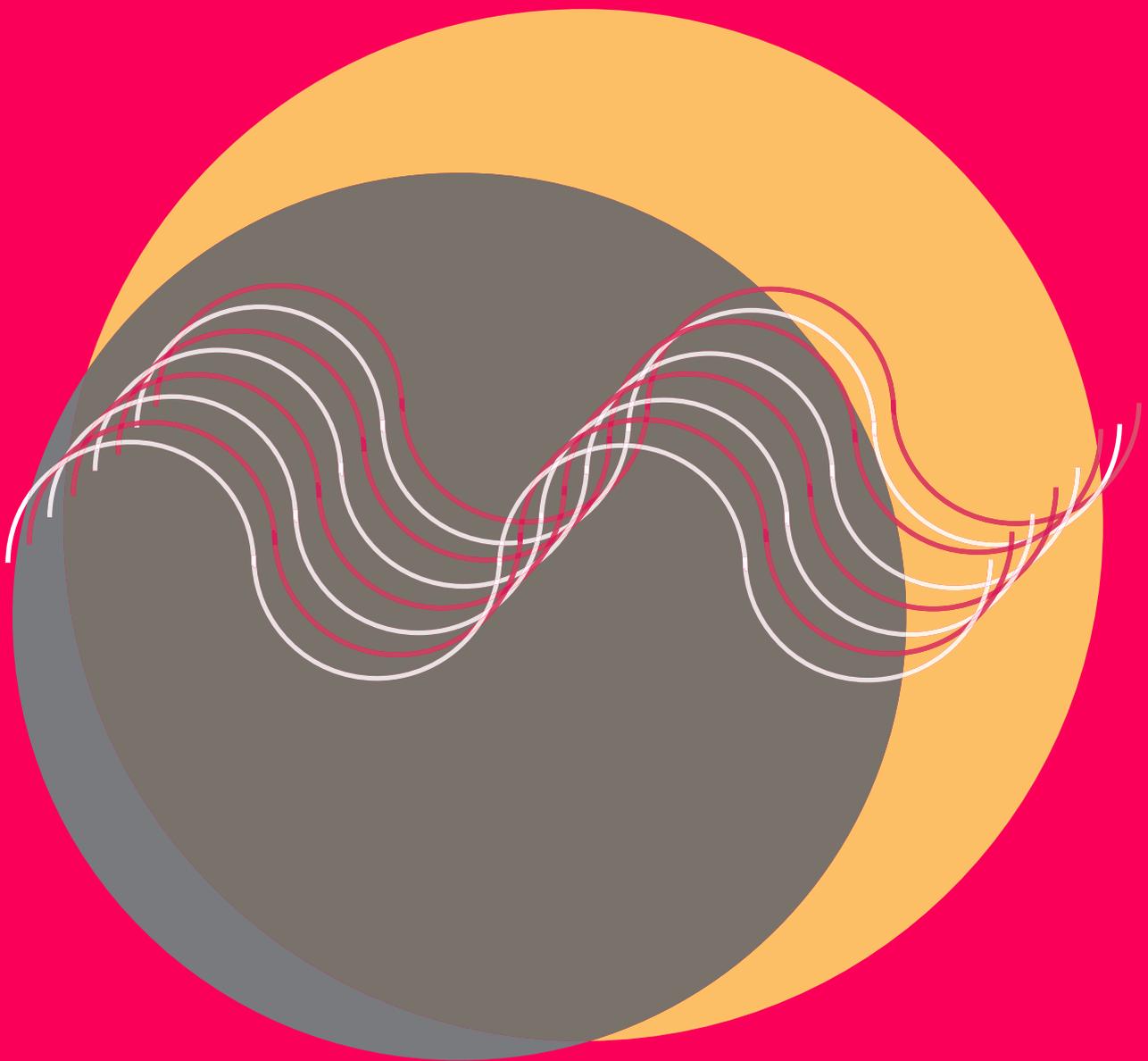


DEMOS

Cancer Costs

A 'ripple effect' analysis
of cancer's wider impact

Sacha Hilhorst
Alan Lockey



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Sacha Hilhorst and Alan Lockey
2019.

Executive Summary

There are now 2.5 million people living with or beyond cancer in the UK.¹ By the year 2030 this figure could be as high as 4 million.² This is a wonderful, joyous fact – the product of ten-year survival rates more than doubling since the 1970s.³ We can perhaps begin to dream of a time and society where cancer is viewed merely as another largely treatable disease.

Yet this welcome story should not obscure two important challenges. First, that despite the upward trajectory of UK cancer survival rates, our cancer outcomes still lag behind most comparable European countries.⁴ Second, that as more and more people survive cancer, the main thrust of cancer policy must also change. It is no longer acceptable to view cancer policy predominately, if not exclusively, through a healthcare lens. With more people surviving, our support systems – whether they are in state, market or society – need to catch up with the modern reality of cancer as a survivable rather than terminal illness. Policymakers now need to focus on a simple question: how can we help those affected by cancer – patients, families and communities - to live freer and more fulfilling lives?

This second challenge is the primary focus of this report. However, given that in 2018 the Government has recently outlined a new cash injection of £20.5 billion extra funding for the NHS⁵ it also seems an opportune moment to remind policymakers just how far the UK falls behind other comparable countries in terms of cancer spending. Therefore, we recommend:

Recommendation One: The Government should commit to a target that requires

NHS spending on cancer to match the European average by 2030. This equates to an extra £2.1 billionⁱ a year.⁶

To assess the broader impact of cancer we developed a ‘ripple effect’ methodology that encompasses both qualitative and quantitative elements: a comprehensive literature review of the personal, social and economic costs of cancer in England; an exploratory quantitative survey in which 227 participants shared insights about the effect cancer has had on themselves and their loved ones; and ten in-depth, semi-structured qualitative interviews with current cancer patients and cancer survivors. Unsurprisingly, we find that cancer has an impact on virtually all domains of life: the effect of the disease ripples out as spouses take time off work, children require mental health support, and organisations miss an employee. More challengingly, we find that gender, region and age significantly shape the cancer experience, with women, freelancers and people over 55 hit particularly hard economically.

In summary, we find:⁷

- Forty-eight per cent of cancer patients make structural changes to their working patterns because of their illness;
- Fifty-three per cent of cancer patients see their income fall at least one income bracket;
- Young people (under 35) and people approaching pension age (55-64) were most likely to see a decline in their financial health because of cancer, at 67 and 60 per cent respectively;

i. UK spend per capita in 2014 on cancer was €128. This amounts to a total cancer spend = £6,697,396,224, based on the 2014 UK population and a mid-year €/£ exchange rate of 0.81. The European average spend on cancer was €169. This amounts to total cancer spend of = £8,842,655,952. Therefore, the UK would have to spend an extra £2,145,259,728 to match the European average.

- Twenty per cent of cancer patients were supported by a family member or friend who had changed their working patterns to offer care;
- Over three in four (76 per cent) describe the impact of cancer on their family life as very or moderately negative, while 10 per cent indicate the impact has been positive;
- Two in three (66 per cent) say cancer has had a negative impact on their family's social life;
- Support from the NHS and from charities was generally assessed very positively by patients, receiving average marks of 7.4 and 8.2 out of 10 respectively.

Drawing on this research and the existing evidence, we are also able to calculate a total economic cost of cancer to the economy in terms of lost wages and benefits of at least £1.4 billion a year, rising to £7.6 billion a year if we take into account mortality.ⁱⁱ

Furthermore, given the on-going fiscal pressures facing the public purse, we focus our recommendations either on policies that are cost-neutral or that could feasibly be delivered through existing departmental spending limits. Therefore, to help mitigate the ripple effect and allow those affected by cancer to live free and fulfilling lives, we recommend:

Recommendation Two: The NHS should fully commit to personalised care. To this end, STPs and ICSs should set out plans to meet their 2021 targets and ensure that financial wellbeing is an integral part of these strategies.

Recommendation Three: Alongside implementation, Macmillan should

ii. For full calculations see Appendix B.

begin reviewing the Recovery Package to explore what interventions might be extended to cancer patients' carers and families. Beyond 2020, the Holistic Needs Assessment should be extended from cancer patients exclusively, to also include their carers and families, as an early intervention touchstone for meeting their psychological needs.

Recommendation Four: All cancer patients should be entitled to one free relationship counselling session with their spouse or family.

Recommendation Five: The Government should trial the Finnish model of part-time sick leave entitlements for cancer (and other seriously ill) patients that have to work less in order to manage their illness, with a view to implementing this model across the whole welfare state.

Recommendation Six: The Government should put carers leave on a statutory footing, with all employees entitled to ten days paid carers leave a year. Companies should be responsible for drawing up their own eligibility assessment criteria.

Recommendation Seven: The Government should legislate to make terminal illness a protected characteristic, protecting workers from unfair dismissal as per the TUC's 'Dying to Work' campaign.

Recommendation Eight: The Government should implement the full agenda of self-employed financial inclusion policies outlined in the Demos report *Free Radicals*, including: state subsidised auto-enrolment, introducing more flexibility to the lifetime ISA for self-employed workers, pushing forward with the NEST 'sidecar' model (for the new auto-enrolment scheme), and using its convening power to explore collectivising income protection schemes to make them more financially viable

(and accessible for self-employed cancer patients in particular).

Recommendation Nine: The Government should extend the 25% tax-free lump sum pensions freedom to diagnosed cancer patients under the age of 55 at no further cost or change to their pension status.

Recommendation Ten: All terminally ill citizens should be able to draw their pension down in full, tax-free – there should be no penalty for previous drawdowns.

Recommendation Eleven: The Government should invest £25m in community transport connected to healthcare visits. This should come from existing Department of Health and Department of Transport budgets as a joint fund.

Recommendation Twelve: The Government should pilot a new cancer specific retraining programme, as part of the new National Retraining Partnership. This pilot should pay particular attention to re-training women with cancer.

Introduction

Jim Valvano, the renowned US college basketball coach cum cancer activist, once said that “cancer can take away all of my physical abilities. It cannot touch my mind, it cannot touch my heart, and it cannot touch my soul.”⁸ Unfortunately, Jim was wrong: cancer can touch your mind – there are a growing number of cancer patients with mental health comorbidities.⁹ And alas, if loving relationships are the currency of hearts and souls, then cancer can wreak an enormous emotional toll upon them too.

This report aims to explore this multi-faceted cost of cancer and document the impact it has upon all the lives it touches – patients, survivors, carers and family members. A great deal of this is economic – a previous Demos investigation, drawing on research from the University of Bristol, found that cancer patients were on average £570 a month out of pocket following their diagnosis.¹⁰ What is more, this economic impact can have a perniciously long tail – cancer survivors, often disadvantaged in the workplace, can find themselves wrestling with the financial aftermath long after their physical health has recovered. This leads to many cancer survivors not fulfilling what economists might call their productive potential, with a sizeable knock-on effect on the national, as well as the family, finances.

Yet of course cancer’s full cost is so much more than that measurable in pounds and pence. The emotional shock of a diagnosis, for entirely understandable reasons, can be enormous. Meanwhile, physical wellbeing, mental health and even civic participation can all take a body blow as debilitating treatments sap a patient’s previous lust for life. Not just for patients either – it is no surprise that family and friends also face emotional turmoil when bearing witness to their loved one’s illness. And then there is the considerable stress and pressure that informal caring relationships can also place upon a family. The bottom line is that cancer - living with it, surviving it, recovering from it, or caring for someone with it – is tough. Tough physically, tough financially, tough emotionally - the ‘ripple effect’ of its costs can be felt in families, firms and communities everywhere in Britain. This report attempts to capture the full nature of that cost for the first time, bringing the lived experience of those affected by cancer to the public policy debate.

For the truth is that tackling cancer’s cost is also an increasingly urgent public policy challenge. There are now 2.5 million people living with or beyond cancer in the UK.¹ By the year 2030 this figure could be as high as 4 million.² And make no mistake: this is a wonderful, joyous fact – the product of ten-year survival rates more than doubling since the 1970s.³ We should, perhaps, finally allow ourselves to dream of a society that sees cancer as just another largely treatable disease. Yet as more and more people survive cancer, more and more pressure is placed upon our existing ‘survivorship’ recovery services. This means the main thrust of cancer policy must also change. For a long time, cancer policy has been seen predominantly, if not exclusively, through a healthcare lens – a task of eradicating illness and, where this proved impossible, offering palliative care and support. These concerns should, obviously, continue – there is much work to be done on cancer survival rates and in this, sadly, the UK continues to compare unfavourably to many similar European countries.⁴ However, alongside this we now need a greater

emphasis on supporting families through their journey with cancer. With more people surviving, our support systems – whether they are in state, market or society – need to catch up with the modern reality of cancer as a survivable rather than terminal illness. Policymakers need to focus on a simple question: how can we help those affected by cancer to live freer and more fulfilling lives?

In Chapter Five of this report we outline some first thoughts about how this might be achieved, while in Chapter One we briefly sketch out the policy background, focusing on the UK's cancer strategy in healthcare and the existing welfare entitlements for cancer patients. Meanwhile, in Chapters Two to Four we present our 'ripple effect' analysis of cancer's true cost.

This 'ripple effect' methodology encompasses both qualitative and quantitative elements: a comprehensive literature review of the personal, social and economic costs of cancer in England; an exploratory quantitative survey in which 227 participants share insights about the effect cancer has had on themselves and their loved ones, including data on earnings, work changes and some open questions on social impact; and ten in-depth, semi-structured qualitative interviews with cancer patients and their survivors. Chapter Three sets out our findings from the comprehensive literature review, while Chapter Four and Five draw on our exploratory survey focusing, respectively, upon the economic and social costs. Furthermore, we have summarised our in-depth, semi-structured interviews that are scattered throughout this report. Personal details – names, ages, hometowns – have been altered and fully anonymised in order to protect the anonymity of our participants.

Further details about our research methodology can also be found in Appendix One and Two.

Policy Background

This chapter briefly sets out the range of existing support for cancer patients and the policy context in which they currently access services.

Cancer and health policy

In March 2015, the Cancer Taskforce put out a straightforward statement:

“[If] we continue with current approaches to funding and delivery of cancer services, we will be unable to meet demand, NHS resources will be spent inefficiently, and patients will not receive the standard of care that they rightly deserve.”¹¹

As the statement implies, mortality rates from cancer are higher in the UK than in many other European countries (see table one). In acknowledgement of this, the Taskforce produced a set of recommendations for the NHS to meet from 2015 to 2020, with an ambition to improve the prevention, diagnosis and treatment of cancer. Among other things, the Strategy suggested the UK should improve early diagnosis and expand treatment options, as well as improving quality of life. If successful, the authors of the Taskforce claimed, an additional 30,000 patients a year would be surviving cancer for 10 years or more.¹²

| Five year survival rate by Cancer Type (2010 - 2014) | | | |
|--|----|-------------------------------|------|
| Cancer Site | UK | Cohort average ⁱⁱⁱ | Best |
| Breast | 86 | 87 | 90 |
| Colon | 60 | 65 | 71 |
| Pancreas | 7 | 10 | 12 |
| Lung | 13 | 18 | 27 |

Table One²¹

Having said this, it is easy to forget that cancer care has made immense strides over the past two decades. Cancer policy as we know it arguably dates back to the New Labour government’s introduction of cancer targets in the year 2000. Alongside a dramatic increase in NHS funding, the new NHS Cancer Plan introduced a series of performance measures that both the NHS and government would then be accountable for delivering.¹³ The introduction of the target-based approach, alongside much-needed improvements to diagnostic tools and medication, correlates with a steady rise in survival cancer rates since 2001, with increases of over ten per cent in one-year survival rates for cancers such as liver, kidney and lung cancer (see table three).¹⁴

iii. Cohort includes (besides the UK) Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Ireland, Japan, Netherlands, New Zealand, Portugal, Spain, Sweden and the U.S.

| | Cancer Spend By Country | |
|----------------|--------------------------|----------------------------------|
| | % Total Healthcare Spend | € Spend per Capita ^{iv} |
| Luxembourg | 6.2 | 311 |
| Switzerland | 6.2 | 292 |
| Germany | 6.8 | 255 |
| Netherlands | 5.7 | 243 |
| Austria | 6.5 | 242 |
| Sweden | 6.8 | 219 |
| Belgium | 6.2 | 216 |
| France | 6.2 | 203 |
| Europe | 6.0 | 169 |
| Norway | 3.4 | 159 |
| Denmark | 4.5 | 156 |
| Italy | 6.7 | 155 |
| Ireland | 5.0 | 152 |
| Slovenia | 6.7 | 137 |
| Malta | 6.5 | 132 |
| Spain | 5.8 | 130 |
| United Kingdom | 5.0 | 128 |
| Greece | 6.5 | 126 |
| Finland | 4.4 | 119 |
| Iceland | 3.8 | 107 |
| Slovakia | 6.2 | 104 |
| Cyprus | 6.3 | 103 |
| Hungary | 7.0 | 102 |
| Czech Republic | 5.4 | 84 |
| Croatia | 6.9 | 80 |
| Poland | 6.5 | 79 |
| Lithuania | 6.2 | 77 |
| Portugal | 3.9 | 76 |
| Bulgaria | 6.8 | 65 |
| Estonia | 5.8 | 65 |
| Latvia | 6.2 | 64 |
| Romania | 6.8 | 53 |

iv. Adjusted for purchasing power.

Table Two⁶

The 2015-2020 Strategy is designed to speed along this upward trajectory. The latest progress report on the Strategy marked the halfway point and, according to the NHS National Cancer Programme, the strategy remains on track. Objectives include improving access to new cancer treatments through a reformed Cancer Drugs Fund, replacing radiotherapy equipment at the end of its life cycle, rolling out a national molecular diagnostics service, and dealing with workforce pressures.¹⁵ Investments have been made into cancer services, in particular a £130 million investment in new radiotherapy equipment and £200 million worth of funding to accelerate rapid diagnoses¹⁵ - which represents a seven per cent increase in spending on diagnostic activity to catch cancer in its earliest stages.¹⁶ The progress report also revealed that 17 new drugs were being funded under new interim Cancer Drugs Fund arrangements, which have been used to treat around 2,300 additional patients.¹⁵

Although the majority of cancer patients do still receive their assessments and treatments within the targeted time lines, NHS England has been struggling to meet its overall performance targets in recent years. The 14-day referral and one-month diagnosis targets are currently being met at the time of writing, with 95 per cent of patients and 97.6 per cent patients receiving these outcomes respectively.¹⁷ However, last year (February 2018) NHS England missed the two months from urgent referral to treatment target, with only 84.2 per cent of patients receiving treatment within this time frame.¹⁸ This meant that over 25,000 people had to wait over two months for treatment after urgent referrals, with over 10,000 waiting more than three months.¹⁸ In fact, the last time the two-month referral-to-diagnosis target was met was December 2015.¹⁹

Speeding up diagnoses will be essential to improving UK cancer outcomes, as survival rates continue to lag behind those of other European countries.²⁰ A recent wide-ranging study in *The Lancet* revealed that the UK was often in the bottom half of the cancer survival tables.²⁰ On the five-year survival rates for four key cancer types – breast, colon, pancreas and lung - the UK currently trails on the average for wealthy countries (see table one).²¹ One contributing factor for this could be a supply shortage in specialist cancer staff. In 2017, the NHS in England had 162 specialist cancer nurse posts and 157 chemotherapy nurse posts vacant.²² The NHS has openly recognised this problem and, as part of the December 2017 Cancer Workforce Plan, will attempt to employ more specialists in order to speed up diagnosis times.²³

Furthermore, at the moment, the UK's spend on cancer per capita is well below the European average. Research by the Institute of Health Economics (IHE) demonstrates that UK spend on cancer is roughly half of what Germany spends per person (see table two).^{v. 6} Indeed, even the newly promised NHS funding boost is unlikely to bring change. The UK would have to spend roughly an extra £2.1 billion a year to match the European average.^{vi} This amounts to 51 per cent of the extra £4.1 billion, which will be allocated to NHS from next year onward. To state the obvious, this seems unlikely - typically, the UK spends five per cent of its healthcare budget on cancer.⁶

v. The most recent data is from 2014 and, therefore, does not include the funding changes following the 2020 Strategy.

vi. UK spend per capita in 2014 on cancer was €128. This amounts to a total cancer spend = £6,697,396,224, based on the 2014 UK population and a mid-year €/£ exchange rate of 0.81. The European average spend on cancer was €169. This amounts to total cancer spend of = £8,842,655,952. Therefore, the UK would have to spend an extra £2,145,259,728 to match the European average.

| One and Five Year Survival Rates in the UK | | | | | | |
|--|-------------------|-------------|----------|--------------------|-------------|----------|
| | One Year Survival | | | Five Year Survival | | |
| Cancer Site | 2001-2005 % | 2011-2015 % | % Change | 2001-2005 % | 2011-2015 % | % Change |
| Skin | 96 | 98 | +2 | 85 | 92 | +7 |
| Prostate | 93 | 96 | +3 | 79 | 88 | +9 |
| Breast | 93 | 96 | +3 | 78 | 86 | +8 |
| Uterus | 86 | 90 | +4 | 71 | 77 | +6 |
| Cervix | 77 | 81 | +4 | 54 | 61 | +7 |
| Bladder | 75 | 75 | = | 54 | 56 | +2 |
| Colorectum | 73 | 78 | +5 | 51 | 61 | +10 |
| Non-H. Lymphoma | 70 | 79 | +9 | 52 | 67 | +15 |
| Myeloma | 69 | 81 | +12 | 34 | 51 | +17 |
| Kidney | 63 | 77 | +14 | 45 | 61 | +16 |
| Leukaemia | 62 | 70 | +8 | 41 | 53 | +12 |
| Ovary | 60 | 71 | +11 | 31 | 43 | +12 |
| Stomach | 39 | 47 | +8 | 15 | 20 | +5 |
| Oesophagus | 36 | 46 | +10 | 11 | 17 | +6 |
| Lung | 28 | 39 | +11 | 7 | 15 | +8 |
| Brain | 26 | 38 | +12 | 8 | 12 | +4 |
| Liver | 23 | 36 | +13 | 6 | 12 | +6 |
| Pancreas | 16 | 24 | +8 | 3 | 7 | +4 |

Table Three¹⁴

Finally, the UK also trails behind comparable countries on the breadth and uptake of its investment in new cancer drugs. The IHE analysed the spending of European countries on the newest cancer drugs – defined as those launched within the last three years. Total sales of these drugs amount to around five per cent of the UK cancer drug market, compared to a continent-wide average of eight per cent overall. ⁶

Survivorship

There are now over 2.5 million cancer survivors in the UK,¹ with the figure expected to approach 3 million by 2020 and 4 million by 2030.² In recognition of this, the NHS has started to increase its focus upon the broader health and wellbeing impact of cancer. For example, people living with or after cancer often have on-going chronic (rather than acute) symptoms that can then impact their long-term work and wellbeing prospects.

Launched in 2007, the National Cancer Survivorship Initiative (NCSI) found that many cancer survivors have unmet needs, and are not supported well enough to handle the end and consequences of their treatment.²⁴ The NHS is now starting to address these concerns by implementing the comprehensive model of personalised care, which includes “a proactive and universal offer with long-term physical and mental health conditions”.²⁵ The NHS long-term plan also includes the ambition that by 2021, all people diagnosed with cancer should receive an offer of an early conversation after diagnosis, a holistic needs assessment and a personal care plan.²⁶ This is an ambitious aim, and a crucial step towards personalised cancer care for all patients. It ought to be a priority for all Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs).

The cancer charity Macmillan runs a variety of additional programmes that attempt to improve the quality of life for people beyond cancer. For example, the Macmillan Living With And Beyond Cancer Programme focuses on the experiences of those with the most common types of cancer in the UK - breast, colorectal or prostate - and will aim to develop new services resulting in fewer hospital visits for patients, more convenient care locations, and more personalised information for patients.²⁷ Indeed, throughout the wider third sector, cancer patients can receive grants, advice on finances, help with transportation, and help paying for their energy bills through Macmillan’s npower programme. Macmillan also runs a widely advertised, ‘one stop shop’ cancer support phone line, often staffed by trained experts in healthcare (nurse specialists), benefits, energy advice and financial planning.²⁸

George and Jillian

George is 76 years old and lives with his 77 year old wife, Jillian near Dundee. He was initially diagnosed with essential thrombocythemia (a form of blood cancer) in 2013. In 2017, a diagnosis of prostate cancer followed. The two are retired university lecturers on full-salary pensions and have two daughters in their forties. One lives close by, and the other very far away.

Given that both George and Jillian are both on final salary pensions which have made their financial situation relatively comfortable, George's contribution towards the household income has been unaffected by cancer. He believes that had this not been the case "life would be very, very different" and feels that his academic background allowed him to cope far better with his diagnosis. He used the research literature to inform himself about his cancer. This was further helped by his involvement with the cancer charities, MPN Voice and Bloodwise who offered a platform for him to discuss his condition with other patients.

From a financial perspective, George doesn't believe that the costs incurred since his diagnosis have had any tangible detrimental effects on himself or his family. He also found the costs of getting to the hospital for appointments to be rather trivial. "We both have bus passes and usually just drive to the park and ride on the edge of Dundee and get the free bus from there up to the hospital, which fits in with what we're doing anyway because quite often we go shopping after or before. So it's no real extra cost."

Although George himself took the news of his diagnosis quite well, his wife and eldest daughter were very concerned, as both had lost close friends and family members to cancer. George decided to send his daughter the research literature he had been reading, as his daughter was also a scientist. This, he felt, had reassured her.

Welfare Entitlements

Understandably, cancer patients receive a variety of welfare entitlements although none are cancer specific. In other words, their eligibility ultimately depends on whether their condition affects their ability to work or changes their disability status.

If cancer does affect a citizen's ability to work, they could be entitled to: statutory sick pay; occupational or company sick pay; working tax credits (which are due to be phased out for universal credit in 2019) and employment support allowance, which is the primary benefit for those unable to work because of ill health or disability.²⁹ Tax refunds are also available for those who have given up work entirely and, as such, may have overpaid tax.³⁰

Furthermore, cancer patients are also protected under the Equality Act 2010 (England, Scotland and Wales) and Disability Discrimination Act 1995 (Northern Ireland) from discrimination at work based on their illness.³¹ Dependent on an assessment, cancer

patients may also qualify for the Personal Independence Payment (PIP) if they have a long-term disability³², or for the Attendance Allowance, if they are over 65 and need an attendant. The assessment is waived for people who are terminally ill (defined as less than six months to live).³³

Both Employment and Support Allowance (ESA) and, more recently, PIP represent significant welfare reforms, with both representing an increase in conditionality and decrease in generosity from the entitlements they replaced (incapacity benefit and disability living allowance, respectively). Yet irrespective of any fiscal and social justice merits, it is fair to say that cancer patients have also widely criticised the implementation process of the reforms.³² Initially, people with cancer were placed in the “work related activity group” of ESA after one year from diagnosis, meaning that their on-going entitlements were conditional upon receiving training and other activities to improve their employment prospects. In effect, this meant that cancer patients could be receiving debilitating treatments such as chemotherapy and, in some cases, even be terminally ill and yet find their entitlements conditional on attending a welfare-to-work programme. Yet after this situation became something of a political scandal, the eligibility rules were changed so that such people are now placed in the “support group” (i.e. their ESA is both more generous and unconditional) as soon as they make and evidence their claim.³⁴

The rollout of PIP fared little better than the ESA implementation several years prior. As it stands, around 56,000 cancer patients currently receive PIP,³⁵ though this is probably an underestimate (PIP statistics are classified by their primary eligibility and, unusual though it sounds, cancer maybe a secondary condition for other eligible classes such as chronic fatigue syndrome). When the benefit was rolled out in 2014, a survey by Macmillan found the average wait time for new claimants was four and a half months – double the time for Disability Living Allowance (DLA).³² Indeed, with more than half waiting over three months and one in four patients waiting at least six months from the point at which they first needed PIP to the time they found out if they would receive it or not. This leads to numerous horror stories in the media of patients having to choose between eating or heating, and even, in some tragic cases, dying while waiting. Even now, PIP is still widely criticised in the cancer sector for overestimating a patient’s ability to work³⁶ – which can be crucial for the wider ripple effect, as only carers who care for someone eligible for PIP are themselves eligible for carer’s allowance.

Finally, people with cancer are also entitled to free prescriptions in England (in Scotland, Wales and Northern Ireland prescriptions are free for everyone) and can qualify for free NHS wigs or fabric support.³⁷ Many hospitals also give patients with cancer free parking, although this is rarely well advertised.³⁸

Michelle

Michelle is 35 years old and lives with her husband and 18-year-old daughter in Manchester. She was diagnosed with stage 1 breast cancer in January 2018. At the time of her diagnosis, Michelle was splitting her time between three jobs. Her husband works as an engineer and her daughter is a part time student at college.

Michelle's estimated household income is roughly £60K and she is a homeowner. Since her diagnosis her contribution to the household income has stopped for several reasons. She had to stop working and was not entitled to sick pay at any of her three jobs. Michelle has compensated for this shortfall by using her annual leave. She is now slowly increasing her hours again. Michelle feels lucky that her household income is enough that the family hasn't dipped into difficulties, although she worries about future costs.

It remains hard to measure the costs of cancer at this stage of her diagnosis but she is aware that new costs are creeping in. For health reasons, she has switched to a new diet which she is finding to be expensive. Also, because of the nature of her cancer and the treatments available, she has had to buy new wireless bras which retail for about £40. Michelle does not know whether she is entitled to any benefits. So far, she has made use of free parking at the hospital and free prescriptions.

Michelle worries about the way in which her diagnosis is impacting on her daughter's college education. Tara, her daughter, has trouble concentrating because she thinks of her mum's condition, particularly around doctor's appointments. Michelle's sister often visits from Northern Ireland to support Michelle in Manchester. This has meant taking off considerable time from her job, but thankfully, Michelle says, her sister's employer is very supportive.

01.

Cancer Costs - The existing
evidence base

This chapter assesses this evidence focusing on two broad classes of how cancer affects citizens' lives and livelihoods – the economic and social impact. Although the ripple effect methodology has not been used per se, there is already a wealth of existing research literature that uses interviews, surveys, diaries and econometric modelling to illuminate specific aspects of the illness' wider impact. We also reviewed the research literature in order to identify the significant policy-relevant gaps in the evidence base. In this respect, we found that by far the most important oversight in our understanding concerns the impact of cancer upon friends, families and communities - i.e. the impact beyond the patient. Throughout the literature, it is widely acknowledged that cancer is not "lived in a vacuum".³⁹ However, this is rarely incorporated into study designs, meaning the wider impact of cancer typically remains underestimated.

The economic impact

Financial burden

It is well documented that cancer patients incur new financial costs as a result of their illness. A Demos analysis of figures obtained by the University of Bristol's Personal Finance Research Centre found that over four in five patients - 83 per cent incurred an additional financial burden, including spending on heating, medication and transport visits.¹⁰ Overall, the research found the average financial cost of cancer to be £570 per month per patient, with the most common additional cost in this 'cancer premium' connected to transport and hospital visits.¹⁰ Other sources of financial strain included additional day-to-day living costs, especially fuel costs and paying for help around the home and garden.¹⁰ Patients also incurred other health-related costs, such as costs for prescription medicine (despite cancer patients being entitled to free prescriptions), dietary supplements and additional dental care. Those who incurred these costs were on average £41 per month worse off.⁴⁰

The Bristol study also found that financial worries can compound patients' stress levels. Indeed, around a fifth (18 per cent) of survey respondents stated they faced a 'constant struggle' in this respect when trying to keep up with the payment of the bills accrued as a consequence of cancer.⁴⁰ The study demonstrates the severe financial impact of cancer, even without taking into account costs incurred by family and friends - who may be financially affected as they provide loans or offer other forms of financial assistance.

Foregone employment

Another significant source of economic costs are the adjustments that many people both living with and beyond cancer make to their working lives. Research by the cancer charity Macmillan has estimated that 25 per cent of cancer survivors suffer from long-term disabilities.⁴¹ As the report points out, this means that over half a million people living beyond cancer in the UK are experiencing long-term after-effects, including chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems and lymphoedema.⁴¹ Inevitably this means that health, work and financial choices are frequently compromised.

The report by Bristol's Personal Finance Research Centre attempts to quantify the financial impact caused by these changing working patterns and foregone employment. In that study, 30 per cent of participants sustained income losses attributable to cancer, losing £860 per month on average in foregone wages.¹⁰ In fact, 15 per cent had to stop working for a period of time, and a further 18 per cent had to quit their job permanently.⁴⁰ There is also some evidence that partners⁴² and, less frequently, children may change their working patterns as well, either reducing their workload to perform care duties or increasing it in order to meet increased financial obligations.⁴³ Unsurprisingly, informal caring can bring extra pressures - half of all cancer carers are in paid employment, while also spending an average 17.5 hours per week providing care.⁴⁴

Returning to the workplace

Furthermore, when cancer patients do return to the workplace, they often face further 're-entry' challenges, which can impact negatively upon themselves, or their colleagues and employers. On the one hand, going back to work can help to establish a sense of normalcy and 'being yourself' again. Indeed, the increased social interaction and feeling of belonging work can provide has been shown to restore a more positive outlook to living with cancer.⁴⁵ Some also felt there was a discouraging atmosphere at their workplace. These negative perceptions of the workplace are influenced by the mental and physical stress people with cancer often continue to face long after remission. Moreover, some studies have shown that fatigue - a common symptom for those living with and beyond cancer - severely hampers functional ability in the workplace.⁴⁶ Fatigue after cancer may be caused by side effects from medication, emerging comorbidities and psychological stress. It is associated with a diminished concentration span and a general feeling of tiredness and weakness, which often leads survivors to struggle with working life beyond cancer.⁴⁶

In addition to this, research by Macmillan found that those diagnosed with cancer sometimes face discrimination when they return to work. Its survey exploring the impact of cancer in working life found that up to a fifth (18 per cent) of those who return to work following a cancer diagnosis had faced discrimination, either from their employer or colleagues.⁴⁷ Examples of discrimination included: being demoted to a lower paid or less demanding role; feeling pressured into reducing working hours; employers implying or suggesting that you would be better off not continuing to work.⁴⁷

Helen and Dominic

Helen is 66 years old and lives in Cornwall with her husband Dominic, who is 64. The two also have a daughter in her thirties. Helen was diagnosed with pancreatic cancer in early 2009 after undergoing surgery for what was initially diagnosed as a shadow on her pancreas in the January prior. She was given the all clear from the condition in 2014. Before taking sick leave as a result of her diagnosis, Helen worked as a head teacher while Dominic continued to work in his position as a surveyor. Their household income is about £35k per year.

Helen's contribution to her household income was covered almost entirely by full salary sick pay, with there only being one month where she didn't get her whole salary. She returned to work part time in the July of 2009. "I really enjoyed getting back to work, but I have to say not everybody on the employer's side was particularly helpful. People were not very kind at all, not very sympathetic or pleasant. But I enjoyed getting back to work for myself, it was the best thing really." Helen got the impression that some people felt she was ready to resume work as normal and that no adjustments were really made to aid her transition back into the workplace. The local education department in particular was very uncaring. But from a financial standpoint, Helen feels that the costs incurred throughout her time with cancer had little to no effect on herself or her family, sparing the increased cost of heating their family home and acquiring travel insurance for her and her husband's extra holidays abroad.

The illness itself was a big cause of worry to the whole family. The diagnosis came just when Helen's daughter was in the crucial final stages of her Master's degree with a view to becoming a barrister the following year. In fact, Helen's daughter, who has two good friends who are doctors, knew more about the condition than Helen herself. "Soon enough, she knew more about it than me because it wasn't until twelve months after I'd been ill when I really realised how ill I had been." Helen had avoided looking up information about pancreatic cancer. "I don't even know why I didn't look it up. Probably because I was scared of what I might find out."

She did have a strong local support system in the tight-knit, rural community where they live. Her husband's employer was also helpful in allowing him time off whenever needed. Finally, Helen is grateful for her daughter's support system at university. The tutors were very supportive, Helen said, and allowed her daughter to see through her master's.

The social impact

Of course cancer can also exact a social cost upon its victims, as well as an economic one. "Ironically, cancer may often undermine one of the strongest potential resources people have in coping with the disease -- their social relationships," noted one early study into the social context of cancer. "In fact, the social relationships of the cancer patient may not only fail to buffer them against the stress of cancer, but may provide additional sources of distress."⁴⁸

This quote underlines how the impact of cancer is not just economic and financial, but also social and emotional. Small-scale qualitative studies have described how cancer patients and their families attempt to reconfigure their relationships after a diagnosis, searching for a new balance in terms of household tasks, finances and emotional labour.⁴⁹ Research has repeatedly argued there are insufficient support networks in place for those who have a loved one with cancer. In fact, the National Institute for Health and Care Excellence (NICE) – which rations treatment across the NHS - has long argued that carers should have emotional support available.⁵⁰

Spouses and partners

On the basis of a review of the cancer literature, one paper concluded that cancer affects gender roles and dependency structures within families, creating new stresses on relationships, especially as patients may be unable to return to work or to continue working full time.³⁹ In the face of all these changes, patients and their families often fight to maintain a sense of normal, everyday life. In one diary-based study, many participants reported difficulties speaking to their partners: “living with someone undergoing chemotherapy treatment was obviously a cause of distress and intensity of emotion, anxiety and the possibility of an unpredictable illness trajectory, often resulted in tensions between participants and their partners/spouses.”⁵¹ Qualitative studies have also reported spouses feeling anxious, fatigued and powerless.⁴²

Furthermore, physical and emotional changes in the patient can also affect their partners. For example, many people living with or beyond cancer experience sexual difficulties or disinterest.⁵² Partners of cancer patients, too, might experience a lower sex drive because of care responsibilities and exhaustion. This can cause stress and frustration, negatively affecting their relationship.⁵³

Children

One literature review of the impact upon parents with cancer and adolescent children found that parents spent a lot of energy trying to maintain their usual habits, especially when it came to their child’s social engagements, but often could not manage to keep it up due to fatigue and treatment side effects.⁵⁴ Children generally reported doing well, but a review of the literature found that children of parents with cancer had a slightly elevated risk levels for so-called ‘internalising problems’,⁵⁵ a category which includes depression, anxiety and eating disorders. Adolescent daughters seemed to be particularly at risk.⁵⁵ Over the past few years, the literature on the mental health of children after a parent’s diagnosis has expanded, but there remain major gaps. Educational performance, for instance, is often left out entirely, even though it has long been known that having a parent with cancer may affect the children’s schooling, access to sports and leisure activities, family lives, and relationships.⁵⁶

Wider community

When it comes to the impact of cancer on the wider community, the literature is even sparser. Although there is some evidence that friendships are important in helping patients cope,⁵⁷ the perspective of and impact upon the friends (as opposed to the

patients) is rarely taken into account.³⁹ One academic paper argues on the basis of a literature review that social service systems are often not designed to help wider friendship- and support networks. Therefore, “it is possible that adult siblings, friends, and co-workers ‘fall through the cracks’ of existing psychosocial support networks for individuals affected by a cancer diagnosis”.³⁹

Conclusion

In summary, the existing literature suggests the impact of cancer extends far beyond the diagnosed individual alone. Socially and economically, a wide range of actors are affected in a variety of ways. Their position, in turn, will influence the cancer patient's experience. For example, financial difficulties may mean the patient's partner has to work longer hours, leaving them unable to also offer support and care. Therefore, in order to better understand the true impact of cancer, not to mention targeting policy interventions effectively, it is crucial to appreciate this web of complex, interrelating factors.

Jeremy

Jeremy is 23 years old and lives with his parents in Wiltshire. In late 2013, while a student at university, Jeremy was diagnosed with a rare, slow-growing type of cancer, which returned in January 2018. Jeremy's prognosis remains unclear. His life expectancy could range between 5 and 30 years.

The family's financial income is currently low due to Jeremy's mother being a fulltime informal carer for Jeremy and her 90 year old mother, and his dad retiring in 2015. Jeremy himself has worked different jobs, but has been out of work since the cafe he worked for closed down. Meanwhile, the family have experienced a variety of extra costs as a consequence of cancer, including fuel and hotel costs. Hospital parking remains a significant expense, as are taxis. Jeremy and his family have received grants from charities to help them cope with financial difficulties.

The personal impact of cancer on Jeremy's social life has been considerable. “It stopped me socialising, because the first two years or so after diagnosis my speech wasn't very good at all, I could hardly walk. I sounded like someone with a very severe lisp. And I couldn't eat out because my mouth was very weak. It affected my socializing a lot, it affected my personality, as I'm generally very outgoing.” Ultimately, cancer has meant that he has become dependent on his parents. He wishes he was able to live independently.

As well as his own stress, the family have felt the strain of living with cancer. George, Jeremy's twin brother, has been seeing a psychologist for his depression. Their mother has also been much affected. “I felt isolated,” she says. “Even now I cannot go shopping on my own as I'm frightened to meet people asking [about Jeremy].” When she spots someone she knows while out shopping, she has found herself escaping to the nearest shop in order to avoid contact with friends and acquaintances.

02.

The economic cost of cancer

Cancer has an impact on virtually all domains of life. The effect of the disease ripples out as spouses take time off work, children require mental health support and organisations miss an employee. Drawing upon the results of an exploratory survey we conducted with 227 current and former cancer patients, this chapter focusses specifically on cancer’s financial and economic impact – upon individuals, families and the economy as a whole. We find that gender, region and age significantly shape cancer’s economic impact, with women, freelancers and people over 55 hit particularly hard. In summary, we find:⁷

- Forty eight per cent of cancer patients make structural changes to their working patterns because of their illness;
- Fifty three per cent of cancer patients see their income fall at least one income bracket;
- Young people (under 35) and people approaching pension age (55-64) were most likely to see a decline in their financial health because of cancer, at 67 and 60 per cent respectively;
- Twenty per cent of cancer patients were supported by a family member or friend who had changed their working patterns to offer care;
- The cost of cancer to the economy is at least £1.4 billion a year in lost wages and benefits alone, rising to £7.6 billion if we take into account mortality – and is almost certainly a great deal more.

Work and Finances

According to our survey, roughly half (48 per cent) of all cancer patients have made structural changes to their working patterns because of their diagnosis (see figure one). Some patients, especially those with non-life-threatening blood cancers,⁵⁸ may have ‘watch and wait’ diagnoses - or as patients in our interviews sometimes called it, “watch and worry” – that may enable them to continue work, while others have to give up work entirely.

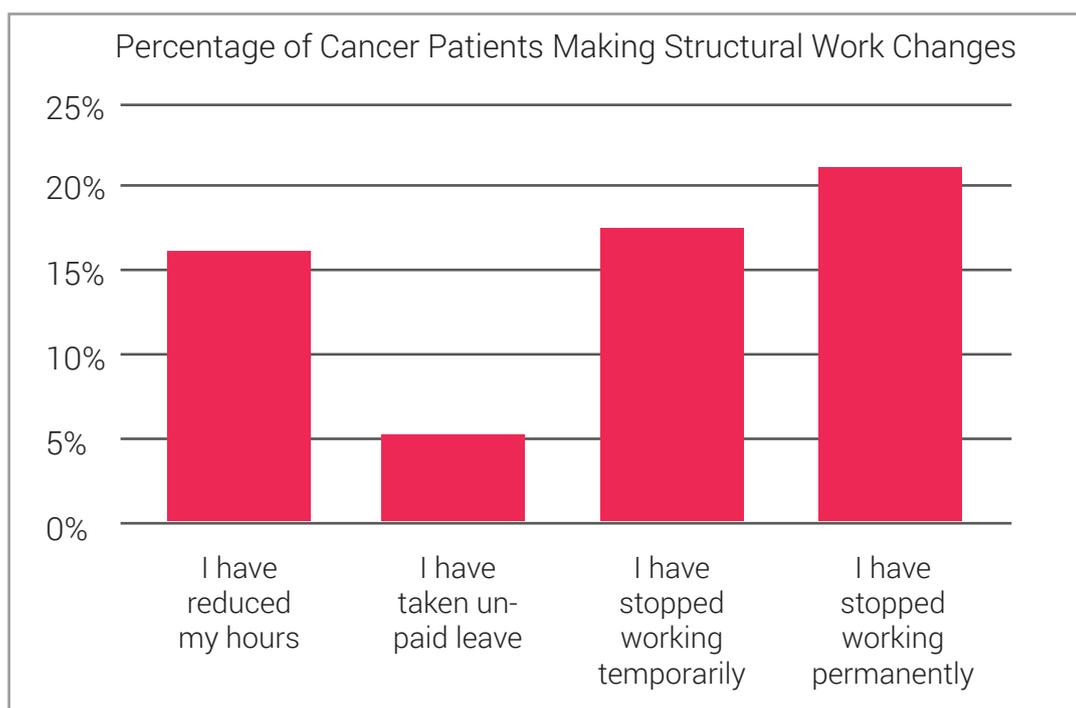


Figure One⁷

Respondents discussed having to reduce their hours because of chronic fatigue, or having to switch to a less physical, more administrative role. Fifty-three per cent reported a significant decline in income (with their income falling at least one income bracket). Similarly, 57 per cent say cancer has had a negative financial impact on them and their family. One woman explained:

“I work when I can. I tell people I work when I want but that’s not true. I work when I can. I can’t do the hours that are expected as an employee because of fatigue - but trying to explain that to someone without sounding like you are not capable is quite difficult” - Woman, 30s, London

Women were more likely to change their work patterns, with 55 per cent making a change, compared to 40 per cent of men (see figure two). These changes ranged from taking unpaid leave to quitting work temporarily or permanently. After cancer, women also had a more difficult time reaching their old level of income again. This is explained in part by the changes in working patterns. But even in the group that made no changes to work, women were more likely to see a fall in income (see figure three).

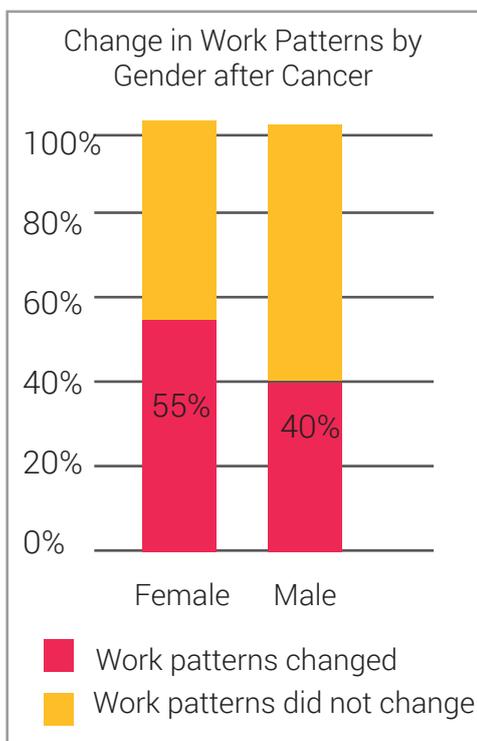


Figure Two⁷

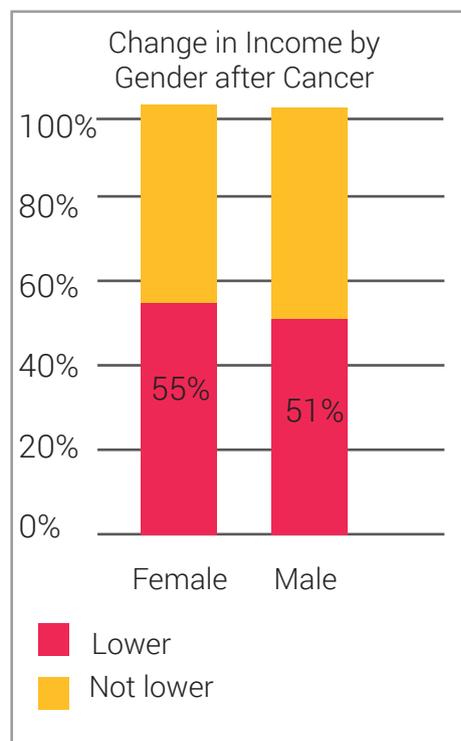


Figure Three⁷

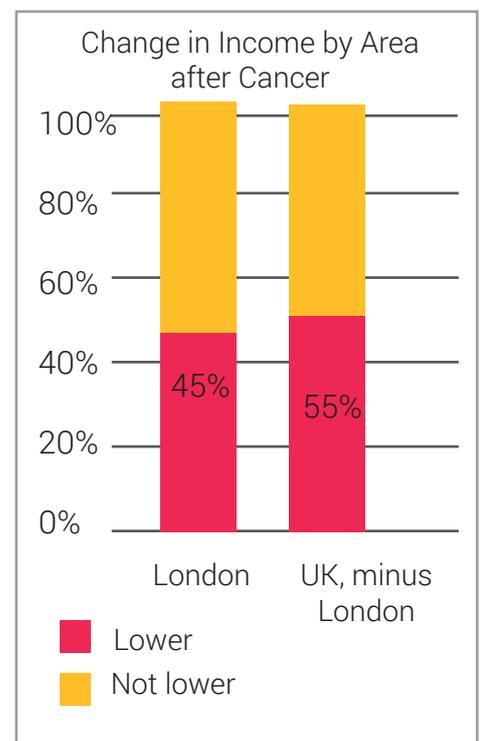


Figure Four⁷

A fall in income was also more common among respondents living outside of London, with Londoners less likely to experience a decline in income: at 45 per cent compared to 55 per cent for those outside of London (see figure four). This was confirmed by the responses to open-ended questions. As one former cancer patient put it: “Patients who live in rural or isolated communities really struggle to get the help and support they need. We have struggled for over eight years and both mine and my husband’s health has suffered, yet we’ve had no help or support.”

Others found they were no longer able to find employment at all. Those in the under-35

and 55-64 age brackets were particularly likely to see their financial health deteriorate after cancer (see figure five). In the case of young people, it is reasonable to assume that, because they are newer to the labour market and perhaps do not enjoy as well-protected jobs, they might have found it harder to pick up where they had left off, after recovering from cancer. For the 55-64 cohort, on the other hand, several factors seem to be in play. Firstly, it has been extensively documented that employers are reluctant to hire older workers.⁵⁹ This means cancer survivors over 55 years of age might be nudged by an age-discriminating labour market to take either a job below their skill level or early retirement (often at a steeply reduced rate). “I went back part time,” one respondent said, “but could not get back up to an acceptable performance so decided to retire permanently as this option was open to me.” In our survey, several respondents indicate they took early retirement voluntarily, having found it too difficult to return to their jobs.

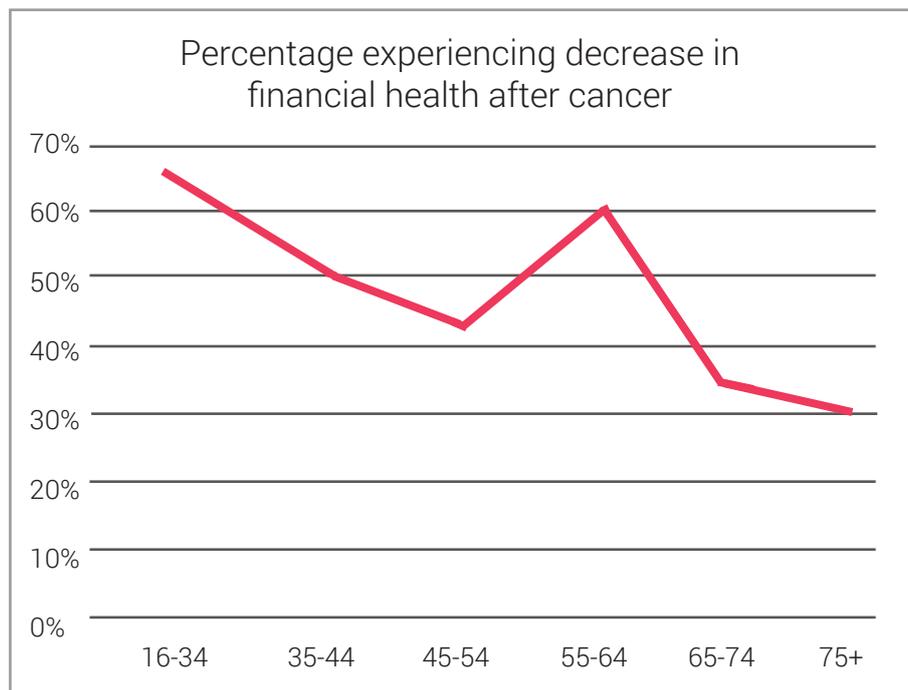


Figure Five⁷

Those who did continue in their old job described having fewer opportunities at work and being given lower appraisal scores. “I am now back to full speed at work,” one woman said, “but am no longer given the same opportunities I had previously, as my new manager took over just after I returned to work and was struggling with fatigue.” Others found there weren’t sufficient structures in place to guide their return to work: “I returned the minute my full pay on sick leave ended. Too soon. My employer thought they were being helpful by leaving everything up to me. In reality, I needed structure and support.”

When the option of working less or retiring early was not available, current and former cancer patients described having to continue working despite dizziness, fatigue and a vulnerable immune system.^{vii} “I have to work when I’m really not well enough. I can’t afford to stay at home and enjoy my last few years with my family,” one woman said.

vii. This reflects new comorbidities patients have to adjust to during and after their treatment. For example, it is common to develop anaemia, which leads to more dizzy spells and fatigue. Many treatments work to prevent some components of the immune system resorting to helping tumours re-emerge and grow; the whole immune system becomes compromised and more vulnerable to infection as a result.

"I have to go to work or we wouldn't be able to pay all our bills," explained another. Our survey also suggests some cancer patients who stayed in work would have preferred to cut their hours but found themselves financially unable to do so.

Retraining

Lack of aftercare and retraining options further hamper a recovering patient's ability to move back into the workforce. "I fear I never will get back to work," one woman in her late 50s said. "It is not the cancer that's life changing so much as the impact of the system. Losing my career has affected my quality of life and self-respect hugely - as well as my income." Even when signs of cancer have completely disappeared, the after-effects can prohibit former patients from taking up their old profession again. One teacher said: "Working with children means you need a robust immune system and lots of energy, which I no longer have. Effectively, I will lose my chosen profession, which I love, but also will have to take a job (if I am able to) that will cut my salary in half." Many respondents missed accessible retraining options for less physically demanding and more flexible jobs. "I need to re-train, and it is a vicious circle as charities don't run simple re-training courses to help one into work, and Job Centres' attitude is that you have been given some benefits so get on with those."

Self-employment and freelance work

As more and more people become self-employed or work freelance, there is also a growing group of cancer patients who are or had been freelancers. This brings with it its own economic and financial problems, not least diminished access to health-contingent welfare entitlements such as statutory sick pay. Although freelancers often have more flexibility in their work arrangements, many of our respondents described not being able to take any time off. "[I was] freelance so had to get back as soon as possible to continue fulfilling obligations and, therefore, earn. It was hard: I was tired, anxious and sore." Freelancers in the survey uniformly reported financial strain as a result of cancer. Many were unable to take time to recover as per their doctor's advice. As one woman put it:

As a freelancer [...] I have never been able to take time off during surgeries, chemotherapy and radiotherapy so there has been no 'transition' back to work. There has been, however, the enormous burden of never being able to fully devote time to recovery - Woman, 40s, London

Others, on the other hand some found flexible working suited them well, either because they were recovering from cancer or because they were caring for a loved one with cancer. The wife of a cancer patient said:

I know there is a lot of bad press about zero hours contracts, and I think if you're relying on that to pay the bills then it's not good but for me it worked really well - Wife of a cancer patient, 60s, North East

When freelancers do take a leave of absence, it can be difficult to get back into the labour market. "[It has been] terribly hard," one man in his late 50s said. "I work very hard to get work (am freelance). Got back to work after first two operations, but since the third I have had no work (for over two years)." This is also a group that struggles to access financial

support. "As a freelancer I was told [on first cancer diagnosis in 2000] that I was not entitled to any financial support. So I didn't even bother to ask with my second cancer in 2014," said one woman. Another said: "So many people are now on brief contracts or working fully freelance, our experience also needs to be heard. Not having any form of sick pay while also going through a frightening and debilitating illness is especially difficult."

Out-of-pocket expenditures

Incomes tend to decline because of cancer, while expenditures go up. As chapter two highlighted, cancer patients incur an additional £570 a month on average due to their illness.¹⁰ Travel and accommodation for hospital appointments, parking fees at hospitals, higher gas and electricity bills and additional care requirements all make a significant contribution.⁴⁰ "Cancer costs more in many ways," one respondent said. "I have had 20 visits to the dentist in the past year, mostly urgent due to abscesses under teeth etc, almost all of these visits were chargeable." Another suggested: "[We experienced] an increase in energy bills, not only for heating, but [for example] washing drenched sheets and clothing daily. Travel for treatment is a big and continuing expense too." One woman said:

If I had more money I would have the heating on much more than I do. I'm cold basically all the time, especially in winter. Being cold just makes you miserable, doesn't it? - Woman, 30s, London

Although the present study is not well-suited to produce an exact statistic of out-of-pocket costs, patient responses overwhelmingly show that the extra cost problems diagnosed in Demos' 2013 report *Paying the Price*, which drew on the University of Bristol research to identify a 'cancer premium', remain largely unsolved.¹⁰

Impact on partners and family

As we also saw in chapter two, it is not just the patient but partners, spouses, friends and family too who are often compelled to adjust their work schedule after the patient's cancer diagnosis. Our survey found that one in five cancer patients had seen a partner, family member or friend change their work patterns in order to support them through their illness. Partners made up the largest share of this group, although a substantial number also reported their children had changed their working patterns in order to provide care (see figure six). One man described trying to balance his personal and his professional obligations:

I tried to keep work and home separate, but for the first time ever I called my colleagues in and said this is what is happening at home, I might need to work from home from time to time - Husband of cancer patient, London, 50s

In some cases, a workload reduction was necessary not only to offer support but also for mental health reasons, as many partners struggled with anxiety and stress. Others reported their partners had not been able to reduce their workload because of financial necessity. "We couldn't get any benefits so my partner had to make sure he kept on working and kept his job," one respondent said.

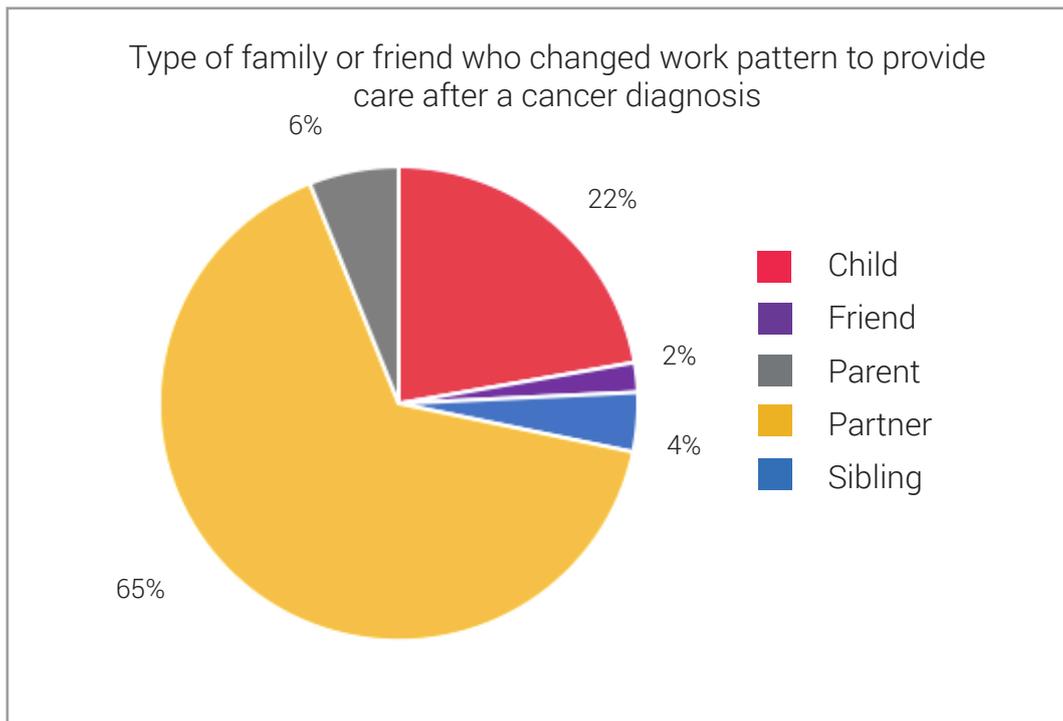


Figure Six⁷

Ben and Catherine

Ben is 46 years old and lives with his wife (44) and his son (19), in Hertfordshire. They also have a 22-year old daughter away at university. He is the co-director of a company with several dozens of staff members, where his wife is his PA. Ben was diagnosed with stage 3 thyroid cancer in 2012. Although he is not expected to reach the remission stage, he has not undergone treatment or operations for the past year. He is monitored up to 4 times a year.

Despite Ben living with cancer for up to 4 years his household income has not changed since diagnosis. Both Ben and Catherine continue to receive the same salary even with them both being off work for a few weeks or months at a time. This is a result of Ben's senior position at his company. The company's senior members agreed with Ben on a 'plan of action' in dealing with the effects of cancer on the business's operations. For example, they planned for his absence by prioritising things and 'dumping' others.

Ben received financial advice from his company's financial advisor, which he found very helpful. He was advised to take out critical illness cover on his mortgage which would enable him to have a smaller and more affordable mortgage. Additionally, his financial situation remained stable as he was medically covered through private healthcare through his work. Ben felt, however, that it was necessary to change to the NHS because the company's insurance premiums were surging, disadvantaging his staff. He does worry about the quality of care. For instance, whereas in private care his cancer was monitored through scans, the NHS will monitor him by blood tests alone, which might be less accurate, Ben fears.

Both Ben and Catherine are anxious around the tests. “There is always that dark cloud,” Catherine says. “I also get anxious when I know we’ve got to see the consultant because even though you know it’s been so awful it must start to get better.” Catherine also says she would have liked to shield her children from the worst information a bit more, but as they are both older now, they have been informed and involved.

Ben and Catherine find that their daughter Jess’s university has been helpful and supportive. Jess’s lecturer often emails her to see how she is coping. Jess has proactively applied for, and been granted, measures for her exams, where they take in to consideration her stresses from home. For example, she was able to re-sit an exam because it coincided with Ben’s operation.

Benefit Access

Accessing benefits is often a massive struggle for cancer patients. “People of working age have terrible problems with the benefit system which adds to their stress and anxiety,” one participant told us. Recent changes to the benefit system – for example, the change for DLA to PIP have left some with reduced or even no financial support from the government. As one woman put it:

I used to receive the lowest amount of what was then the DLA. But my benefits have since been taken away because with a chronic blood cancer you don’t fulfil the criteria for a ‘normal cancer patient’. I did reapply last year, for the new one, PIP. I had an assessment at home and because I can dress myself, wash myself and feed myself I wasn’t eligible for it - Woman, 30s, London

Others had heard bad stories, which put them off applying, or baulked at the bureaucratic process:

When I looked at the PIP form it was about as thick as my arm. I read a lot of horror stories, cases of people with terminal cancer being turned down for it. And I didn’t feel like having to explain my illness to people so I didn’t bother - Man, 20s, South West

This is a recurrent theme – patients being either unaware or unprepared to take full advantage of the policy support available. This too can have a ripple effect – not only do patients lose out financially without successfully claiming for PIP, their carers become ineligible for a carer’s allowance too.

In our survey, about one in four patients indicated they had received additional benefits. DLA, ESA and statutory sick pay were received most frequently (see figure seven). However, many found that they did not fit the requirements for benefits, despite no longer being able to work as they did before their diagnosis. “Benefits are often dependent on a claimants’ ability to work and cancer doesn’t usually mean you are unable to work,” one respondent said. “There are not enough forms of help for more complicated, less clear-cut cases.” As one woman said:

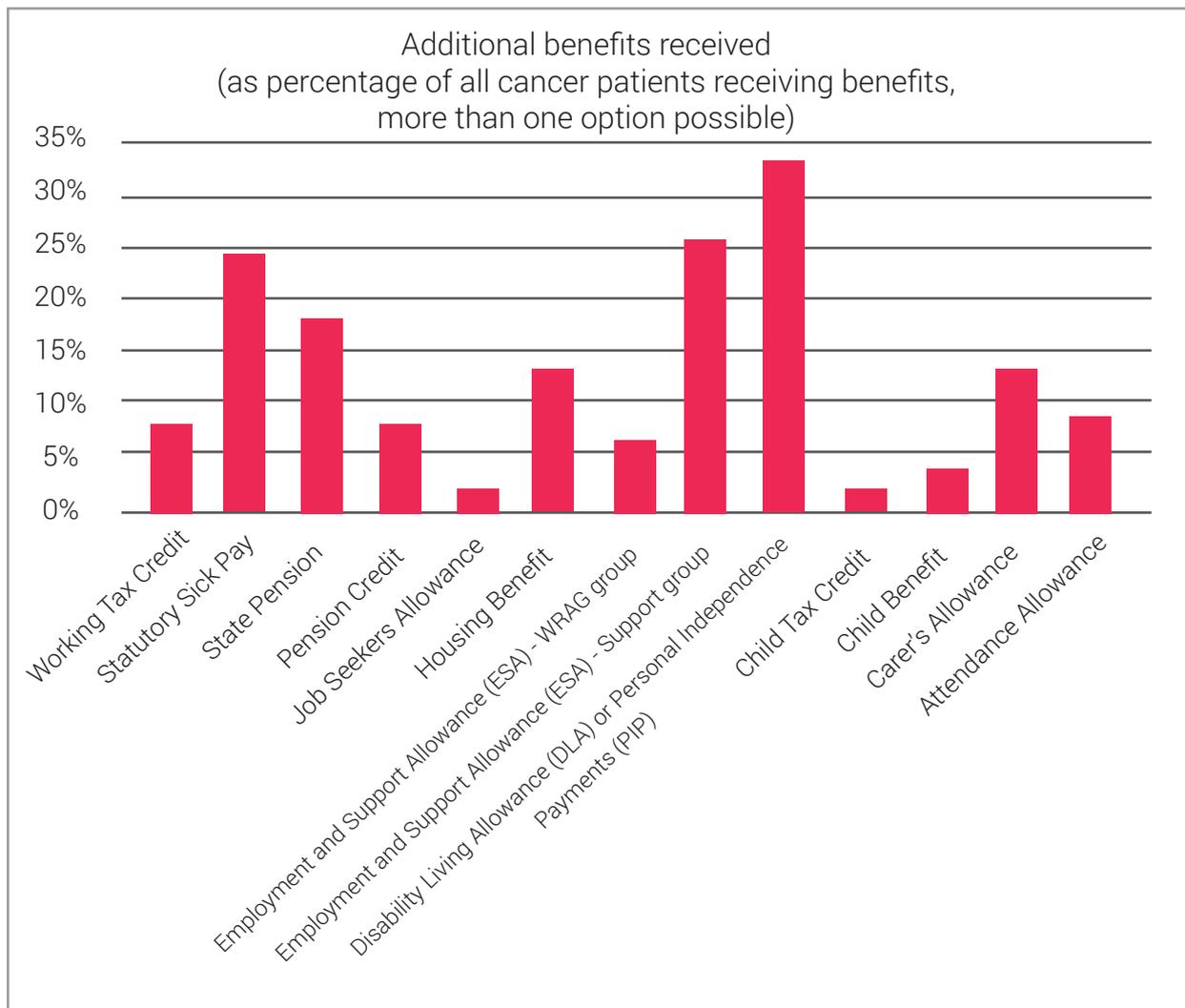


Figure Seven⁷

Chronic fatigue is a very funny thing that's not really fully understood by anyone in the medical profession. I look 100% fine and I'm physically able. It's just that absolutely everything is a mental battle, I'm exhausted before I get out of bed. I think, because I live on my own I'm seen as fit and healthy and capable - Woman, 30s, London

Impact on the UK Economy

When cancer patients and survivors stop working, either temporarily or permanently, the UK economy obviously misses out on lost potential and productivity. But attempting to quantify this amount is difficult. Estimates vary on key figures such as the number of cancer survivors returning to work. Furthermore, studies may calculate the full potential productivity of cancer survivors for the rest of their working lives (the human capital approach), or only the time until they are replaced by other workers (the friction period approach). The two approaches yield vastly different estimates.⁶⁰

Previous attempts at estimating the productivity loss due to cancer-related morbidity have varied – some put the cost at under £1 billion a year, others over £5 billion, with one report, *The Cost of Cancer* by Policy Exchange suggesting the number could be around £5.3 billion.⁶¹ However, the Policy Exchange report seems to somewhat underestimate

the number of cancer survivors who return to work, as The Cost of Cancer uses a figure that is based largely upon diagnostic data from the 1970s.^{viii} ⁶² Moreover, the estimate disregards the fact that employees who quit their jobs because of cancer will eventually be replaced, bar in exceptional cases. We believe this makes the figure less reliable.

Other reports have offered much lower estimates. Research from Oxford University academics in 2013, based on 2009 data, estimated that UK cancer patients' inability to (fully) return to work had an economic impact of 682 million euros, or £552 million (at the average 2012 exchange rate).⁶³ It must be noted that this study opts for a friction period approach, taking into account only the productivity loss until workers are replaced, which is estimated at 90 days on average.⁶² Where the human capital approach tends to yield overestimates, the friction period approach tends to underestimate costs, because not every worker can be replaced by an equally-suited unemployed person within 90 days.

There are additional reasons to believe that Oxford University's £552 million is a significant underestimate. For one, the figure provided is highly dependent on benefits data, which, our data suggest, is an inadequate proxy. Many patients struggle to claim benefits, or have given up trying, even if they are ultimately entitled to PIP or ESA. Furthermore, the estimate disregards those who have been turned down for benefits – but our research suggests these people are still likely to take economically significant decisions - scaling back their hours, taking unpaid leave, taking an early retirement etc. Therefore, our data suggest that a large proportion of cancer patients may not be accounted for in this model.

Our calculations balance these risks. Following the Oxford University model, we assume that economic cost due to morbidity consists of three parts: costs due to sick leave, costs due to employees not returning after sick leave (e.g. taking early retirement), and costs due to employees returning to work at a lower productivity (for example because they can only return to work part-time). Also following the Oxford study, we assume that those who do not return to work, or only return part-time, will be (partially) replaced after three months. However, where the Oxford study uses benefits data, we use estimates from the academic literature on the number of days of sick leave, the rate of return to work, and the rate of disability. Adding up the numbers, we find that each year, cancer-related illness and disability costs the UK economy £1.4 billion through lost productivity alone. This estimate would be higher still if we incorporated the effect on spouses and children.^{ix}

We have also calculated the income lost because of cancer mortality. Cancer Research UK estimates that over 163,000 people die from cancer each year in the UK, including just over 33,000 people aged 15-65.⁶⁴ Our calculations show that their average weekly earnings - adjusted for average employment rate and salary for males and females across different age groups - would have been £11.2 million. Therefore, in a given year, the total earnings lost due to cancer mortality would be over £582 million. Extending this

viii. The Policy Exchange paper cites Spelten ER, et al., "Factor reported to influence the return to work of cancer survivors: a literature review", *Psychooncology*, vol 11, pp 124-131, 2002. The Spelten et al. (2002) publication is a meta-review, with the actual statistic derived from De Lima et al. (1997) cited here. In other words, the return-to-work statistic used by Policy Exchange was originally found by De Lima et al. (1997), then cited in the Spelten et al. (2002) meta-review and subsequently cited by Policy Exchange.

ix. See Appendix B for a more detailed methodology of this modelling.

across their entire working lives (up to 65), yields a figure in excess of £6.2 billion in lost earnings. Of course this projection does not consider the likelihood of these individuals dying before 65 from reasons other than cancer – yet it still provides an accurate ballpark of the long-term ripple effect to the economy from cancer morbidity.

Altogether, this suggests that both diagnosing and treating cancer at an early stage, and effectively supporting survivors in their possible return to the labour market, could save the UK economy hundreds of millions of pounds. Across the EU, cancer mortality is several percentage points lower than in the UK.⁴ Assuming that the difference is spread evenly across age categories, and assuming that survivors can return to work, each percentage point of improvement would yield £62 million in savings to the economy. Matching the EU average in terms of survival rates could, therefore, save hundreds of millions of pounds.

Sarah and Gary

Sarah is 62 years old and lives with her husband, Gary (57), and two daughters in their twenties in Edgware. She was diagnosed with chronic lymphocytic leukaemia (CLL) in March 2017, and is currently on watch and wait. Shortly before her diagnosis, Sarah retired from working as a speech and language therapist with the NHS, keeping a part-time job at a college and planning to set up her own practice. Her husband is the CEO of a voluntary sector organization. Her youngest daughter is the primary carer for the eldest, who has a chronic illness.

Sarah's estimated household income is roughly £60k and they have a mortgage. Because of her diagnosis, Sarah has been unable to set up her own practice. Additionally, she had to reduce her working days from three to two because of her fatigue, resulting in a one-third drop in her income. Her cancer has weakened her immune system, and she has suffered two major bouts of infection that forced her to take sick leave, for five weeks in 2017 and three weeks in 2018. Her employers have been very helpful and flexible in adjusting her work schedule and time off. Gary's income has not been impacted, although he has been working from home more than he used to. Sarah's sister decided to postpone looking for a new job in order to be able to support Sarah if necessary.

The family has been able to adjust to the reduced income and extra expenses, such as cabs or hospital parking, fairly well. Sarah also spends money on alternative remedies. They have cut back on luxuries such as takeout and holidays. Sarah's exhaustion makes it difficult for her to participate in many activities, so the family's overall expenditures have likely gone down or stayed the same. When Sarah was very ill, Gary also took a step back from his hobbies, such as DJing and music reporting, as he wanted to prioritise supporting Sarah, but since she has been getting better, he is able to enjoy his hobbies again.

Although she receives support from her family, with whom she now spends more quality time than before the diagnosis, Sarah still has unmet support needs. It takes her a long time, and many phone calls, to link up with a specialist nurse. She wishes she had more access to specialists, since the CLL Association's hotline is run by people who have CLL and not health care professionals. She finds it difficult to know what advice online is accurate and relevant to her.

03.

The social cost of cancer

In the previous chapter, we discussed the financial and economic impact of cancer. Now, we will turn to the social and emotional impact on individuals, their families and their communities. Besides the stress and anxiety a diagnosis can trigger, there is the mundane reality of living with or beyond cancer, which can mean being too tired for birthdays, having to miss social events for hospital appointments or being too fragile for family outings. Partners and children may be affected in their mental health, their ability to focus on their education and their own social life. Moreover, prior to a diagnosis many people are carers themselves, providing support for elderly parents or grandchildren who subsequently have to do without. In short, it is, as one of our respondents put it, “one person, one diagnosis, but a whole family impacted”.

Drawing once more upon our exploratory survey, in summary we found⁷:

- Over three in four (76 per cent) describe the impact of cancer on their family life as very or moderately negative, while 10 per cent indicate the impact has been positive
- Two in three (66 per cent) say cancer has had a negative impact on their family's social life
- Support from the NHS and from charities was generally assessed very positively by patients, receiving average marks of 7.4 and 8.2 out of 10 respectively

Family life

Cancer changes family life in profound ways. “All our plans have been put on hold. We don't know if holidays etc will be possible again,” one respondent from the South West said.

A common theme was lack of spontaneity. One woman described the treatment process:

We live from scan to scan. [...] I get ‘scanxiety’. And then if it's alright, you've got 12 weeks before the next one, so you can plan anything and just get on with your life and then you get to a couple of weeks before the next one and you are going ‘ah, what if everything has kicked off again...’ - Woman, 50s, North West

Most cancer patients (58 per cent) report that their illness has had a moderately negative effect on family life (see figure eight). A minority (10 per cent) reports a positive overall effect. These people describe becoming closer as a family because of cancer and reorienting themselves to the things they find truly important. “My immediate family have been extremely supportive and we are a lot closer,” wrote one woman with leukaemia. “It strengthened our marriage and made her more aware of our priorities in life,” said a man who was in long-term remission. But this is decidedly a minority view. Three in four experienced a moderately or very negative impact. As one participant put it:

The ripple effect of informing family members of the diagnosis is sad to see and experience. Constant negative thoughts and the time implications of appointments et cetera have changed what was a relatively normal happy life - Woman, 60s, South East

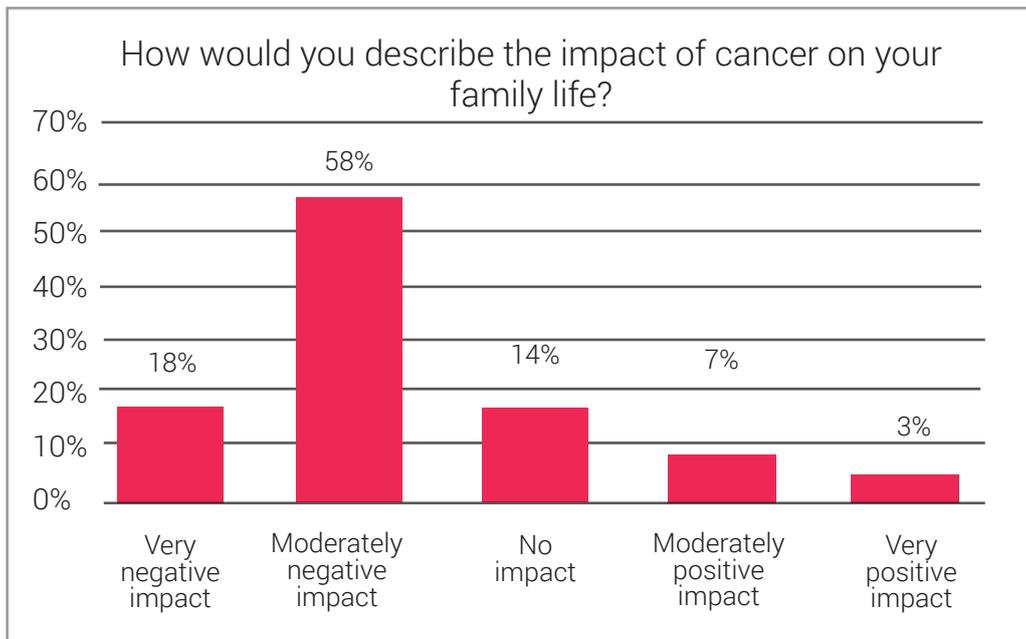


Figure Eight⁷: Impact of cancer on family life

Jack and Laura

Jack is 66 years old and rents a house in Redditch with his wife Laura, 58. Jack is a former freelance project manager and his wife worked as a social worker on a zero-hours contract. He was diagnosed with non-Hodgkin lymphoma initially in 2007, which returned in 2009, before Jack underwent a stem cell transplant in 2011. Jack has two sons with his current wife and two daughters from a previous marriage.

Jack and Laura currently have a combined income of £22k and own a house in Dorset. Their combined income has dropped considerably since Jack was diagnosed with cancer. Before Jack's treatment he was earning an estimated £40-60k annually. Jack stopped working once he was diagnosed with cancer. During the prolonged and recurrent cancer treatments over a period of 8 years, Jack and Laura spent their savings and lived off Jack's private pension (which consequently disqualified him from any type of government benefits). Throughout this period, Laura worked on a zero hours contract which allowed her the flexibility she needed to support Jack. She did accrue extra costs in terms of fuel spent, parking charges and meals eaten out while visiting Jack. Furthermore, Jack lost a considerable amount of weight, and he had to buy suitable clothing and turn up the heating in their home because he was feeling constantly cold.

Despite the financial impact, particularly on their diminished savings, they both decided not to return to work once Jack was better. As a result, they had to let go of their retirement dream of a holiday home 'in the sun'. They both, however, remain optimistic because 'instead of having second homes', Jack says, 'we just got our home and a good quality of life and I'm still alive'. They are closer to their families now, and have both become more involved in the community, particularly their local parish.

Sharing the news

Cancer patients in our interviews often wanted but struggled to protect their loved ones from the stress and anxiety. One mother explained:

I lied to my daughter at first. I came home from the hospital with the scars of the biopsy on my chest. I came out and I see her, she went 'well?', I went 'I'm absolutely fine' [...] She said, you're lying, and I said, yes I'm lying - Woman, 30s, North West

Patients worried about the effect of the news, especially on their children.

I hadn't told [my daughter] anything and when she came home at Christmas I had to tell her - that was just awful... I think the impact that it can have on children is quite drastic really. She was really upset at the time and after Christmas she went back to London and had to do all her exams... - Woman, 60s, South West

Reconfiguring family relations

After diagnosis, the entire family has to adapt, which can strain family relations. Some survey respondents described feeling alone and isolated when their families failed to understand the burden of cancer. "My family don't see or understand the 'invisible' effects of my cancer... The tiredness or occasional anxiety," said one respondent. The pressure of the illness can be too much to bear for some family members. "[My] husband [was] unable to cope with my changed needs and perspectives, became very angry, which had a divisive effect on the whole family, the youngest of whom had just started secondary school at the time of my first diagnosis," said one younger woman.

These pressures can be even more acute if - as some of our respondents alleged - cancer medication triggers a personality change, making patients more emotional, anxious or aggressive. This can have disorienting effects on their partners and children. "Cancer brought us together, but the evil hormone drugs that I was on post-cancer nearly destroyed us," said one breast cancer survivor. One man in his twenties described the effect of steroids:

I think the first six to eight months were hard for my mother, because I went a bit nuts. I called my parents and brother every name under the sun. I was on steroids, which make you very moody and fat. I think I called them f***ing c****s and all sorts. I threw things as well. I was proper psycho mode. It was bad" - Man, 20s, South West

Health and Wellbeing

In other cases, partners and family members saw their own health suffer in their efforts to support their partners through the illness. Often, family members offering informal care, ignored their own needs, did not even notice their own health deteriorating. The husband of one cancer patient explained:

It's only now that my wife's been a bit better, that I've realised, oh, no wonder I was feeling exhausted all the time a few weeks ago - Husband of cancer patient, London, 50s

Another patient explained:

My 84 year old mother became my main carer, although I tried to be as self-sufficient as I could but there were days I could not cook, eat, clean, walk the dog etc. This took its toll on her health - Woman, 60s, Scotland

Many also felt unsupported: "My husband has health conditions of his own that have been made worse by having to become my carer. Neither of us have had any help or support. I feel guilty for the deterioration in his health because of having to look after me."

Mental health

Patients may have difficulty coming to terms with their diagnosis, which can lead to mental health issues and destructive behaviour. One woman described how her diagnosis made her drink to excess:

When I got diagnosed, I was a student and I was drinking way too much. In hindsight it was definitely a coping mechanism. I took a year off, and ended up going out every single night of the week with different people and the drinking was bad. I didn't know if I was going to be a good drunk or a bad drunk that night, but more often than not I was a bad drunk - Woman, 30s, London

Moreover, in a substantial number of cases, the cancer diagnosis triggered or intensified mental health problems in patients' partners and children. In our relatively small sample, there were over 20 respondents who spontaneously described severe anxiety or other mental health issues in their partner or children. "[My husband's] mental health has taken a pounding. More so than mine, as I got all of the love and support," wrote a survivor of uterine cancer. Almost all respondents discussed the anxiety their partners felt, which sometimes spiralled into depression. One woman said:

My husband has to think about what will happen to him after I die. He has veered between depression and being in denial. The NHS has provided clinical psychologist support for him - Woman, 60s, Scotland

This also complicated the situation for the patients themselves, who often felt they had to protect their partners and children from anxiety-inducing information. "My partner was affected badly. He became anxious and easily upset. I found it difficult to discuss my cancer with him, for fear of upsetting him." Some encouraged their spouses to seek treatment:

My husband swung from being in total denial or total depression, neither of which I found helpful. That is why I wanted him to see the clinical psychologist – Woman, 50s, North West

Children, too, struggled with their mental health. "My youngest daughter was diagnosed

with mental health problems after my treatment finished,” one parent and former patient said. Available counselling options were ill-adapted to the situation, said another: “My teenage daughters could have done with more specialist help. The eldest was given antidepressants and the youngest has tried speaking to several people via school and doctors but no one was offered who has experience with the impact of cancer.” In some cases, this led to suicidal ideation: “At the time they struggled with the extra pressure and worry that their mum may not recover. Their friends dropped them and school was not supportive. Exam pressure on top caused both of them to have suicidal thoughts.”

Many participants mentioned an adverse effect on their children’s performance in education, highlighting the importance of institutional support. “The emotional impact to my children has been very negative,” one mother said, suggesting her child had dropped out of university. Another mentioned their child’s grades had suffered. “Our youngest was at university at diagnosis and had an out-of-character poor exam shortly after being told. This impacted his final degree grade.” This is corroborated by testimony from the children of cancer patients, who often describe losing focus at work, their apprenticeship or at university:

I feel like sometimes when I go in and my mum’s got an appointment or something, especially on them days. It’s like I’m not really in college if you know what I mean? I sort of sit in a daze - Daughter of a cancer patient, North West, 20s

In short, the overall wellbeing of partners and children was affected in a variety of ways by a family member’s diagnosis. Many suffered a hit to their mental and physical health. We also heard of parents and siblings who ended up taking on a heavy burden of care. These situations are even more difficult when families hit financial difficulties or when the patient undergoes a personality change. Overall, roughly three in four cancer patients considered the impact on their partner and children to have been negative, at 72 and 74 per cent respectively (see figure nine). Children were affected somewhat more strongly, with over one in five parents with cancer (21 per cent) indicating their child or children had been affected very negatively (see figure ten).

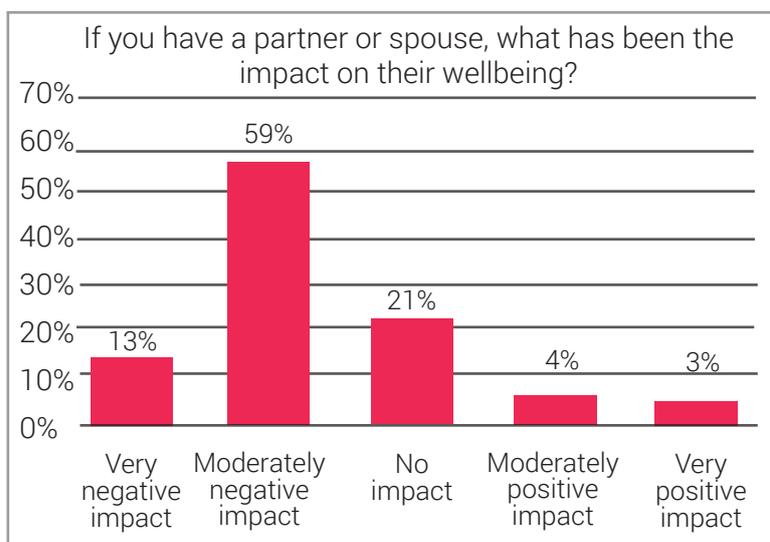


Figure Nine⁷: Impact of Cancer on Significant Others’ Wellbeing

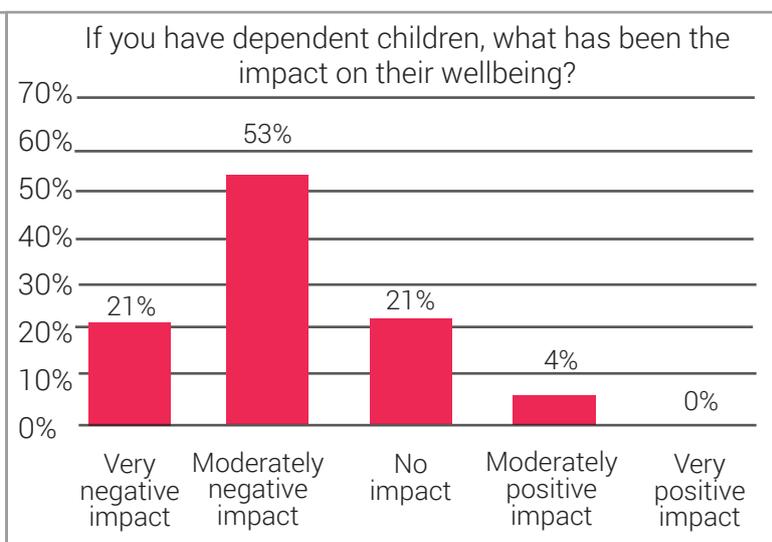


Figure Ten⁷: Impact of Cancer on Wellbeing of Patient’s Children

Social life

Even when cancer is not an immediate threat to a patient's life, it can certainly have severe impact upon their social life. Many cancer patients find themselves unable to attend social events, unable to support friends and family and often less mobile, which can sometimes lead to a sense of isolation. One highly typical response to our survey read: "I had to stop work, stop active sports, reduce my social life." One woman described conflicting desires after her diagnosis:

It's not the financial impact, it's the mental health. When you are diagnosed with something like this, obviously my daughter's got to go to college, my husband, he's a workaholic, so I'm like, get out the house, go to work, and then I'm sat here on my own. Don't get me wrong, there's people that call wanting to come round, but the only way I can explain it is... it's like you want people to knock on the door, but you don't want to open it. You want people to call, but you don't want to answer it. You want people to text, but you don't want to reply - Woman, 30s, North West

Some may also prefer to withdraw entirely after the shock of their diagnosis. One woman said:

I have been newly diagnosed and am finding it tough to accept. I don't mean to give anyone a hard time but cannot see any further forward than the word cancer. It had knocked me off my feet and taken all the enjoyment out of life. I cannot watch a film read a book or hold a conversation at the moment - Woman, 60s, Midlands

Isolation

For those living with cancer long-term, social isolation can become a permanent reality. One woman describes the effect on her social life:

I basically cancel everything all the time so friends have stopped inviting me to stuff, which is really upsetting. On the one hand, you're all d**ks, why the f**k can't you try to understand what I'm going through but then it's like, well, at what point do you keep on inviting someone to things when you know that on the day they're going to send a message saying 'I'm really sorry, I'm too tired I can't come' - Woman, 30s, London

This is compounded in some cases by persistent spells of dizziness and other impairments that make it difficult to drive.

Many participants also mentioned having suppressed immune systems, which meant they could not visit relatives or friends who were ill. "I am prone to infection so have to avoid family and friends when they are ill. I get tired more easily, and can't stay late at social events," one man with a stable form of leukaemia reported. "My immune system suffered after my initial chemotherapy," said another, "and I couldn't visit my ageing mother for a very long time." This can mean (former) cancer patients have to completely

reinvent their social circle and acquire new hobbies:

Tiredness and a low immune system prevents me from doing many things I once enjoyed such as gardening, housework, walking, swimming, socialising etc. I am still young but now feel I cannot find a partner due to my cancer and its impact on my life span - Woman, 40s, Midlands

Another said: "When people ask how I am doing, I tell them I lead a little life."

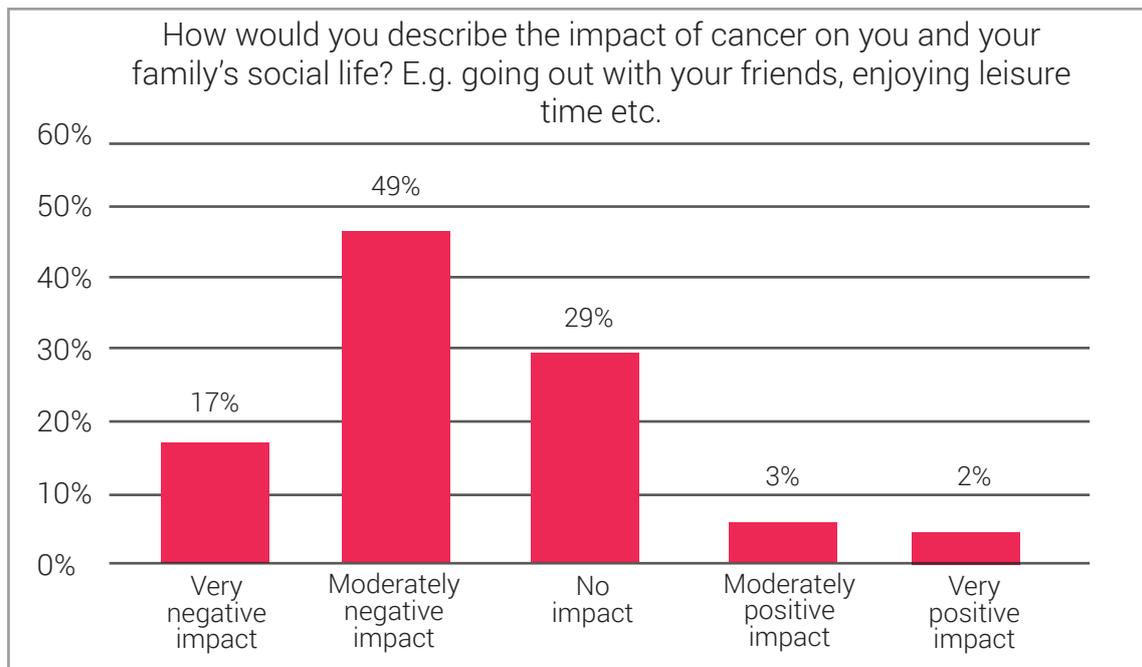


Figure Eleven⁷: Impact of cancer on a (former) patient's social life

Community involvement and volunteering

On the other hand, a small number of cancer survivors find they want to 'give back' after recovery. They become involved in cancer advocacy and peer support, which allows them to be more social and more involved in the community than they had previously been. This is a small minority of (former) patients, but nevertheless noteworthy. One man said:

I have been cancer free for nearly seven years. I felt I now had something to give back, which was rare [for me]. I became a Volunteer Peer Cancer Advocate. In this way I have helped many older people affected by cancer. This involved lots of listening and empathising, assistance with benefits claims, housing, transport, being beside them at hospital appointments, understanding their conditions and treatment options. I also help local community projects and my church when I can provide practical support. This would not have happened had I not recovered from mantle cell lymphoma. I count myself lucky and blessed to be in such a position - Man, 60s, South East

He was one of the handful of people in our sample who indicated cancer had a very positive effect on their community involvement – though the usual warnings apply in that survey respondents, by their nature, may be more actively engaged than the typical citizen.

Care duties

Assessing the ripple effect also reveals just how many cancer patients were carers prior to their diagnosis. When they become patients themselves, they are unable to continue taking on smaller or larger care duties, which often means that whoever they care for can suffer. Although councils offer some services when carers fall ill, our respondents said those services were difficult to access, short-term and insufficient. The stress of not being able to take care of others anymore heightens anxiety around the illness. “It has been harder,” one woman said, “because I haven’t been able to make as much time to care for my disabled 92 year old mother with dementia and that has increased the pressure on my sister who is also trying to support me.” In other cases, there was no one available to take over the care duties. A now-widowed woman from the South West said: “My husband had had a serious stroke and I was his carer. His life became sadder, and emotionally harder.”

The effect on children of any age is exacerbated when their parents are also their carers. “I have an autistic son who has become more anxious because of my health,” said one woman from Scotland. Another woman said: “I have always been the rock of the family – working, providing support to a chronically ill daughter – I am having recurring infections and needing care myself during these times, placing pressure on other members of the family.” Many of our respondents who fell into this category felt overlooked and unrecognised. One woman from the North East said: “My son is not a child but will always be dependent. [No one] takes into account when the carer is also the patient.”

Level of support

In terms of the level of support received from the NHS and charities, people living with and beyond cancer were generally positive. When asked to rate the NHS, the largest group of cancer patients (24 per cent) marked it a full 10 out of 10. Others were less positive: one in four (25 per cent) gave the NHS a mark of five out of 10 or lower. “There is a myth about being supported through cancer treatment, spread by charities in their appeals and to some extent by the NHS,” one woman from London said. “I am in treatment but do not have a specialist nurse or anyone. My GPs seem unaware of the situation. Thus I have absolutely no support.”

But in general patients were positive. The average mark was 7.4 (see fig twelve) One man from the South East said: “The role of the GP, consultant, pharmacist and nurses cannot be overstated. I had a fantastic team. In addition I had a very understanding boss and colleagues and that all combined to keep me in a very positive state of mind.” He rated the support nine out of 10. Others suggested there was still a lot to win through cooperation with charities. “[The] NHS is great but overworked. [The NHS] needs to connect [patients] to trusted charities much more closely. i.e. I was diagnosed with CLL[Chronic lymphocytic leukaemia]. I had to find the relevant charities, but when found

they offered fantastic info and support.”

Most were enthusiastic about support from charities as well. Of those who had received support from the voluntary sector, roughly one in three (34 per cent) marked the charities a 10 out of 10. The average grade was 8.2, with only eight per cent rating it a five out of 10 or lower. Patients were grateful for services such as the Macmillan Support Line, where people can receive advice on different issues related to cancer, including financial

Diane and Bob

Diane is 58 years old and lives in Yorkshire with her husband, Bob. She was formerly a teacher for 28 years and is currently working as a freelancer in education training. They have two daughters in their thirties. Diane was diagnosed with Bowel Cancer, which was thought to have disappeared completely by August 2015. But in October 2016, medical specialists diagnosed her with bowel cancer again, which had now advanced to Stage 4. Her oncologist told her she had 6 months to live.

Diane and Bob have a combined income of £70k and are mortgage free homeowners. Diane has experienced a considerable loss of income since her diagnosis and prognosis. They have managed to cope because she was able to take out a cash lump sum from her teacher’s pension. In retrospect, however, Diane doubts whether this was the correct long-term decision. She is already living much longer than the doctors expected and the chemotherapy seems to be working. ‘It’s the unpredictability that makes the planning difficult.’

At the time of her second diagnosis, Diane was ‘juggling’ several short-term contracts. She was able to easily cancel most of those, while keeping on her two favourite projects. Because Diane now feels fit for work again, she is able to make contact with her clients and pick up on the contracts she previously cancelled.

Her costs have remained lower than anticipated in a number of ways. For example, Harrogate general hospital offer free parking for cancer patients. Diane also found that the PIP allowance, although it is quite small, has allowed her some sense of security. Macmillan helped her apply for financial support, and she now receives more than she had expected to get. ‘I might end up on the front page of the Daily Mail!’, she jokes.

Diane and her family have gained a lot of support from a highly rated Macmillan centre close to her area. Her husband suffers with depression and has been seeing the clinical psychologist from the centre for about 9 months. Her youngest daughter was offered by her employer ‘as much compassionate leave as she wanted’ and since has visited regularly. Diane thinks that in some ways the cancer has improved the relationship with their daughters. She also gets to see her grandchildren more often. The family do, however, suffer from anxiety and are exhausted by the ‘two-week cycle’ of tablets and infusions. This cycle ‘keeps going and going’. ‘It is like a part-time job’, Diane says.

difficulties and applying for benefits.

However, people with rarer forms of cancer had a more difficult time accessing services, especially if they lived in more remote, rural areas. Another issue that came up frequently was lack of support for those with 'watch and wait' diagnoses, where patients are closely monitored but not (yet) treated. Lacking a clearly outlined medical path, this group of patients seems to slip through the cracks. They often suffer from just as much stress, anxiety and fatigue, combined with the uncertainty inherent in 'watch and wait', but feel they are offered none of the support.

Charities are highly appreciated by those who receive support from them, but only three in 10 patients recalled having received any help from charities. Our data set does not allow us to distinguish between those who did not want additional support and those who could not access it. Nevertheless, the high number of patients without charity support suggests there are gains to be made in connecting patients with the right support. Possible sources of support could be (and often already are) listed in information leaflets in the hospital. One respondent suggested there should be more and better guides, including on the non-health aspects of cancer, available immediately after diagnosis. "Consultants and hospitals need 'help pack' guides at finger tips to offer newly diagnosed cancer patients. Saves them a lot of questions!"

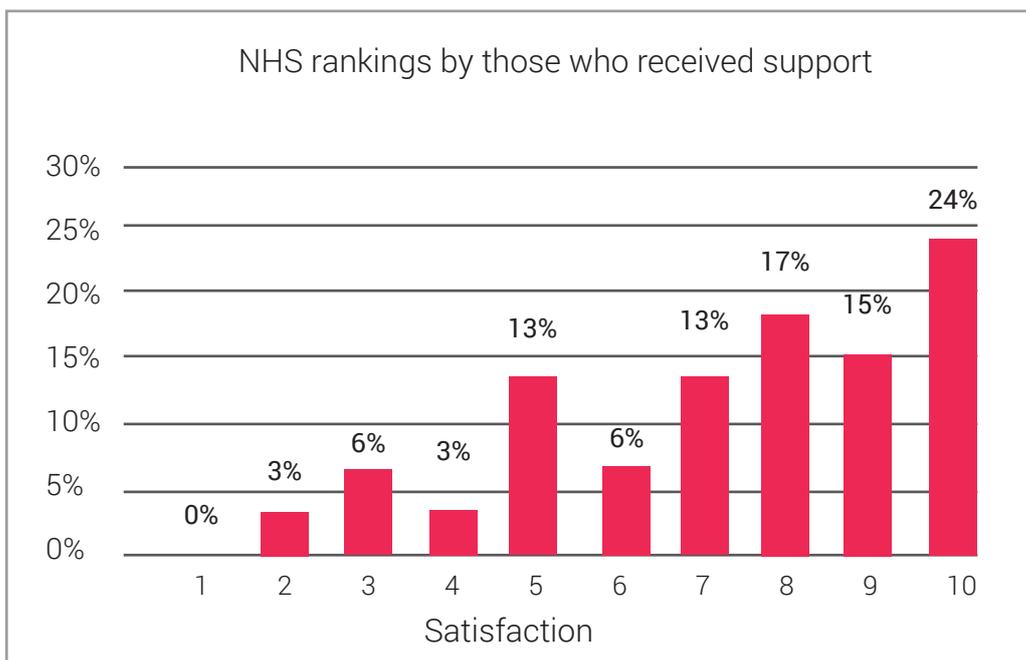


Figure Twelve⁷

04.

Reducing the ripple effect

In the last three chapters we set out our 'ripple effect' analysis of cancer's true cost to families, communities and the economy. In this chapter, however, we turn to answering the question we set for policymakers in our introduction: how can we help those affected by cancer to live freer and more fulfilling lives?

Some caveats: first, we have tried to focus our recommendations either on policies that are cost-neutral or that could feasibly be delivered through existing departmental spending limits. That is not to say that Demos disapproves of large spending commitments on, for example, raising PIP entitlements. In fact, we want to see a much more generous welfare settlement, with a much more compassionate approach to eligibility (i.e. less conditionality) and, where needed, would also argue for tax rises to advance this. However, such an agenda would first require more in-depth research - to call for it purely for its impact upon cancer, without looking at the systemic impact, would be unwise; to restrict such measures to cancer patients only would be unfair.

Equally, it should also be stressed that it is not the main purpose of this report to look directly at cancer strategy from a healthcare perspective. That being said, as we outlined in length during chapter one, the UK currently lags other comparable healthcare systems on cancer outcomes – and this is not something we should accept in the long-term. Too much prescription is again beyond the scope of this report and the challenge of tackling cancer from a healthcare perspective should almost certainly be viewed as a holistic one – better and more effective drugs, more specialist staff and a clearer accountability regime for speedy diagnostics arguably all have a significant role to play. But as the Government has recently outlined a new cash injection of £20.5 billion extra funding for the NHS (with £4.1 billion frontloaded for this year)⁵ it seems an opportune moment to remind – as we set out in Chapter One – just how far the UK lags behind other comparable countries in terms of cancer spending.

As Chapter One stated, the UK currently spends around five per cent of its healthcare budget on cancer, which is one per cent less than the European average and equates to a €41 per head funding gap.¹ To use the recent funding injection to recover this seems unrealistic – it would require an extra £2.1 billion a year, which would be over half of the money provided. A more realistic target would be to ask the NHS and the Government to commit to meeting the European average by 2030:

Recommendation One: The Government should commit to a target that requires NHS spending on cancer to match the European average by 2030. This equates to an extra £2.1 billion a year.

This is an ambitious target given the other rising health demands, not least mental health which we would also dearly like to see receive a higher proportion of health spending – our survey shows how prevalent mental health challenges are among cancer patients and their families. But if it is not met then the average European will have received almost £27bn worth of extra cancer funding by 2030 – and that is not something any Government should feel comfortable with given there seems to be a relatively clear correlation with survival rates.

Recommendation Two: The ICSs and STPs of the NHS should fully commit to per-

sonalised care, set out strategies to meet their 2021 targets and ensure that financial wellbeing is an integral part of these strategies.

The NHS Long-Term plan sets out the ambition that by 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.²⁵ This is a part of a larger shift in the NHS. As the Plan itself puts it: “the NHS also needs a more fundamental shift in how we work alongside patients and individuals to deliver more person-centred care, recognising – as National Voices has championed – the importance of ‘what matters to someone’ is not just ‘what’s the matter with someone’”.²⁵ In addition, the plan promotes social prescribing, which is particularly welcome given the findings in this report that cancer can make people feel cut off from their community. The findings in this report underline the importance of such personalised care strategies. It is crucial that ICSs and STPs meet the 2021 targets and they should set out their strategies for doing so as soon as possible. It is also important that financial wellbeing is not forgotten in the needs assessment. Anecdotally, we have heard that healthcare professionals are often hesitant to discuss financial matters, because it is felt to be outside of their remit and outside of their expertise. But the financial consequences of cancer can be severe, as this report shows, and a huge additional source of stress at a time when people need it least. When for example a self-employed person receives a cancer diagnosis they will need to be offered adequate support to minimise the financial damage.

Recommendation Three: Alongside implementation, Macmillan should explore what interventions might be extended to cancer patients’ carers and families. Beyond 2020, the Holistic Needs Assessment should be extended from cancer patients exclusively, to also include their carers and families, as an early intervention touchstone for meeting their psychological needs.

Our ‘ripple effect’ research also shows both how central strong relationships are to dealing with the various aspects of cancer and also how they are placed under enormous pressure as part of this. The NHS has, historically, prescribed relationship counselling as part of specific mental health interventions. We, therefore, do not believe it unreasonable to ask the NHS to fund, from its existing budgets, an entitlement of one free relationship counselling session for all newly diagnosed cancer patients, as part of the Recovery Programme:

Recommendation Four: All cancer patients should be entitled to one free relationship counselling session with their spouse or family.

One of the other clear policy challenges that emerged from our research is the need, for both social justice and productive reasons, to help cancer patients return to and retain their full labour market potential. In our 2013 report *Paying the Price*¹⁰ we called for the Finnish model of ‘part-time’ sickness allowances to be explored as a way of introducing cancer patients and survivors more flexibility and control over their working lives. In several Scandinavian countries, most notably Finland, cancer patients – and indeed anyone suffering from long-term health conditions – have the possibility to reduce their hours and still claim part-time (i.e. partial) statutory sickness entitlements. This allows

people to work as many hours as they feel capable of while still enjoying some welfare protections – in Finland, it kicks in after a citizen has received 60 days on full sickness allowance. We believe this model would have clear benefits for both society and the economy – individuals would have much more flexibility to manage their condition than they do in our ‘all or nothing’ model of sickness protection. Of course, this may mean some workers reduce hours they might have kept otherwise, but this should, at least in theory, help their condition from a health and wellbeing perspective. On the other hand, the extra flexibility might keep a lot of people in the labour market who might otherwise drop out completely, thus potentially boosting overall labour market participation from citizens with long-term health conditions (it has been widely credited with delivering this outcome across the Nordic countries).⁶⁵ As in 2013, we still believe this could be a radically transformative model for boosting both health and economic outcomes for citizens with chronic health conditions and we would like to see this model placed at the heart of a broader welfare reform programme. It should be piloted first in order to assess its effect on labour market participation, health and wellbeing outcomes, and its overall fiscal impact. But we are optimistic that it would actually reduce overall absenteeism – a Finnish randomised control trial (for musculoskeletal conditions) found that sickness absence was 20% lower than in the control group after twelve months.⁶⁶ This would suggest that such a scheme may easily pay for itself, potentially freeing up money in the long-term to improve the generosity of sickness entitlements in the UK:

Recommendation Five: The Government should trial the Finnish model of part-time sick leave entitlements for cancer (and other seriously ill) patients that have to work less in order to manage their illness, with a view to implementing this model across the whole welfare state.

A more straightforward but badly needed policy that would also greatly benefit the lives of those affected by cancer’s ripple effect would be to put carers leave on a statutory footing. The overwhelming majority of companies already have policies in place to ensure carers have the flexibility they need to balance their caring and professional responsibilities. Nevertheless, to ensure that this is a right that all carers can benefit from, we propose putting carers leave on a statutory footing, with every worker entitled to ten days paid care leave:

Recommendation Six: The Government should put carers leave on a statutory footing, with all employees entitled to ten days paid carers leave a year. Companies should be responsible for drawing up their own eligibility assessment criteria.

Statutory guidance could be provided to ensure that companies draw up appropriate certification policies so that this entitlement was not abused. However, we would worry that universalising this process would be both too statist and potentially insufficient if it had to fall back upon the very narrow eligibility requirements for carers allowance. Equally, for a number of years, the TUC has been running a voluntary campaign called Dying to Work, which aims to sign up companies to accept terminal illness as a “protected characteristic” i.e. something which cannot result in dismissal.⁶⁷ The campaign has successfully registered hundreds of thousands of workers through their employers but we believe it is right to put it on a statutory footing: nobody should be dismissed because they have been diagnosed with cancer or any terminal illness:

Recommendation Seven: The Government should legislate to make terminal illness a protected characteristic, protecting workers from unfair dismissal as per the TUC's 'Dying to Work' campaign.

Alas, one group of workers – vocally represented in our survey – who would not stand to benefit from this change due to the lack of an employer, is self-employed workers. Ill-health is a persistent bane of the self-employed experience - recent Demos research found that 49 per cent of self-employed workers were either “concerned” or “very concerned” about not being able to work due to illness or injury, second only to worries over income irregularity.⁶⁸ In the report accompanying that research, Free Radicals, we recommended a number of policies that might help build up saving levels for the self-employed, as well as policies to make those savings more accessible in times of crisis.⁶⁸ Certainly, these policies do not add up to a perfect world – an effective and viable income protection insurance market would arguably be the ideal solution (at the moment the terms for self-employed workers are rarely generous enough because of self-selection: those who buy policies, are overwhelmingly those who are most likely to need them, jeopardising the viability of the risk-pooling unless excesses or costs are prohibitive). Nevertheless, we reiterate those policies here as the most pragmatic, short-term solution to what is rapidly becoming a crisis:

Recommendation Eight: The Government should implement the full agenda of self-employed financial inclusion policies outlined in the Demos report Free Radicals, including: state subsidised auto-enrolment, introducing more flexibility to the lifetime ISA for self-employed workers, pushing forward with the NEST ‘sidecar’ model (for the new auto-enrolment scheme), and using its convening power to explore collectivising income protection schemes to make them more financially viable (and accessible for self-employed cancer patients in particular).

However, such is the financial cost of cancer, all cancer patients, not just self-employed ones, could do with greater flexibility and access to their savings. For cancer patients of retirement age (i.e. 55 and above) the range of options are obviously greater, with the pensions market providing a number of ways to access savings, particularly after the 2015 Pension Freedom reforms. However, cancer patients under the age of 55 are less lucky. The Government should address this by extending the 2015 reforms tax free lump sum arrangement – where 25% of a pension pot can be taken as a tax-free lump sum⁶⁹ – to diagnosed cancer patients under the age of 55. Crucially, this option should not change the status of the patient’s pension i.e. it should need to be converted to drawdown. This way, younger cancer patients could have some access to their accrued savings, while still maintaining a pension pot, which can receive further contributions. For us, the 25% tax-free rate also strikes the right balance between the flexibility needed to manage the crisis costs of cancer and the need to maintain a later-life savings vehicle, given the increased likelihood of survival. Therefore, we recommend:

Recommendation Nine: The Government should extend the 25% tax-free lump sum pensions freedom to diagnosed cancer patients under the age of 55 at no further cost or change to their pension status.

There is also a rather anomalous and punitive situation that concerns the pension status

of terminally ill cancer patients. As it stands, terminally ill citizens have the right to take their entire pension pot, tax-free but not if a lump sum has already been drawn at some stage as that 'crystallises' the pension pot. This is a meaningless and punitive distinction – the Government should scrap it:

Recommendation Ten: All terminally ill citizens should be able to draw their pension down in full, tax-free – there should be no penalty for previous drawdowns.

Finally, we would like to see two small spending commitments that can be met from existing budgets:

Recommendation Eleven: The Government should invest £25m in community transport connected to healthcare visits. This should come from existing Department of Health and Department of Transport budgets as a joint fund.

Recommendation Twelve: The Government should pilot a new cancer-specific retraining programme, as part of the new National Retraining Partnership. This pilot should pay particular attention to re-training women with cancer.

Research has consistently shown how transport expenses, usually associated with hospital visits, can massively increase the cost of cancer.⁷⁰ From time to time, the Department of Transport seems to find small pots of money to invest in community transport, ameliorating some of the impact of local government austerity measures. The last time it did this was 2016's £20m Sustainable Transport Fund,⁷¹ therefore it does not seem entirely unreasonable to call for a £25 million fund, dedicated to hospital community transport such as dial-a-ride schemes, to be met through existing Departmental spending limits. Equally, in the Spring budget 2017 the Government announced £40 million to test innovative new approaches to adult re-training in order to inform the new National Re-Training partnership that has been promised alongside the Modern Industrial Strategy.⁷² The Government should find the money necessary - £5 million perhaps – to test a dedicated re-training scheme for cancer patients, working with cancer charities like Macmillan. Our ripple effect research shows just how difficult it can be to return to work – and, therefore, we believe that a cancer-specific programme might prove more effective at managing the complex needs of cancer patients and survivors. Equally, our research also showed that the re-training problem is particularly acute with women – so any investment should be targeted, in particular, towards developing re-training that can help female cancer patients return to work.

Holly

Holly is 33 years old, renting by herself in London. Holly has what she describes as “old man cancer,” more officially known as chronic myeloid leukaemia. She was diagnosed in January 2007, halfway through her undergraduate studies at Edinburgh University. Though not considered a terminal illness, CML cannot be cured, only managed. Holly also writes a blog on her experiences dealing with CML, interacting with other patients and survivors online.

The year after her diagnosis, Holly was working as a PA in a regular 9-5 working week. At a time when blood tests started to get worse and she was feeling the effects of her medication more, Holly became miserable at work. Her health was declining, causing her to suffer from increasing fatigue. Meanwhile, employers were making her work until 10pm. “It’s hard to know what was the impact. Was it the long hours or my health, or both?” Holly is currently self-employed; her salary fluctuates but is typically between 15k and 20k. She prefers the freedom of self-employment as she doesn’t think she could manage more rigid hours expected of an employee.

Holly’s diagnosis did have an effect on her parent’s work life, who both have always been self-employed. They had to balance the travel between Edinburgh and their home in London while maintaining an uninterrupted working week. Holly doesn’t believe the travelling affected their finances too much, but certainly had an impact on their marriage.

The rent for living alone in London has been a major financial constraint for Holly, but her parents have supported her when she needed it. She’s thankful that she has a Freedom Pass, which means the cost of transport around the city and to her regular hospital appointments do not add to the financial burden. Holly aspires to have children when ready, but this has meant paying for IVF treatment, with borrowed money from her grandmother. The cost of the yearly egg storage has been supported by Macmillan. At the moment Holly is ineligible for PIP, which is often the case for those with chronic blood cancers, as chronic fatigue is often not recognised as a disability.

Holly’s social life has suffered as a consequence of her condition, as her friends have stopped inviting her to events. She believes that the fact she is open about her cancer, coupled with not drinking when she does go out, have made it difficult

to date someone. Holly's siblings both have children, something she has always wanted, but perhaps can never have, as her cancer might cause infertility. This has caused tensions with her siblings, who do have children. "I thought that I'd be married with children by now and babies are very much on my radar. I don't know if I will ever be able to have children. I have really struggled with the fact that my sister who never wanted children or to get married has done both." She adds: "Last week, a family member announced their pregnancy, I was like oh my God that's amazing and then properly started sobbing in the corner, because once again I was like, this is not fair, this is what I want and it's been taken away from me."

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Appendix A: Survey methodology

For this project, Demos used a survey of 227 adults living with and beyond cancer. They answered questions about themselves, their health, their earnings, their partners and children, their social lives and their community involvement. The survey was distributed digitally, through social media, dedicated forums and digital mailing lists. Many cancer charities assisted in the distribution of the survey. This may skew the sample towards those who are more involved and more connected.

In the survey, respondents were also asked whether they would be willing to participate in an in-depth interview as well. From those who said they did, and offered their contact details, we selected ten people for interviews. They were chosen to reflect as broad a spread as possible of age, gender and region. Where possible, they were interviewed along with other family members, to capture the impact of cancer beyond the individual. These ten interviews were condensed and anonymised to form the pen portraits scattered throughout this report.

Appendix B: Cost analysis methodology

For the analysis of economic cost due to cancer, we obtained the most recent data on cancer incidence and mortality in the UK from Cancer Research UK (2013-2015 and 2014-2016 respectively), split out by gender and age. These data were matched to the most recent (2018) employment rates, from the Labour Force Survey, and average weekly earnings, from the Annual Survey of Hours and Earnings, all via the ONS.

From the period 2014-2016, Cancer Research UK calculated the average number of deaths per year from cancer was 163,864. The number of those who were working age (15-64) was 33,254. These figures were also stratified across age and gender. The total number of 'would-be' employees in this group was calculated from the employment rate for across five age groups for both males and females in the period February-April 2018, reported by the ONS in a Labour Force Survey.

The average annual pay for males and females across different age groups was taken from an Annual Survey of Hours and Earnings, via ONS, which reported gross weekly pay for all employee jobs in the United Kingdom for 2017. From this, the average annual pay for males and females across different age groups was calculated and a cumulative total for the rest of their working lives (until 65) was also calculated, adjusting for employment rate and average earnings changes over the working life when entering each age group. The mean age for each age group of lives lost to cancer was used to make lifetime earnings projections.

In estimating the cost due to morbidity, we followed previous studies in identifying three parts: costs due to sick leave, costs due to people not returning to work (e.g. taking early retirement), and costs due to people returning at a lower capacity. For costs due to sick leave, we obtained the average leave taken by cancer patients, which was 30.2 weeks. We multiplied this by the number of cancer patients in each gender and age group, multiplied by the group's employment rate and average weekly earnings.

We assumed 75 per cent of cancer survivors would return to work after their sick leave, based on a meta-analysis of several studies. The same meta-analysis suggested that some 20 per cent of those who do return, do so with a lasting disability. Data on the exact productivity losses are hard to obtain, with estimates varying widely. We have assumed a 33 per cent loss in productivity. We have also capped the economic impact of those not returning to work, or returning only part-time at 3 months (13 weeks), as workers are likely to be replaced after that period. This does mean the estimate is likely on the conservative side.

Mehnert A. Employment and work-related issues in cancer survivors. *Crit Rev Oncol Hematol.* 2011;77:109-30.

Therefore the total cost due to morbidity can be summarised as follows:

$$(I * E * W * 30.2) + (I * E * W * 0.25 * 13) + (I * E * W * 0.2 * 0.33 * 13)$$

Where I = Age- and gender-specific cancer incidence per year

E = age- and gender-specific employment rates

W = age- and gender-specific weekly earnings

The first part of the equation represents the cost due to sick leave (30.2 weeks average leave multiplied by weekly wages), the second part represents the costs due to employees not returning to work at all (25 per cent) and the third part represents the cost incurred through those who return, but at a lower productivity (20 per cent, working at two thirds of their previous capacity).

Steiner JF, Nowels CT, Main DS. Returning to work after cancer: quantitative studies and prototypical narratives. *Psychooncology.* 2010;19:115-24.