patients to be offered specialist benefits advice at diagnosis and at key points thereafter in the patient journey. Effective referrals mechanisms need to be built into care pathways to ensure that patients get the advice they need at the time they need it.
- The prohibitive costs of patient travel and parking also need to be addressed urgently. Macmillan's research, attached to its Better Deal campaign, shows that 89% of hospitals in Wales now charge patients for parking and that cancer patients in Wales are spending on average £229 on travel and parking while undergoing treatment – money that could be spent elsewhere. Of those hospitals in Wales, only Prince Charles hospital in Merthyr Tydfil and Velindre hospital in Cardiff do not charge for car parking. Charges vary wildly throughout Wales, with the University of Wales hospital charging the most - £2.10 (min. stay) - £20.80 (24 hr). Macmillan wants cancer patients to have their travel costs reimbursed through HTCS without a means-test, for hospitals to exempt cancer patients from parking charges and for the HTCS to be properly publicised.

Simon Blackburn & Carys Thomas
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