



Care and support
through terminal illness

The cost of dying

The financial impact of terminal illness

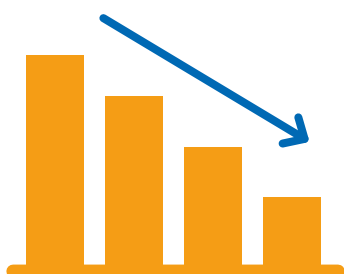


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Key facts

The total cost of living with a terminal illness in the UK can be between £12,000 and £16,000 per year

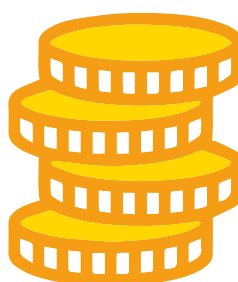


More than 4 in 5 families living with advanced cancer face income loss as a result



43% of people caring for someone at the end of life say they struggle financially

Many carers spend over 40 hours a week caregiving – with impacts on their own work and income



Average out of pocket costs are £3,300 per patient and £1,500 per carer, every year

60%

of people living with some terminal illnesses rely on benefits as their main source of income

More than **17,000** people in Great Britain have died waiting for a decision on a PIP claim since 2013

The average cost of home adaptations in the UK is £16,000

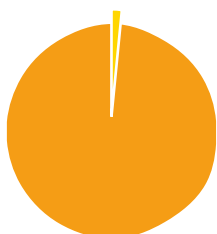


The average daily cost of hospital car parking in England is £7 per day

Two-thirds of households affected by terminal illness experience financial strain as a result



Disadvantaged families can spend as high as **98%** of their income on the added costs brought on by terminal illness



Under current UK law, terminally ill people must prove they have fewer than six months to live to get fast track access to benefits


Many families build up a 'debt legacy' to meet costs of living and care



Introduction

Being told you have a terminal illness is devastating. In an instant, instead of planning for the future and pursuing long-held goals and dreams, in the aftermath of a terminal diagnosis many families are left to adapt to rapidly-changing circumstances and the reality of living with a life-limiting condition.

As well as adapting to the new reality of their condition and making plans to make the most of the time they have, for many terminally ill people the aftermath of their diagnosis brings significant financial impacts.


Up to 2/3rds two-thirds of households with somebody living with advanced cancer suffer from financial strain as a result of income lost or additional costs

For some, increasing disability and declining capacity as their illness develops will diminish their ability to work. For others, the limited time their condition leaves them means they wish to focus on spending time with loved ones and making memories instead of working. For many more, the added expense of living with the disability caused by their terminal illness is a significant additional cost at a time when their income may be declining – or, if they are retired, when they are already living on a fixed income.

The financial impact of terminal illness is substantial. Brain Tumour Research states that on average, families with a brain tumour patient are nearly £15,000 worse off every year, while the Motor Neurone Disease Association estimates the financial impact of living with motor neurone disease is around £12,000 per year and Parkinson's UK estimates people with Parkinson's disease lose around £16,000 in income per year on average¹.

Up to two-thirds of households with somebody living with advanced cancer suffer from financial strain as a result of income lost or additional costs², with the most significant strain faced by low income families³.

Advances in treatment and diagnosis mean that many more people can live with many terminal conditions for longer than at any time before. While we should celebrate the extra time this gives terminally ill people with their loved ones, an unfortunate side-effect of these welcome medical advances is that families can end up living with a longer period of illness, disability and financial strain due to reduced household income.

For those households where a partner or other family member is providing care for a dying person, the 'double burden' on household finances can be catastrophic and lead to families building up a debt legacy to meet the costs of terminal illness which lingers long after the end of life.

Too often and for too long, the benefits system that should provide the support families need has failed to come to the aid of many terminally ill people when they need it the most. While terminally ill people are entitled to fast track access to many benefits without going through the normal, onerous assessment process, the law currently only recognises a dying person as eligible for this access if they have fewer than six months to live.

This rule has no clinical relevance and is opposed by most doctors, nurses and charities working with terminally ill people. It means too many people miss out on the support they need and are forced further into financial difficulties while they wait for benefits.

The Scottish Government is amending the law from 2020 to scrap the six month rule and entitle all terminally ill people to access benefits quickly and easily, if a medical professional certifies they have a progressive condition that can be reasonably expected to cause their death.

For these reasons and in light of the serious financial burdens that terminal illness can cause, Marie Curie is campaigning to scrap this six month rule across the UK and allow all terminally ill people and their families fast track access to benefits and other vital financial support.



Ben Gold/Marie Curie

Find out more about the campaign by visiting:

www.mariecurie.org.uk/policy/campaigns/scrapsixmonths

Marie Curie also provides support and advice to people living with a terminal illness, and those who care for and support them, including on the benefits system.

For information on benefits and finances for anyone affected by terminal illness, contact the Marie Curie Support Line on **0800 090 2309** or visit www.mariecurie.org.uk/benefits

Income loss

Being diagnosed with a terminal illness when of working age can lead to major disruptions to a person's employment; in the UK, more than four in five advanced cancer patients report income loss because of their condition⁴.

As terminal conditions progress, their symptoms can eventually cause a premature loss of employment capacity for working-age people. Many find that they have to miss work due to attending medical appointments early in their illness, before later finding they need to work reduced hours due to the impact of their condition on their health – and many are ultimately forced to give up working entirely. For many others, their condition progresses rapidly and forces them to give up work altogether soon after they are diagnosed.

As the TUC's Dying to Work campaign⁵ has highlighted, on an employee being diagnosed with a terminal illness their employer goes through the process of establishing whether they are still fit to do their job and any adjustments needed. This then sets a bar, making it easier for the employer to dismiss that person if their condition deteriorates. If a terminally ill employee is dismissed in this way, they will not only lose their immediate income but will lose the right to any death in service benefit their employer may offer.

These impacts on employment capacity and income are felt by people living with many different terminal illnesses. Studies have shown that more than half of brain tumour patients may be unable to work due to their condition, while the rate of full-time employment for adults with

congenital heart disease decreases as the condition progresses and employment capacity is significantly affected for people living with progressive neurological conditions like Parkinson's disease or motor neurone disease⁶.

The severity of a person's illness has a direct impact on their ability to, and desire to, work during a terminal illness. Those who are more severely and more immediately impacted by the health effects of their condition are significantly less likely to want to work through their illness⁷.

Many people will be forced to begin working longer hours to cover additional illness-related expenses and out of pocket costs at the start of their period of illness, before subsequently being forced to reduce their time at work or, ultimately, stop working altogether as their illness becomes more severe⁸.

The progressive loss of employment capacity can cause a significant financial strain on a household living with terminal illness. While some employers do provide their employees with occupational sick pay, many employers only pay Statutory Sick Pay (currently £94.25 per week), which is only available for up to 28 weeks.

This is significantly below the UK average salary⁹ and, as it is only paid for six months, may expire while somebody is still living with their terminal illness, ultimately leaving them unable to work, with no income and struggling to meet their expenses.



Ben Gold/Marie Curie

For those households where a family member reduces or stops working to care for a loved one living with a terminal illness, the impact on income is compounded – potentially having both earners out of the workforce at the same time creates a ‘double burden’ on household finances¹⁰.

Despite the huge social and economic value of unpaid caregiving – relieving pressure on overstretched NHS services and saving the state around £132 billion per year¹¹ – many individual carers receive little support to help them cope with the financial impact of caring and 43% of carers looking after palliative patients say they are struggling financially¹².

Many carers report spending over 40 hours per week caregiving¹³ which can unsurprisingly interfere with their own employment – whether through reduced productivity through fatigue or stress (known as presenteeism), or through absences from work (known as absenteeism)¹⁴. Carers of terminally ill people are less likely to work full-time than the general population¹⁵ and one in five carers looking after someone at the palliative or end of life stage reported having to reduce working hours to provide care¹⁶. Many working-age carers who have stopped working to care for a loved one also worry about their ability to return to work after their family member passes away¹⁷.

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Prudence's story

Prudence was diagnosed with terminal breast cancer in 2019

"I'm still employed, but my employers have a really strict policy on attendance so it's likely I'll be dismissed.

I hadn't planned to give up work at this stage. I really enjoyed working. It was something to keep me going. I'm nearing retirement, so there's nothing to lessen the blow. It's all crumbling.

Because I was concerned about the financial impact of my disease, I contacted DWP for advice in April and they suggested I contact my GP for a DS1500 and claim under special circumstances. Although my GP had felt the special circumstances applied, because we hadn't tried all treatment options, the oncologist wasn't able to say that I had less than six months. So basically, I had to go through the standard process.

"I've only cried twice since diagnosis. Both times were when dealing with DWP or their agents."

I found the whole assessment traumatic. It was the reality of having to actually having to own up about how bad things were. I've only cried twice since diagnosis. Both times were when dealing with DWP or their agents. I found the whole process really distressing. To tell someone the most intimate detail of the impact of having an incurable disease is heart-breaking.

When I did finally get PIP, it made a massive difference. It took some of the financial pressure off, but it was also good to know that for the next two years, I don't have to do any fighting or worrying about some elements of money.

I find I'm colder so we're using more fuel and it's things like having to have decent nightwear in case you're rushed into hospital. It's not having to worry about when to pay to get to places or buy stuff to keep us comfortable.

It buys a bit of comfort as well as a bit of financial security."

Additional costs

For many terminally ill people and their families, a loss of household income comes at a time when they are also experiencing higher living costs and additional expenses as a result of the illness.

These costs often escalate as the disease progresses¹⁸ and can reach their highest level in the terminal illness phase¹⁹. Combined with income loss, the additional expenses incurred can leave families struggling to manage and maintain their normal standard of living²⁰.

While palliative care for terminally ill people is free at the point of use throughout the UK, social care – support with daily living such as washing, dressing and preparing meals – is not. In England, local authorities may provide funding for some social care but families with more than £23,250 in savings are ineligible and must pay for all care costs themselves.

In Northern Ireland, Health and Social Care Trusts (HSCTs) carry out a financial assessment to determine who should pay for care; the majority of care in people's own home is provided for free, but nursing and residential home care is means-tested. In Wales, home care costs are capped at £70 per week and care home costs are means-tested based on income. Personal care is free in Scotland, but the cost of residential care is means-tested.


Where families do have to pay for some or all of a person's social care needs themselves, over time these costs can eventually run into the thousands of pounds. The average hourly rate for a carer, for example, is around £20 and a live-in carer can cost around £650 a week²¹. The

average cost of residential care in the UK, meanwhile, is around £600 per week for a care home and £800 a week for a place in a nursing home²².

People living with some terminal illnesses may need adaptations to their home or vehicle to continue living at home with the disability caused by the condition. In England, these adaptations should be paid for by local authorities if they cost less than £1,000 – minor adaptations such as handrails or widening a doorway typically cost less than this.

Major adaptations such as installing a wet room or a stairlift can be expensive – the mean cost of major adaptations is over £16,000²³. In Scotland, at least 80% of the costs of any adaptations are covered by a mandatory grant²⁴, while in England, Wales and Northern Ireland, grants such as a Disabled Facilities Grant may cover these costs. These grants are income-based, so individuals may be required to make some contribution – and some families do end up having to self-fund part or all of the required modifications²⁵.

In addition to care costs, families can also face significant out of pocket costs as a result of terminal illness. The cost of travelling to seek treatment (such as hospital car parking charges), for example, often on a regular basis, can be high and can amount to a considerable proportion of income²⁶. Transport and parking costs will be especially keenly felt by people living in more rural areas further away from hospitals, where the time and cost of traveling to receive treatment, and particularly travel to specialist centres, is higher.



The average hourly rate for a carer is £20 and a live-in carer can cost around £650 a week.

Most terminally ill people prefer to be cared for at home rather than in hospital²⁷ – this means that if they need to visit hospital for treatment on a regular basis they can face substantial travel costs. Even when people are cared for in hospital, family members face similar costs to visit them, with the average daily cost of hospital parking running at over £7 per day in England²⁸. Between 2015/16–2017/18, Health Trusts in Northern Ireland reportedly received almost £13 million from hospital parking charges²⁹.

Other out of pocket costs may include the cost of meeting special dietary requirements brought on by illness and increases in the cost of utility bills – especially heating. Between 2014 and 2016, for example, people with cancer in the UK spent an additional £15.7 million on energy bills; an average of £177 per person, per year³⁰. Families often underestimate the scale and impact of these added costs³¹ and may neglect to account for their impact on finances, especially at a time when they may be adapting to a lower household income.

On average, these additional costs may be altogether as high as £3,300 per patient and £1,500 per family carer, every year³². Higher-income families experience higher overall costs³³ as they are ineligible for government support for things such as paying for social care or home adaptation.

Lower-income families, however, are more likely to spend a higher proportion of their household income on the additional costs brought on by illness – and therefore experience a higher financial burden as a result. The proportion of household income spent on costs related to terminal illness can range from 16% to as high as 98% depending on income³⁴.

For retired people, any additional costs incurred because of terminal illness are likely to come at a time when their incomes have fallen, or they are on a fixed income from pensions or other savings. As they are therefore less able to absorb new costs, the additional expenditure caused by terminal illness can have serious financial implications for older people³⁵.



Layton Thompson/Marie Curie

Valerie's story

Valerie's husband, Barry, died from terminal cancer in 2016

I retired from work in February 2011 and by the November, Barry had been diagnosed with prostate cancer. By Christmas, he'd been diagnosed with stage 4 metastatic prostate cancer which had gone into his bones, so we were told we were on the final stage.

When mobility became an issue, we soon had to buy another car for Barry to be able to get in and out of easily, so we lost money on that. Then there was the fact that we needed to buy wheelchairs. I borrowed one from the Red Cross but found I couldn't lift it in and out of the car because they're so heavy, so we decided we needed a lightweight one. All these things have to be purchased and all the time you're thinking 'what's next?'

The thing that I really feel fell short for us, was it wasn't until his last nine months that someone suggested we could get help. All through this time we're backwards and forth to hospital and didn't know about benefits or that we were entitled to them. We were retired and obviously having to use our limited income.

Where we lived you had probably 30 miles each way to get to the hospital. So, in the end we were getting transport and it really was expensive, but I would do it because

he wanted peace of mind and needed me there.

It wasn't until he was discharged home for palliative care that even the hope of Attendance Allowance was mentioned at all and obviously we did need it then because Barry's care was very, very expensive. His care bill used to be over £2,000 a month.

The money we got as Attendance Allowance was quite insignificant in the end, but maybe if we'd had that five years previously when he was diagnosed, it might have eased things.

Having those benefits would have meant we could have gone forward more freely. I wouldn't say we stinted on anything, but you don't know what the impact is going to be. You've still got to pay council tax and water rates and heating. That's the other issue when you've got someone who's poorly, the heating's on 24/7. Barry was very mindful of the heating and how expensive it was, but he obviously needed it for his own comfort.

If we could have had access to benefit earlier on, we would have been able to laugh it off and say, 'That's OK.' It would have taken some pressure off. You wouldn't have had to think twice before doing things."

The impact of financial strain

The combination of reduced or lost income and higher costs brought on by terminal illness can leave families facing substantial financial difficulties – around two-thirds of households affected by terminal illness experience financial strain as a result³⁶, with disadvantaged families being the most likely to experience financial distress³⁷.

More disadvantaged families have lower income than affluent families and spend a higher proportion of their income on out of pocket costs and other additional expenses related to illness³⁸, and so are more likely to experience significant economic distress

as a result – the impacts of this can be catastrophic on a family's finances.

Faced with the impact of additional costs and lost income, families living with terminal illness can struggle to pay important living expenses such as household utility bills or housing costs – those who do not own their home outright can be left struggling to pay their rent or mortgage³⁹.

The sudden change in financial circumstances that can be brought on by a terminal diagnosis leaves families facing rapid changes to their consumption



Ben Gold/Marie Curie

patterns to get by – this can be a significant challenge and often leads to households turning to savings that have been put aside for other reasons, or to borrowing money to make ends meet⁴⁰.

Running down savings or accumulating debt can have severe long-term consequences, with many families building up a ‘debt legacy’ to meet the costs of terminal illness⁴¹, with surviving family members left to meet the costs.

For many families, this debt legacy is only compounded after death – the high cost of funerals means many families are forced take on additional debts after their family member has died, with one in ten people in the UK say they have taken on debt to pay for a loved one’s funeral⁴². While the Funeral Expenses Payment scheme can provide some assistance for families struggling to meet the costs of a funeral, the payment has not risen in line with inflation and is inadequate to meet the high costs of paying for a funeral⁴³.

This can be challenging for families to cope with in situations where the person who has died was a significant contributor to household income, and can be particularly severe if a partner or family member has given up work to care for their terminally ill loved one, as family carers often worry about their ability to return to work after their family member has passed away⁴⁴.

In addition to long-term economic consequences, experiencing financial strain can also have profound health and wellbeing impacts on people living with

terminal illness. The stress and anxiety caused by financial distress, as well as the impact upon a person’s quality of life (from, for example, eating less well or cutting down on using heating or other utilities to save money⁴⁵) is associated with high levels of patient anxiety and depression and even lower mortality⁴⁶.

This can even have a circular relationship with a patient’s health, where the economic burden of terminal illness causes further stress and reduces their quality of life, impacting their health and creating a greater need for care – which may then end up compounding the economic burden still further⁴⁷.

Similarly, terminally ill people facing income loss can experience significant feelings of dependence upon family members – both for care and economically – which can lead to feelings of ‘incompetence’ (especially where they may have been the main breadwinner before becoming ill) and even shame⁴⁸, leading to further feelings of depression and negative impacts on their wellbeing.

Exacerbating these health impacts, people experiencing financial difficulties may forego or delay treatment⁴⁹ and are less likely to supplement NHS care, provided free at the point of use, with social care or other health care services which may come at an additional cost⁵⁰. People experiencing financial difficulties are also less likely to be able to cope with the additional economic burdens of care they may need to remain at home at the end of life⁵¹, and are less likely to die at home as a result⁵².

Amanda's story

Amanda was diagnosed with terminal bile duct cancer in 2018

I became ill quite a long time before I had my diagnosis of Stage 4 bile duct cancer in June 2018. Before then, I had my own business, but I had to stop and do a little bit of tutoring to survive because I was so unwell.

It became impossible for me to work, but I found it very hard initially to even find out what financial help I could get. It was like a full-time job for my poor daughter – she was on the phone every day to people and it took weeks and weeks, if not a couple of months and eventually someone came to the hospital to identify me. Even then it took weeks of processing. So, I actually had no income for months.

I was in hospital, so I didn't need much money, but I just had absolutely nothing coming in and because prior to my diagnosis I'd been getting increasingly more ill, I'd been working less and less so I was already up the proverbial creek without a paddle.

“It became impossible for me to work, but I found it very hard initially to even find out what financial help I could get.”

I was struggling financially before my diagnosis, but because I hadn't got a diagnosis I didn't think I could really ask for help. I'd been seen at the hospital for two years and tested for everything, and they couldn't find anything so without a diagnosis or a reason why I was struggling so much, I couldn't get any help. I was living on virtually nothing.

I was only working about four hours a week. Fortunately, I could command quite a high hourly rate as a tutor but even so it's not enough to live on. I was already on the breadline before I even started to apply for benefits.

I'm very lucky in that I have a family who deposited money into my account to cover bills, but I just kept saying what on earth does someone do if they don't have family who can afford to do this for them?

I remember getting terribly upset thinking about other people and how they manage.

Now I've finally got PIP, it's made such a difference because now I know what's coming in, I know my bills are covered. I just don't worry about it anymore because it's all settled.”



Ben Gold/Marie Curie

Welfare benefits and financial support

The benefits system can be a lifeline for families living with terminal illness and facing the financial burden it can bring. For those who are unable to work because of their condition, it is often the difference between being able to manage and falling into financial distress – as many as 60% of people living with some terminal illnesses, such as neurodegenerative conditions, rely on benefits as their main source of income⁵³.

Welfare benefits can support families living with terminal illness in several ways, from replacing income lost through being unable to work, supporting people to pay for care in the home or to meet additional costs caused by their illness, and supporting carers to take time off to care for a loved one without losing out on income as a result.

However, it is estimated that each year more than £400 million in disability benefits goes unclaimed in the UK⁵⁴ and estimates suggest over £9 million of this is entitled to patients or carers at the end of life⁵⁵. Many families are left to struggle with the financial impact of a terminal diagnosis on their household without the support of benefits to which they are entitled.

For many people, the shock and distress they experience in the immediate aftermath of a terminal diagnosis means they do not prioritise or even consider dealing with the benefits system, with many feeling that the period after being diagnosed is a bad time to have to deal with financial matters⁵⁶.

Many others do not know what their entitlement to benefits is and lack the knowledge of how to claim⁵⁷, with many patients and carers highlighting that professionals do not alert them to what benefit entitlements they may have or advise them on how to find out⁵⁸.

Families rely on professionals to signpost them to information that can help them cope with terminal illness, including financially, and it is vital that health and social care services are equipped to let them know if they may be able to claim benefits.

Even when families are aware of their entitlements to benefits at the end of life, they can face significant difficulties in accessing them. While terminally ill people are able to access some benefits (Universal Credit, Attendance Allowance, Personal Independence Payments and Employment and Support Allowance) on a fast track basis without going through the normal assessment process, at present the law only recognises a dying person as eligible for this access if they have fewer than six months to live⁵⁹.

This rule has no clinical relevance – advances in treatment mean many people can live for longer with terminal conditions but still be at risk of significant financial distress without the support benefits provide. Being forced to go through the normal benefits application process leaves terminally ill people facing significant delays before getting financial support, as well as inappropriate assessments and complex

forms. More than 17,000 people in Great Britain (not including Northern Ireland) have died waiting for a decision on a PIP claim alone since 2013⁶⁰.

As receipt of these benefits is required to unlock the payment of Carer's Allowance for family carers, the six month rule can potentially cut not only a terminally ill patient but also their carer off from what may be a vital source of income and leave them both in difficult financial circumstances while they wait to access benefits under the normal rules.

In Scotland, the law will change for devolved benefits from 2020 to scrap the six month rule and entitle all terminally ill people to access benefits quickly and easily, if a medical professional certifies they have a progressive condition that can be reasonably expected to cause their death. This will, however, create a two-tier system in Scotland for reserved benefits and inequality across the UK.

For these reasons and in light of the serious financial burdens that terminal illness can cause, Marie Curie is campaigning to scrap this six month rule across the UK and allow all terminally ill people and their families fast track access to the vital support that benefits provide.

The problems caused by this definition go beyond the benefits system. For instance, the six month rule is also used in the rules governing patients seeking to access their own pension savings (in the form of a terminal illness lump sum) in many cases – further compounding the financial stress placed on families⁶¹.

For other families, restrictive definitions of terminal illness similarly mean that insurers may not pay out on any life insurance policies they hold – life insurance policies usually include terminal illness cover as standard but will only pay out the sum assured if a person's doctor has made a prognosis that they are likely to die within 12 months⁶².

The average size of a pension pot in the UK is £71,342⁶³ and the average UK life insurance policy is £78,323⁶⁴ – being able to access these funds easily can significantly reduce the financial burden of terminal illness, but restrictive rules on when families can access them that have no clinical relevance make it unnecessarily difficult for many families to access the financial support that can make the difference between coping and falling into debt and despair.

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