

WEST DUNBARTONSHIRE COUNCIL

Report by the Acting Director of Social Work Services

Health Improvement and Social Justice Partnership: 22 November 2006

Subject: Improved services for cancer patients and carers

1. Purpose

- 1.1 To inform the Partnership of the work, completed and ongoing, carried out by Social Work Services in partnership with Macmillan Cancer Support to address cancer poverty in West Dunbartonshire.
- 1.2 This includes summary of annual outcomes and an update on discussions taking place to establish a model of best practice in advice & support being made available to all patients attending Beatson Oncology Centre, Glasgow for treatment, through a pilot project, incorporating the West Dunbartonshire experience.
- 1.3 A report on this subject was taken to the Social Justice Committee on 8 November seeking the support of the Committee.

2. Background

- 2.1 Council, Welfare Rights Representation Unit (WRRU) was developed to address the needs of those affected by cancer in West Dunbartonshire. A funding package of £327,000 to cover the first 3 years of the project was put in place by the charity and the initiative was launched in March 2005.
- 2.2 This is the first statutory sector partnership that the charity has entered with a Local Authority in the UK. The project is focused on referrals from primary care, which would provide a model of service delivery. The project team has developed and maintained close links with local acute hospitals, health centres, cancer clinics, other patient treatment centres and cancer charities.
- 2.3 A cancer diagnosis frequently results in a drop in income as jobs are lost and savings are eroded. This happens at a point where expenses of daily living are likely to increase due to, for instance, increased travel expenditure to and from appointments, hospital parking charges and the cost of prescriptions, increased telephoned bills, heating and new clothes due to changes in weight during treatment. For those affected by cancer, financial concerns are a significant cause of stress (second only to physical pain). Providing services, which are easy to access and focused on those affected by cancer, ensures these worries are alleviated as much as possible and those affected by cancer are supported in the process of claiming the money they are entitled to.

- 2.4 Sixty-four percent of those diagnosed with a terminal cancer in Scotland do not access the appropriate disability benefits. Scotland has the lowest claim rate in the UK. It is estimated that this equates to approximately £15 million in unclaimed disability benefits alone. Research confirms that financial problems encountered by people with a terminal diagnosis are also experienced by the increasing numbers of people who are living with cancer, but who are not terminally ill. Carers are also offered appropriate assistance from project staff.

3. Referrals

- 3.1 Referrals to the project are received from a wide range of sources, including District Nurses, Carers, GP, Home Care, people living with cancer, Palliative Care Teams and Social Work Services. Initial contact is usually achieved on the same day as referral and not more than 3 working days.
- 3.2 Services are available to people throughout their whole cancer journey and in many cases contact is maintained with bereaved relatives for a period to ensure that benefit issues and other financial affairs are in order. The majority of cancer patients receiving services are over 60 years of age. This reflects the fact cancer is a disease predominately affecting our ageing population.

4. Project outcomes

The outcomes of the project's first full year have been significant.

- Annual income generated by the project was £1million from 468 claims
- In addition to above amount; over £50,000 was awarded from 139 Macmillan Patient Grant applications
- The project has developed based on identified needs of cancer patients within the local community
- The project maintains a holistic approach to welfare benefits and financial matters
- The project collects statistical information to demonstrate that the range of interventions are efficient, effective and reflect "best value"
- The project networks effectively with all key stakeholders throughout West Dunbartonshire
- Training and education of both project staff and wider stakeholders has been a key aspect of the initiative.
- The investment in training has resulted in increased cancer awareness and further publicizing the project.

5. Patient evaluation

- 5.1 To comply with West Dunbartonshire Council quality assurance procedures a brief questionnaire was sent to 50 patient users of the Macmillan Benefits Project. A free post envelope was included with the survey form. There was

an eighty percent response rate of questionnaires issued. The results of this exercise were very positive and included the following information.

- All of the respondents were satisfied that project staff were well mannered, friendly and professional
- All of the respondents considered that their contact with the project was a positive experience
- Over 74% of respondents agreed that the work of the project resulted in an increase in their weekly income
- Over 95% of respondents agreed that they were advised of Macmillan Patient Grants
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Patient comment

I didn't think would get any help because my wife was working. So when a letter came telling me how much I would get I can't tell you how much pressure that takes off you on a financial level.

6. Cancer poverty a national challenge

6.1 Cancer incidence in Scotland

It is predicted that, in Scotland, diagnosis of some cancer types are expected to increase by 50% compared to levels experienced in the nineteen-nineties. A recent report predicted that by 2011 there will be over 31,000 cases of cancer diagnosed each year compared with over 26,000 per year between 1996 and the year two thousand. More than 1,000 patients will have a diagnosis of malignant melanoma of the skin each year compared to around 600 at present; it is also predicted there will be more than one thousand confirmed cases of colorectal cancer. Most worryingly, breast cancer is forecasted to rise by 23 percent in Scotland. Cancer Research UK has recently expressed concern at the increased incidence of womb cancer among older women. The rate of cases of this cancer among women aged from 60 to 79 has risen by more than thirty percent in less than ten years. This affects around 6,000 women in the UK each year and it is responsible for about 1,500 deaths annually. The predicted increase in incidence in some common types of cancer in Scotland confirms the need for dedicated advice projects for patients and carers.

6.2 Cancer poverty: towards a national response

Discussion initiated by our colleagues at Macmillan Cancer Support has established that the standard of service delivered by the partnership in West Dunbartonshire is not available in all local authority areas in Scotland. Council officers have been working with the charity to examine the logistics of extending the advice & support facility to all patients attending the Beatson Oncology Centre, Glasgow through a pilot project. There have been a number of expressions of interest in a fresh approach to cancer poverty. Consultations have taken place with senior strategy officers at COSLA and the appropriate Executive Group will hear a joint presentation

on dealing with cancer poverty from Macmillan and WDC in November. Following a productive intervention at the ADSW Standing Committee on Community Care in June a more detailed joint presentation was made by Macmillan and WDC at the October meeting of ADSW.

6.3 A presentation was heard by the Cancer Research UK; Scotland Against Cancer Conference in September and there was great interest in the WDC/Macmillan proposals on cancer poverty. Senior management and clinicians from the Beatson Oncology Centre have confirmed their interest in an on-site advice & support facility using this model.

6.4 NHS Greater Glasgow and Clyde have taken up the issues to explore across their 11 CHP/CHCPs.

6.5 Kenneth Macintosh MSP and David Davidson MSP joint chairpersons of the Cross Party Group on Cancer in the Scottish Parliament have expressed interest in the issue of cancer poverty and the proposal to extend the advice & support facility to all patients at the Beatson. Sir David Carter; Chairman of the Health Foundation was supportive of the idea that advice & support for cancer patients deserves a more important position on the patient care agenda and referred to the partnership in his summary remarks to the conference. These are some examples of the interest in the West Dunbartonshire model to tackling cancer poverty by adapting these new approaches to local circumstances.

6.6 **Aims**

The Council, in partnership with Macmillan Cancer Care and Support, is working to develop policies and services to tackle cancer poverty. The aims include:

- Working with Macmillan Cancer Support to create a platform for discussion with Local Authorities (CoSLA), ADSW and other partners in Scotland to improve advice services for cancer patients and carers throughout Scotland
- To establish a pilot project which offers advice & support facility to all patients attending the Beatson Oncology Centre
- To raise awareness on the issues of unclaimed benefits and to begin to develop potential solutions to cancer poverty
- To present the need for better inter-agency working to provide cancer patients and carers with effective advice, advocacy and information on welfare benefits, and crucially, to ensure that there is equity of provision for Scots irrespective of where they live
- To utilise the experience and learning from the Macmillan advice projects to help shape improved service delivery throughout Scotland

- To develop effective and sensitive services to meet the benefits advice and non-clinical, pastoral and social support needs of cancer patients and carers in Local Authority areas throughout Scotland
- To ensure consistency and continuity of service quality and delivery in Local Authority and Community Health Partnership areas throughout Scotland
- To establish or access a database, following ethical guidelines, in order to, monitor the number of claims, the uptake of benefit and the financial outcomes in Local Authority areas throughout Scotland.
- To prioritize and identify areas of unmet needs in relation to financial advice and social care for cancer patients and carers in Local Authority areas throughout Scotland.
- To continue to raise awareness of the causes, effects & impacts of cancer and to play an informative role within communities in Local Authority areas throughout Scotland.
- To consider the most appropriate methods of partnership working at an operational level (including cross-council cooperation) and managed Clinical and Care Networks.
- To act jointly as a force for changes in the development of the UK benefits system and how it applies to cancer patients
- To ensure that cancer poverty is included in the national cancer plan for Scotland which is currently under review.

7. Summary

- 7.1 The purpose of current partnership projects and proposed initiatives are to firstly, improve the advice & support given to cancer patients and secondly, to act as '*path finders*' in the wider development of financial advice and support services across Scotland. Experience gained from current projects has established the issue of unclaimed benefits seriously affecting cancer patients and their families and has served to illustrate the critical success factors which need to be mainstreamed into the provision of advice services for this vulnerable section of society.
- 7.2 A pilot project at Beatson would be a benchmark for future service delivery using experience, patient opinion and acquired statistics to

develop models of best practice which could be applied at cancer treatment centres throughout the UK.

8. Recommendations

8.1 The Health Improvement and Social Justice Partnership is asked to:

- (i) support the aims and outcomes of the joint working with Macmillan Cancer Support and the initiatives contained within this report.

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Wards affected: All

Background papers: None