

**WE ARE
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CANCER SUPPORT**



**CANCER
COSTS**

**The hidden
price of getting
treatment**

'Petrol and parking were just another thing to deal with on top of organising someone to look after the children, worrying about picking them up and dealing with my cancer.'

The hidden price of getting treatment

Many cancer patients and their families are dealing with a huge financial burden as a result of their illness. One year on from the publication of Macmillan's report *Free at the Point of Delivery?*, our new research reveals that the financial picture for people with a cancer diagnosis has not improved at all. Nine out of 10 cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer.

This research, the result of more than 1,100 interviews with people affected by cancer, reveals that:

- The most widespread cost facing cancer patients is the cost of travel to and parking at hospital.
- On average patients who incur these costs make 53 trips, costing £325 during the course of their treatment.
- Far too many cancer patients are not made aware of the help that may be available to them, such as through the Hospital Travel Costs Scheme or the NHS Low Income Scheme.

Background

Macmillan Cancer Support launched its Better Deal campaign to focus attention on one, largely unrecognised, side effect of cancer: its impact on patients' financial situations.

Our earlier report, *Free at the Point of Delivery?* published in July 2005, provided qualitative evidence of the hidden cost of travelling to and parking at hospital for cancer patients undergoing treatment. This new piece of work builds on the first. It reinforces the seriousness of the financial pressure faced by cancer patients at a time when they, their families and carers are already coping with the strain of a cancer diagnosis and the debilitating effects of treatment.

Why prioritise travel and parking costs?

Travel and parking costs are a serious issue for cancer patients for three reasons:

- These are the most widespread extra costs faced by people affected by cancer.
- Existing schemes are not working for cancer patients.
- Many more people are travelling for cancer treatment; they usually have no alternative but to travel by car.

Key findings

- 91% of cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer.
 - Most cancer patients' households face additional costs, nearly four in 10 (36%) also suffer a loss in income.
 - The picture is even more serious among under 55s where seven out of 10 suffer a loss in household income.
 - Among those suffering a loss in household income, the average fall is 50%.
 - 70% of cancer patients face extra costs just to get to their treatment.
 - 58% face travel costs to hospital/treatment centre
 - 45% face parking costs whilst having treatment.
- The combined impact of the cost of travel and parking means that seven out of 10 patients find themselves out of pocket simply by going for their treatment. This is alongside other costs which can include higher utility bills, special diets, clothing, wigs and prescription charges.
- Among patients incurring travel costs, the average number of trips made in the course of their treatment is 53. The average overall cost for travel and parking is £325 per patient.
 - Our research revealed actual costs for travel and parking, whilst receiving treatment, range from

less than £10 to in excess of £10,000.

The amount a patient pays is dependent on a range of factors including the type of treatment required and the length of time they are ill.

- **There are significant variations in the cost of travel and parking across the UK.**
Our research has highlighted the range in travel costs across the country. When combined with the number of trips they have to make this can have a significant impact on the overall cost to patients. This can be seen in the results for the South West, where a number of patients have been ill for some time and as a result accumulated huge costs (see Figure 1).
- **78% of those incurring travel and/or parking costs have received no financial help with these costs.**
Of those who do get help, significant numbers rely on help from charity grants or friends and family, rather than existing government schemes.
- **Two-thirds of those who are not getting help with travel and parking costs are unaware of schemes that exist to help with these costs.**
This is despite government guidance which states hospitals should publicise these to patients.

One-third of patients said that they were finding it more difficult to make provision for their future, including paying into their pension. Others reported that they had fallen behind with their mortgage payments, credit card bills or run up other debts. Others had problems supporting their children financially or have had to move to a cheaper home.

Problems with travel and parking

In *Free at the Point of Delivery?* we outlined the existing help that is available to patients on low incomes and discussed the discounts and exemptions available to patients parking at hospital.

Existing schemes

NHS patients who receive specified means-tested benefits are entitled to reimbursement of their travel and parking costs under the Hospital Travel Costs Scheme (HTCS). There are equivalent schemes in each of the devolved nations. In Scotland there is also a separate non-means tested scheme for residents of the Scottish Highlands and Islands.

Guidance on these schemes advises hospitals to display information in patient areas and to advise patients in appointment and admission letters.

Difficulties accessing statutory support

Evidence from *Free at the Point of Delivery?* indicated that only 19% of health professionals reported that patients were being informed about the schemes in line with the guidance. The methods of claiming back travel costs could also be bureaucratic and stressful for patients undergoing cancer treatment.

	Average number of trips	Travel cost per trip (£)	Parking Cost (£)	Percentage also incurring parking costs	Average total cost (£)
North	41	5	2	56	250
Midlands/East	47	5	2	68	298
London/South East	64	5	3	62	439
South West	101	7	2	46	792
Wales	50	4	2	29	229
Scotland	37	10	2	34	395
Average	53	5	2	57	325

Figure 1; Regional variations in travel costs

*The sample in Northern Ireland was too small to provide robust data.

'I have been travelling back and forth to hospital for the past eight months... the car park costs £3 an hour and I am usually there for two hours or more. The alternative to driving is to take a taxi but that costs £10 a time anyway. It got to the point where it was so expensive that it was raising my anxiety levels.'

Our new research indicates that:

- only 4% of those facing travel and/or parking costs receive help through existing schemes
- two-thirds of those not getting help with these costs were unaware that these schemes existed.

Public and patient transport are unsuitable

The Government has suggested that patients with a medical need for transport can have their travel needs met through Patient Transport Services. However, *Free at the Point of Delivery?* demonstrated that this isn't suitable for most cancer patients because of the lengthy journeys involved where patients are often picked up at the beginning of the day and dropped off at the end of the day. Public and patient transport is also unsuitable for cancer patients who have a compromised immune system as a result of their treatment or who are suffering the side effects of chemotherapy and radiotherapy, such as nausea and fatigue. The report did however highlight the use of ambulance cars as an option for cancer patients.

Charging cancer patients for parking

In 2005 Macmillan carried out an audit of car parking charges and policies at the main cancer centres across the UK. We found considerable variations in the exemptions and reductions available. Patients are travelling on average 53 times so even a small charge makes a huge difference. Although many hospitals provide some form of discount scheme, these are not always publicised and often do not cover all patients travelling regularly for treatment.

Of those with car parks only

- 3 of the 43 cancer centres in England
- 1 out of 3 in Wales
- 1 out of 5 in Scotland and
- 0 out of 1 in Northern Ireland

provide free parking for all cancer patients attending appointments.

More patients travel regularly for treatment

The treatment for cancer differs from that for most other diseases: it often requires frequent trips to hospitals or treatment centres. More cancer patients are now treated as outpatients. A typical course of radiotherapy could involve a daily trip to hospital on every weekday for several weeks. Radiotherapy is usually delivered in specialist treatment centres, which serve a large catchment area. While there are undoubted benefits to this concentration of expertise, a consequence is a lengthy and expensive journey for many patients.

NHS Savings

Over recent years, hospitals have made huge savings by delivering cancer treatment on an outpatient basis. They have also generated additional revenue from introducing, and then increasing, parking charges. Both of these changes have effectively shifted some of the burden of the costs of cancer onto patients.

The influential NHS Modernisation Agency¹ has estimated that trusts could save £200 a day from treating patients through day surgery rather than as inpatients. Macmillan estimates that a hospital could, therefore, save £6,000 by delivering a six-week course of radiotherapy on an outpatient basis. A small fraction of these savings could be used to help cancer patients with their travel costs.

Good practice example: Churchill Hospital, Oxford

All radiotherapy and chemotherapy patients receive a parking permit to display in their cars to enable them to park for free (the standard rate for parking at the hospital is £3).

Patients are told about the parking permits at their initial planning appointment before they start treatment.

The hospital recognises the importance of supporting cancer patients with their parking costs.

1. NHS Modernisation Agency, 10 High Impact Changes for service improvement and delivery: a guide for NHS leaders (September 2004).

ROBIN'S STORY



Robin Reid

I was diagnosed with laryngeal cancer in October 2000. I made 60 trips to hospital in total and always went by car as it was so much more convenient and economical than taking public transport. If I had taken the train I would have had a long walk or taxi ride from the station. It was a 16-mile round trip and cost me £1.50 in petrol each time.

Before I started my course of radiotherapy I had to visit the hospital for biopsies, scans and consultations. On these occasions we had to load up the parking meter as we didn't know how long we would be and there were signs up warning about clamping. On five occasions we spent £15 a day on parking.

My course of radiotherapy consisted of 33 sessions – I had to drive in and park every weekday for six weeks. As well as the £1.50 on petrol costs for each trip I had to pay £2 for parking each time. But when I was half way through the course of radiotherapy I heard two other patients talking about parking permits – they told me that if I was having radiotherapy I could get a pass that would entitle me to free parking. I did this for the rest of my treatment, although I couldn't use it when I was going for scans or consultations or surgery. I wish I'd known about it before, but it hadn't been advertised anywhere in the hospital.

In total I spent over £250 in just a couple of months just to get me to hospital so I could receive treatment for my cancer. This had a real impact on my financial situation, particularly as I am self-employed and couldn't work at the time. When I found out that I was to have further surgery I decided to draw on my pension plan as I didn't want to have to worry about all that again.

CALLS TO ACTION

Tackling travel and parking costs

Travel and parking costs affect many cancer patients at a time when they can least afford it. Their income is often depleted and they are dealing with the stress and anxiety of the disease and its treatment. Tackling these costs will make a huge difference to their lives.

Review assistance with travel and parking costs

We believe that it is morally wrong that any cancer patient – regardless of income – who is undergoing regular treatment for a potentially life-threatening disease should be forced to pay for unavoidable travel and parking costs. Our vision is that all patients undergoing treatment for cancer should be eligible for assistance on a non means-tested basis under the Hospital Travel Costs Scheme and its equivalents.

There is an urgent need for a review of the financial assistance available for patients travelling for treatment. This review should consider:

- current levels of take-up
- publicity and awareness of the schemes
- reimbursement procedures
- the effectiveness of guidance for hospitals

- regional variations in travel and parking costs
- whether people with cancer are being treated fairly in relation to other groups of disabled people and people without disabilities
- the availability of ambulance cars for patients with a compromised immune system.

Remove parking charges

We believe that cancer patients travelling regularly for treatment should not have to pay for parking. We are calling on all hospital trusts and health boards to consider the impact of their parking policy on cancer patients under the Disability Equality Duty of the Disability Discrimination Act 2005.

Remove tolls

Patients travelling to hospital for cancer treatment should be exempt from all charges and tolls for using roads, tunnels and bridges.

Macmillan's campaign

It is important that policy makers understand the difficulties cancer patients face. We are encouraging people affected by cancer to contact their elected representatives to tell their story and urge them to take this issue up with ministers.

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Research objectives

The objectives of the research were to explore:

- the overall financial impact of cancer
- awareness and take-up of benefits designed to help with some of these costs
- the consequences for cancer patients.

Research methodology

Macmillan commissioned an independent research agency, RDSi, to carry out this work.

Just over 1,100 people affected by cancer were interviewed; of these, 942 were patients, the rest were carers. The vast majority of the interviews were conducted by a 15-minute telephone interview; a few respondents were unable to take part in a telephone interview and completed a postal survey. Interviewing took place between November 2005 and February 2006.

The sample of respondents was generated by Macmillan issuing requests for volunteers to take part. To ensure that this did not bias the type of volunteers and thus responses, the requests described the survey in very general terms and did not mention that it would focus on the financial impacts of cancer. The sample achieved was weighted by national statistics for the cancer population (gender, age and type of cancer) to ensure that it was representative of the national picture.

Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ
Tel 020 7840 7840 Fax 020 7840 7841 www.macmillan.org.uk

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Macmillan Cancer Support is the trading name of Macmillan Cancer Relief, registered charity number 261017. Isle of Man charity number 604.

MAC4031

Ayesha Owusu-Barnaby
Katie Austin
Amanda Fallows, Erda Ltd.
RDSi