

COUNTING THE COST OF CANCER

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CANCER SUPPORT**



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A report by Macmillan Cancer Support in Wales

FOREWORD

“When people think of cancer they don’t usually think of money. But the sad fact is that for many people who get cancer, money is one of their biggest worries. Cancer is the toughest fight most of us will ever face. A cancer diagnosis can mean taking a long time off work, and this means a big drop in income. At the same time, there are a lot of costs associated with cancer – dozens of trips to and from hospital and increased heating bills to deal with the cold chemotherapy brings. At a time when people should be focusing all their energy on getting better, we know that sadly, many spend their time worrying about money.

But help is available – different charities and organisations provide services, support lines and information to help people deal with the cost of cancer across Wales. Macmillan wants every person affected by cancer in Wales to be made aware of their rights and entitlements from the point of diagnosis and at key points on their cancer journey. We know from speaking to people with cancer and from our research that this just doesn’t happen for everyone at the moment in Wales.

Our ‘Counting the Cost of Cancer’ campaign is aimed at raising the awareness of these issues, and making sure that every person affected by cancer in Wales has the chance to access advice and support to help them deal with this part of their cancer journey.”

Susan Morris

General Manager for Wales, Macmillan Cancer Support

Cancer poverty in Wales

For many people in Wales, cancer poverty is a very real issue. The word 'poverty' can be a sensitive one and often people think it doesn't apply to their situation or can be reluctant to talk about their finances. But a cancer diagnosis can change everything. We know from our research and from speaking to people affected by cancer that finances and the cost of cancer is an increasing issue for people in Wales, particularly at the moment. Jobs are being squeezed, welfare benefits are under scrutiny and the cost of basic living expenses, such as food and fuel, is spiralling. Added to this is the fact that average earnings in Wales are more than £80 a week lower than the UK average.

The number of people affected by cancer in Wales is growing and is set to rise even further. It is estimated

that in the next 20 years, the number of people living with cancer in Wales is set to double to almost a quarter of a million if current trends continueⁱ. In many cases the financial pressures deriving from a cancer diagnosis have a major personal impact. Over 50% of people with a cancer diagnosis say they are worried about their finances. These pressures can impact on an individual's emotional and mental health, with 41% of patients feeling more stressed as a result, and can cause strain on personal relationships for almost a quarter of people living with cancerⁱⁱ.

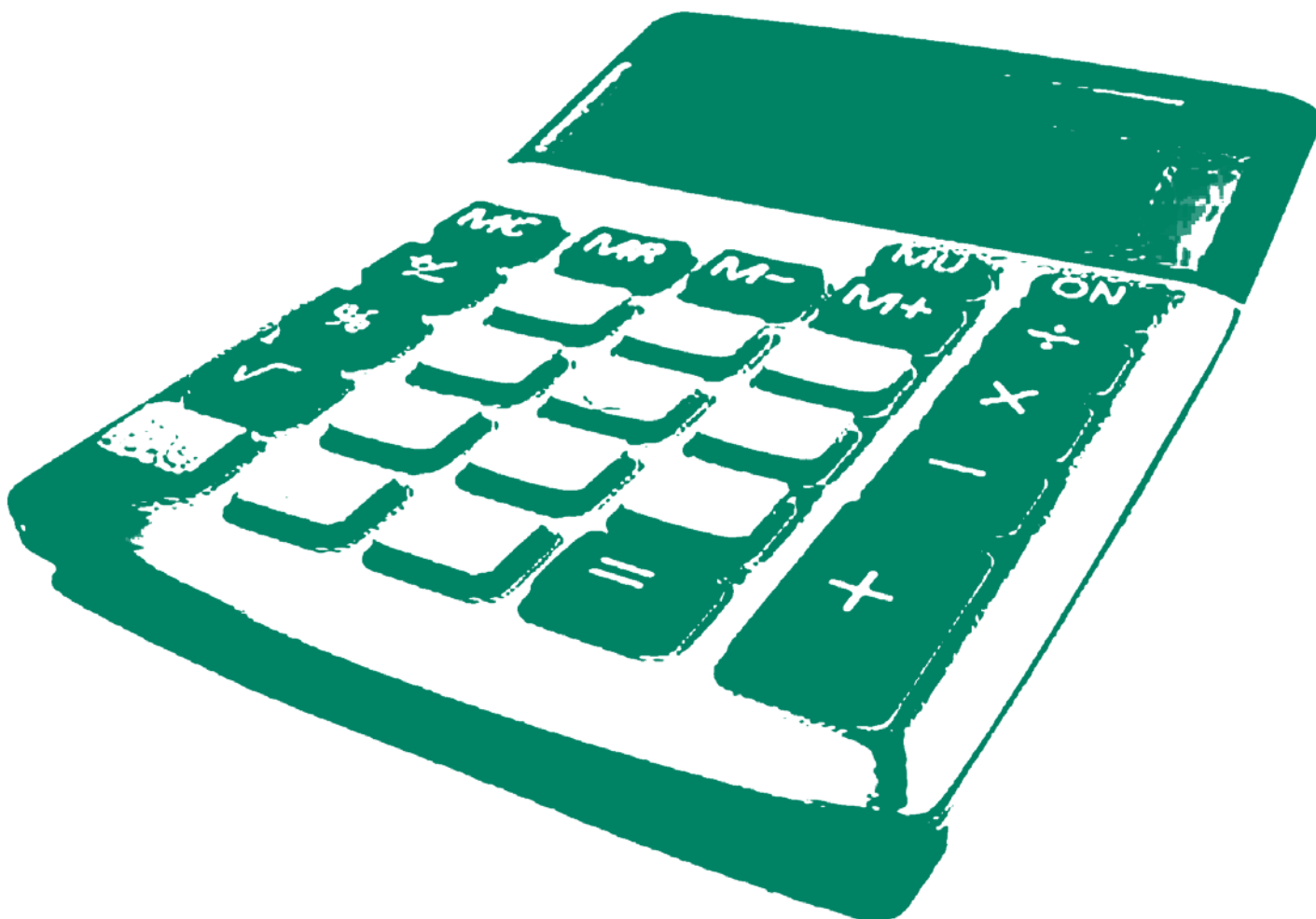
Advice and support can change everything but at the moment, patients and their families are not routinely offered access to financial advice and support when they receive a diagnosis. Fewer than half of people with a cancer diagnosis in Wales say they receive financial advice or support from any sourceⁱⁱⁱ. This figure falls even further among the over 65s, where fewer than one in three receive support^{iv}. Only a quarter of people with cancer discuss their financial situation with a health or social care professional, and again this figure is reduced among the over 65s to just 11%^v. We know that money worries are prevalent among cancer patients across the UK, but barriers to accessing information is a particular issue in Wales, due to rurality and a disproportionately older population. Macmillan would like this to change.

At the moment people affected by cancer are not routinely offered the opportunity to have appropriate financial support throughout their cancer journey. Access to timely and appropriate welfare benefits advice can significantly reduce financial hardship, alleviate anxiety and stress, improve quality of life and help people make informed choices throughout their cancer journey. The downturn in the economy also increases the risk of reducing clinical and non-clinical posts that have traditionally provided informal information and support around the cost of cancer.

The aim of Macmillan's Counting the Cost of Cancer campaign is to reduce the financial impact of cancer for people in Wales by:

- a. Raising awareness of the financial impact of cancer amongst the public, supporters and stakeholders.
- b. Influencing stakeholders to understand, recognise and respond to the importance of making financial advice and support routinely available for people affected by cancer in Wales.
- c. Ensuring that every person diagnosed with cancer in Wales is routinely offered the opportunity to access financial advice and support as part of the assessment and care planning process
- d. To ensure that support and advice services are sustained and, where there are gaps in provision for people affected by cancer, these are addressed.

We commissioned The Monitor Group to pull together existing research in order to model the financial impact of cancer on people diagnosed with cancer in Wales – in terms of loss of income and increased costs over a one and five year period after diagnosis^{vi}. We have also spoken to many people affected by cancer regarding their experiences. But the extent of cancer poverty could be even greater than our evidence shows. We have not, for example, been able to calculate the cost implications for friends, families and carers of people affected by cancer – for the fuel costs, for example, of all those lifts back and forth to hospital appointments or to the shops to run errands. Our research has provided an estimated financial impact of cancer over five years, as costs continue well after diagnosis. We are aware however, that costs may well continue after this point. What is in no doubt, however, is that cancer poverty is an issue affecting every community in Wales.



The cost of cancer

“The change in what I can eat was costly as I had a tumour at the base of my tongue and radiotherapy has damaged my saliva glands. It was trial and error to start with and a lot of food was wasted.

I also felt the cold a lot more when I came home from hospital. We had the heating on most of the time, which doubled our gas bill and we had to dip into our savings.”

Derek, Caerphilly

Having cancer is expensive. Our existing research shows that more than 50% of people with a cancer diagnosis in Wales are worried about their finances and one in four have to cut down on normal household expenditure^{vii}. One in five people have problems paying their bills, rent or mortgage, and we know from speaking to patients that in some extreme cases they've become homeless following diagnosis.

Loss of income is one of the greatest financial implications for people diagnosed with cancer. 43% of those in employment at the time of diagnosis experience loss of income^{viii}, while the income of a spouse or partner might also be affected if they need to give up work or reduce their hours to care for a person affected by cancer. Of those employed at the time of diagnosis, around 15% will have to stop work altogether while three out of 10 will have to change their working status in some way^{ix}.

Loss of income is greatest in the first year after diagnosis, when the average person loses an estimated 20% - £5,500 in Wales – of their employment earnings. Over five years, the average loss of income is an estimated £16,500. The range in this impact is vast. For example, if we remove from the figures the people who do not change their working status, around 50% - £13,500 – of employment earnings are lost in the first year. The impact is also particularly felt by those who do not work. Although they do not experience loss

of earnings, the increased costs associated with a cancer diagnosis are likely to take up a large proportion of their fixed and typically low incomes.

The main increased costs faced by cancer patients and their families include:

a) Travel costs

An additional cost faced by an estimated 95% of patients are travel costs getting to and from hospital appointments^x. On average, this amounts to an estimated £275 per patient in the first year and £400 over five years. Cancers such as breast cancer and leukaemia typically require the most number of hospital appointments while people living in Powys face the longest distances to their nearest cancer centre, with round trips averaging four hours. The cost of travel over five years for a patient in Powys is, at an estimated £1,440, significantly higher than the Wales average.

Every patient's cancer journey is different. Many patients have to travel to multiple cancer centre sites for treatments. We anticipate that we have underestimated the true travel costs faced by cancer patients due to the complex nature of cancer treatment and the spread of cancer centres in Wales. Our research has only looked at the patient's journey to their nearest cancer centre, but we know that many patients are unable to access treatment at their nearest centre due to the nature of their cancer, or their treatment. We have also not factored in the travel costs faced by friends and families, which in many cases are substantial.

b) Clothing costs

Treatments such as chemotherapy can cause substantial weight loss or gain. An estimated 40% of patients face this cost^{xi}. As a result many people find they need new clothes – not just one or two items but a whole wardrobe. They might also need items such as wigs and bandanas. The average cost for people who need such items amounts to an estimated £400 over five years, with the majority of the expense experienced in year one.

c) Increased bills

Household bills can dramatically add up after a diagnosis. Fuel bills can escalate as patients are at home more than usual and more likely to feel the cold during treatment. Phone and internet bills can rise as people need increased social interaction to combat isolation and loneliness. Food bills can increase, particularly for patients who need to follow a special diet. Many patients report the need to buy items they would never have considered, such as extra-thick duvets, specialist toiletries and particular types of toothbrushes. Even the inexpensive items mount up to a significant sum.

d) Other costs

Additional costs also affect some people with cancer, such as household modifications, childcare costs, and overnight costs. We know these costs can be very significant for patients who face them but have not been able to include them within the research.

"As soon as my husband was unable to work, the bank recalled a loan and we were made bankrupt. You should not be penalised for having cancer. Without Macmillan I really do not know how we would have survived as we had no money coming in.

It's the little things which you don't think of. Ian needed new clothes as he had lost so much weight and we needed thicker duvets to keep him warm. We also needed £500 to fill up the oil tank for winter."

Nikki, Ceredigion

The wider picture

Welfare reform

The UK Government has recently changed the way the welfare system works. The Welfare Reform Act 2012 could mean that up to 7,000 cancer patients across the UK will lose up to £94 a week^{xii}. The changes to the benefit system could leave people with

cancer without vital support when they need it most and pushing them into poverty.

Fuel Poverty

Many people affected by cancer are in fuel poverty. A household is in fuel poverty when they have to spend more than 10% of income on fuel to keep warm. People affected by cancer not only face the financial pressures outlined here, but in many instances cancer can exacerbate fuel poverty as fuel bills can escalate because patients are at home more than usual and are more likely to feel the cold during treatment.

Stress

Money worries can trigger stress in cancer patients at the time they need it least. More than four in 10 cancer patients say the financial impact of cancer has made them feel more stressed or anxious, while around a quarter say it has caused a strain on their personal relationships^{xiii}. Stress can have a major impact on a patient, resulting in emotional and mental health issues – all of which can affect how long it takes for a patient to recover from cancer.

I am self employed but I am just not up to the physical demands of running a guest house now. I lost two and a half stone following my surgery and find it hard to maintain my weight because eating is so uncomfortable. I have had to put the business up for sale but while I find a buyer I still have to cover the bills.

Luckily, I was talking to a nurse one day in hospital who told me that I might be entitled to support and she directed me to a Welfare Benefits adviser. I do get some help now but as I am self employed it doesn't cover all my costs.

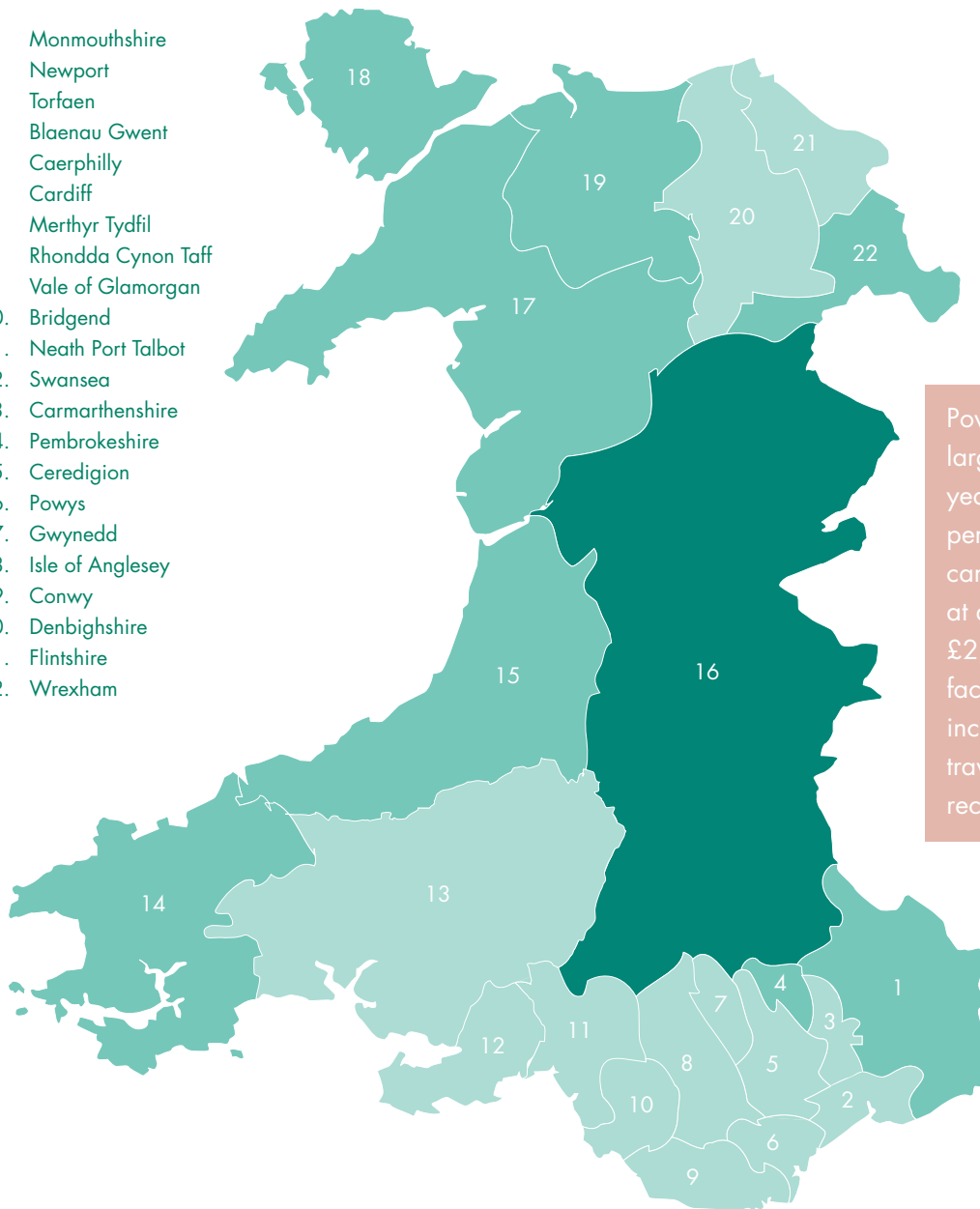
The reality is that if you are self employed and you can't work you don't earn but still the bills come in – there isn't a safety net for the days when it's a struggle to get out of bed.

Sheila, Llandudno

INCREASED COSTS OVER FIVE YEARS AFTER DIAGNOSIS

The financial impact of cancer on people diagnosed with cancer in Wales in terms of increased costs over a 5 year period after diagnosis, based on the modelling work by The Monitor Group. More information can be found in the table in Annex A.

1. Monmouthshire
2. Newport
3. Torfaen
4. Blaenau Gwent
5. Caerphilly
6. Cardiff
7. Merthyr Tydfil
8. Rhondda Cynon Taff
9. Vale of Glamorgan
10. Bridgend
11. Neath Port Talbot
12. Swansea
13. Carmarthenshire
14. Pembrokeshire
15. Ceredigion
16. Powys
17. Gwynedd
18. Isle of Anglesey
19. Conwy
20. Denbighshire
21. Flintshire
22. Wrexham



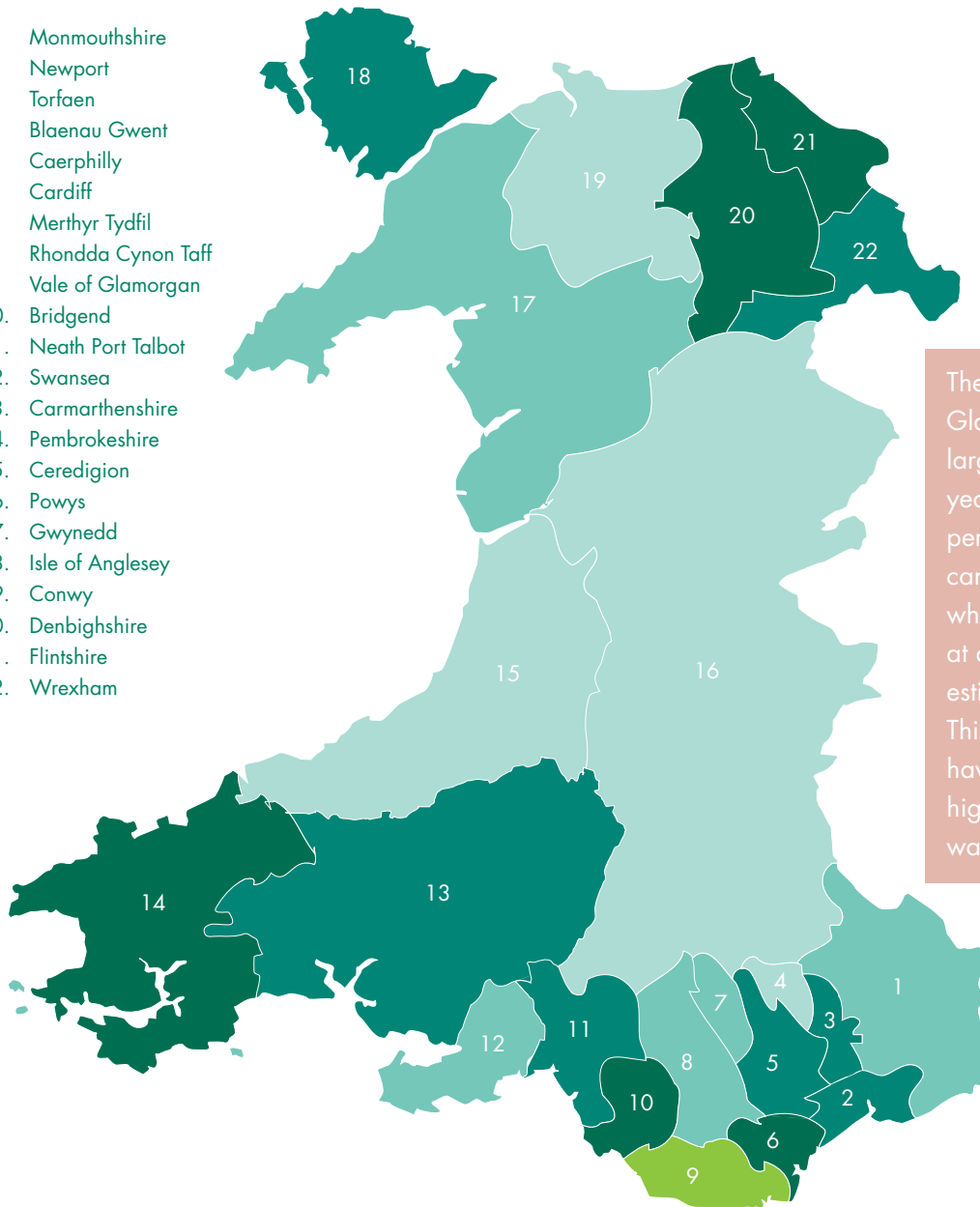
Powys has the largest average 5 year increased costs per person with a cancer diagnosis at an estimated £2,556. A large factor in these increased costs is travelling costs to receive treatment.

£1,000 - £1,500	
£1,501 - £2,000	
£2,001 - £2,500	
£2,501 - £3,000	

LOSS OF INCOME OVER A FIVE YEAR PERIOD AFTER DIAGNOSIS

The financial impact of cancer on people diagnosed with cancer in Wales in terms of loss of income over a 5 year period after diagnosis, based on modelling work by The Monitor Group. More information can be found in the table in Annex A.

1. Monmouthshire
2. Newport
3. Torfaen
4. Blaenau Gwent
5. Caerphilly
6. Cardiff
7. Merthyr Tydfil
8. Rhondda Cynon Taff
9. Vale of Glamorgan
10. Bridgend
11. Neath Port Talbot
12. Swansea
13. Carmarthenshire
14. Pembrokeshire
15. Ceredigion
16. Powys
17. Gwynedd
18. Isle of Anglesey
19. Conwy
20. Denbighshire
21. Flintshire
22. Wrexham



The Vale of Glamorgan has the largest average 5 year loss of income per person with a cancer diagnosis who was employed at diagnosis at an estimated £18,200. This is linked to it having amongst the highest average wages in Wales.

£14,000 - £15,000	
£15,001 - £16,000	
£16,001 - £17,000	
£17,001 - £18,000	
£18,001 - £19,000	

Helping people manage the cost of cancer

"I had been working abroad and came back with next to nothing. The housing association were great and gave me a flat but I didn't have a stick of furniture to put in it. Macmillan gave me a grant to buy furniture and do some decorating. I couldn't have done it without them. I had never claimed a penny before and didn't have a clue about benefits."

Colin, Merthyr Tydfil

Help is available for people affected by cancer and their families. Macmillan funds Welfare Benefits Advisers in many parts of Wales, who can advise patients which benefits they are entitled to and to help them fill out lengthy and complex forms. Macmillan Welfare Benefit Advisers based in Wales helped over 2,000 people affected by cancer to access nearly £7m in benefits and provided a range of advice on debt, housing, employment and energy efficiency in 2011.

Our welfare benefits team can also advise patients on Macmillan grants – one-off payments to help with specific costs such as heating bills, clothes or special equipment. In 2011, 1,763 people in Wales were given Macmillan grants totalling over £600,000. There are also other sources of help and guidance across Wales, and ensuring that these services are sustained is vital.

Many people need support but they don't get it, very often because they don't know it is available until too late in their diagnosis. Many people simply aren't being asked if they need advice.

We want every person diagnosed with cancer to be offered the opportunity to access financial support and advice. Our aim is for health professionals to routinely raise the cost of cancer in their initial discussions with people affected by cancer. Macmillan in Wales is working with the Welsh Government to introduce personalised assessment

and care planning for every person diagnosed with cancer and we want to ensure that the financial cost of cancer is included in this.

We do not want or expect health professionals to become welfare rights advisers; we simply want them to raise the question at the outset by routinely asking patients if they are aware that financial advice may be available to them and their families or carers. By signposting patients to welfare services including the Welfare Benefit Advisers based locally and the Macmillan Support Line – where trained advisers talk to callers about practical, medical, emotional and financial issues – every patient will be a step closer to a tailored care plan which suits their individual needs.

"I was laid off as soon as I told my employers about my diagnosis. Suddenly I had no income but we still had bills coming in and the mortgage to pay. You don't need that extra worry when you have cancer. Luckily our neighbour is a district nurse and she told us about Macmillan. I was able to get a grant for clothes because I had lost so much weight."

Graham, Bridgend

We want to ensure that people affected by cancer concentrate their energy on fighting cancer and not on worrying about financial matters. Advice and support is available. Macmillan Cancer Support wants every person with cancer in Wales to be made aware of their rights and entitlements from point of diagnosis and at key points on their cancer journey. Macmillan Welfare Benefits Advisers are available across many parts of Wales and people affected by cancer can also contact the Macmillan Support Line for help, advice and information regarding their local services.

Cancer is the toughest fight most of us will ever face but you don't have to go through it alone. We have a team of experts who can answer any questions you have, offer support, or simply listen if you need a chat.

**Call Macmillan free on
0808 808 00 00**

References

- i Macmillan Cancer Support estimates based on Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*. 2009. 101: 541-547. Crude estimates made for the end of 2010, 2020 and 2030 assuming that the current rate of increase (3.2%) continues. (Estimates assume any increase is consistent across each nation and remains unchanged over the 20 years, as such they are indicative only, are not statistically reliable and could change as more information becomes available.
- ii Macmillan Cancer Support/YouGov online (Aug 2011) survey of 1,697 people living with cancer in the UK. 197 respondents from Wales. Survey results are not weighted.
- iii *ibid*
- iv *ibid*
- v *ibid*
- vi 'Cancer Poverty in Wales: Holistically measuring and demonstrating the extent of cancer poverty in Wales'. November 2011. The Monitor Group. www.macmillan.org.uk/cost
- vii *ibid*
- viii Monitor internal analysis, based on Macmillan Cancer Support/YouGov (Feb 2010) online survey of 1,912 people living with cancer in the UK. 173 respondents from Wales. Survey results are not weighted.
- ix Macmillan Cancer Support/YouGov (Feb 2010) online survey of 1,912 people living with cancer in the UK. 173 respondents from Wales. Survey results are not weighted.
- x Monitor internal analysis, based on Macmillan Cancer Support/YouGov (Feb 2010) online survey of 1,912 people living with cancer in the UK. 173 respondents from Wales. Survey results are not weighted.
- xi Monitor internal analysis, based on L Sharp, Timmons A. The Financial Impact of a Cancer Diagnosis. 2010. National Cancer Registry Ireland/Irish Cancer Society.
- xii Macmillan estimates that 7,000 cancer patients could lose up to £94 a week. This figure is based on estimates of the number of cancer patients on contributory benefits who are in the Work-Related Activity Group of ESA or currently claiming Incapacity Benefit but will be placed in the Work-Related Activity Group following the reassessment of all Incapacity Benefit claimants. For more info please see: http://www.macmillan.org.uk/Aboutus/News/Latest_News/Cancerpatientstoloseupto94aweek.aspx
- xiii Macmillan Cancer Support/YouGov online (Aug 2011) survey of 1,697 people living with cancer in the UK. 197 respondents from Wales. Survey results are not weighted.

Annex A

	Population (over 65s)	Employment Rate	Average Wage (£'000s) <i>Full time average gross annual earnings</i>	Deprivation % of Lower <i>Super Output Areas (LSOAs) in the most deprived 10% of Wales</i>	Incidence (Absolute)	Incidence (Crude Rate)	Loss of Income (£'000s) <i>Average 5 year loss of income per person with a cancer diagnosis who was employed at diagnosis</i>	Increased Costs (£) <i>Average 5 year increased costs per person with a cancer diagnosis</i>
Merthyr Tydfil	55.7 (17%)	40.10%	25.1	25%	353	634	15.8	1,367
Blaenau Gwent	68.6 (18%)	37.30%	23.1	23%	433	631	14.3	1,522
Rhondda, Cynon, Taff	234.4 (17%)	40.40%	25.8	18%	1,379	588	15.8	1,352
Cardiff	336.2 (13%)	47.30%	28.6	16%	1,494	444	17.9	1,180
Newport	140.45 (17%)	41.60%	26.5	16%	831	592	16.9	1,317
Neath Port Talbot	137.4 (19%)	39.40%	27.2	15%	843	613	16.6	1,172
Caerphilly	172.7 (16%)	40.90%	26	15%	961	556	16.5	1,412
Swansea	231.3 (18%)	42.40%	24.8	12%	1,275	551	15.4	1,203
Bridgend	134.2 (18%)	42.30%	27.7	11%	856	638	17.4	1,453
Denbighshire	96.7 (21%)	42.50%	27.6	10%	608	629	17.5	1,473
Torfaen	90.7 (18%)	39.20%	26.5	7%	575	634	16.8	1,476
Wrexham	133.2 (17%)	48.20%	25.8	6%	751	564	16.4	1,551
Vale of Glamorgan	124.6 (18%)	45.30%	28.9	6%	700	562	18.2	1,322
C'arthenshire	180.8 (21%)	41.40%	26	5%	1,135	628	16.6	1,477
Gwynedd	118.8 (20%)	43.70%	23.9	4%	765	644	15.2	1,626
Flintshire	149.9 (17%)	48.50%	27.8	4%	879	586	17.8	1,472
Pembrokeshire	117.4 (21%)	43.30%	27.9	4%	789	672	17.6	1,829
Conwy	111.4 (24%)	42.30%	22.6	3%	871	782	14.2	1,747
Isle of Anglesey	68.8 (21%)	41.70%	25.4	2%	501	729	16.3	1,654
Powys	131.7 (22%)	43.80%	22.5	1%	926	703	14.1	2,556
Ceredigion	76.4 (21%)	43.10%	22.8	0%	389	509	14.7	1,934
Monmouthshire	88 (20%)	45.40%	24.6	0%	538	612	16	1,581