Behind the Headlines: the unequal impact of the cost of living crisis

Background and context

In the first report in our 'Behind the Headlines' series, we've gathered insight and intelligence from our members on what the cost of living crisis means for people living with ill health. Living costs are rising, with inflation at a 30-year high and increasing food, fuel and energy prices while neither wages or benefits are keeping up¹. As a result, increasing numbers of people are unable to meet their basic living needs such as adequate heating for the home, appropriate clothing or adequate nutrition which will likely lead to increasing ill health.

These worsening costs are not being felt equally across society. People on low incomes and in poverty will face even greater costs, paying more for essentials like energy – this is known as the 'poverty premium'. On average, the lowest income families proportionally spend twice as much on food and housing bills as the richest families³.

Poverty and health are closely linked. People living in poverty are more likely to be living in poor health⁴. The opposite is also true - lack of support for people living with ill health and disability can make people poor. At a neighbourhood level, healthy life expectancy is higher where the percentage of households living in relative poverty is lower. There are also many health conditions which are exacerbated by both inadequate heating and poor nutrition. It is really important therefore, for us to build a better understanding of what the cost of living crisis means for people living with health problems and what can be done to mitigate against this.

We know from our members that many people living with long-term conditions already face additional costs, such as for treatments and prescriptions, transport, greater domestic bills and insurance as well as the knock on effects of not being able to work, including reduced lifetime savings. To illustrate this, a piece of research conducted by Scope in 2019 found that disabled people on average face further costs of £583 a month and for 1 in 5 disabled people this burden increases to more than a £1000 a month⁵.

In this report, you can read a number of examples from our members of how the cost of living crisis is impacting on people living with illness or disability.

What we've heard

Musculoskeletal conditions

A survey commissioned by Versus Arthritis in September 2021 found that one-in-three people experiencing a musculoskeletal condition have had treatment delayed or cancelled. They have found that those waiting for surgery face an additional cost of $\mathfrak{L}1,739$ a year on average as people continue managing their pain through physiotherapy, over the counter medications, private healthcare, and prescriptions⁶. One-in-three are concerned that the amount of money they are spending while waiting for surgery is unsustainable.

"It's not just medical bills, arthritis adds a cost to your daily life. I initially thought this was a temporary situation, as did my daughter, so she was initially able to help me with normal day to day activities like cooking, shopping, cleaning and dog walking. But because I've been waiting for so long, I can't rely on my daughter anymore. So along with my loss of income comes the expense of a cleaner, a dog walker, someone to paint my fence, put pictures up on my wall... the list goes on."

Cancer

Macmillan Cancer Support have reported that heating costs is currently the number one issue that people with cancer are asking Macmillan for grant support with. They have given over £1 million to support patients with their heating bills over three months.

"Financially it's been an absolute drain. When you get cancer, your wage goes away but your bills and your rents don't go away. You don't save for cancer. I was completely unprepared." The current energy crisis has left her "scared of the spiralling energy bills and dreading the next lot of her direct debits for them".

Crohn's & Colitis

People with Crohn's and Colitis face additional costs associated with managing their long-term condition and/or disability. Keeping their home warm, extra bathing and laundry, and travel costs when they cannot walk, cycle, or use public transport accumulate quickly. Prescription charges are an additional burden and barrier to many people taking vital medicine to keep themselves well.

"Our fuel bill has increased from £150 to £320 already in the last 12 months, and that's before the April increases. The stress of money is really weighing heavy on me, as I know stress has triggered my last flare (relapse)."

"It is costing a fortune at the moment as I am currently flaring so having to rely on using my car to ensure I reach places on time. As I get anxious using transport in case I have an accident (going to the toilet) and also sometimes they do not run on time. I have had to also change face-to-face appointments with the hospital where possible to telephone appointments to try and keep fuel costs down."

Kidney conditions

As a group already disadvantaged by poor health, many people with kidney disease are on low incomes, cannot work or are pensioners and are only just managing at the moment, and these rises in costs could be difficult to manage. Home haemodialysis currently costs between £590 and £1,450 annually, prior to any rise in the cost of living⁷. Data from the UK Kidney Association shows that almost 1 in 4 (24%) of people facing these costs are in the most deprived group and almost half (44%) are in the two most deprived groups in society⁸. Last year Kidney Care UK saw a huge increase in demand (47%) for their £300 'immediate hardship grants'⁹.

In some parts of the UK, home dialysis patients are partially reimbursed for additional utility costs by their hospitals, but this often doesn't meet the full costs incurred and reimbursement is usually only given after the money is spent. To further compound the problem, reimbursement isn't uniform across the UK and has not taken into account the rises in utility costs in 2022.

This is what Phoenix Halliwell, who is on home dialysis, has to say:

"It's costing me more and more just to stay alive. Like many families facing a cost of living crisis, we've already tried to shave off every expense. We've asked for financial help from family and have sold unwanted items to raise funds. The only remaining option was to turn the gas central heating right down to below 12 degrees celsius. Effectively, turning it off. Rising fuel costs are making just staying alive even harder and it feels like we're being priced out of existence."

Mental Health¹⁰

People from lower income households are more likely to experience a mental health problem¹¹. Research from Mind has shown that people receiving benefits have been hit particularly hard by the pandemic and are experiencing increasingly severe and complex problems with their mental health¹².

"My struggle to earn money is a big trigger for my anxiety so the cost-of-living hikes are stressful. We were forced to move in the middle of lockdown, which had a huge impact on my mental health, this resulted in having to call an ambulance and my councillor."

Older People 13

Pensioner poverty is at its highest level since 2008. Age UK research found that three-quarters of older people in the UK are worried about the rising cost of living.

"I have poor health, asthma and heart failure and diabetes, all of which would be affected if I can't afford to stay warm or cook hot food."

"I am 71, retired and living on my own. I am disabled and have emphysema and asthma, I also have widespread osteoarthritis in all of my joints, I need extra heat to try and offset my condition in some sort of way. I need heat and a good balance of healthy food which I can't afford."

Homelessness¹⁴

Research by Groundswell found poor health and issues with benefits are causes of homelessness and are continued challenges for people experiencing homelessness.

Melanie has been sofa surfing and living in hostels for over 10 years. She had multiple physical and mental health conditions that made her feel suicidal. She is not receiving benefits because she was sanctioned for being late for a Jobcentre appointment. She spoke of how the sanction made her feel ashamed, and it had caused "stress, panic, isolation, lack of sleep and a poor diet". As a result of the sanction, she was unable to afford some of her medication for her asthma and the money for travel to get the pharmacy.

Mo told us that not long after he became homeless, he was sanctioned for 26 weeks after a serious operation and a stay in hospital. There had been a mix up between the Jobcentre and GP, and the Jobcentre was not informed about his situation. He was not well enough to go to the Jobcentre after the operation to sort out the problem...he told us that this situation with his benefits made him suicidal.

Recommendations

1. The Government should invest in fiscal measures which better protect people at the sharpest end of the cost of living crisis

The cost of living crisis will hit people living on low incomes the hardest, so the Government should proportionately respond to the level of need, for example, through increasing benefits to match inflation and ensuring support for housing costs increases in line with rents¹⁵. The measures outlined in the Spring Statement do not go far enough for people living with ill health and an emergency budget is now urgently needed.

2. The Government should invest more in targeted support for disabled people and people living in ill health affected by the cost of living crisis

The cost of living crisis will hit disabled people, people living with ill health and carers the hardest, so the Government should invest in targeted measures to mitigate against this, for example, through longer term capped energy tariffs for those with medical treatment needs such as those who do dialysis at home. As another example, by not raising prescription charges.

3. The Government should work with the charity sector and people with lived experience to better understand how the cost of living crisis is impacting on health and wellbeing

Decision making about the cost of living crisis has serious and long term implications for people's health and wellbeing, and their use of health and care services. The Government must work with disabled people and people living with ill health to better understand the impacts of the cost of living crisis and mitigate against them.

4. Health and care system leaders must work proactively to understand and respond to the cost of living crisis in their area

The cost of living crisis has serious implications for people's health and wellbeing and use of health and care services. System leaders must work to understand how the cost of living crisis is affecting people in their area, then work proactively to mitigate impacts of the crisis on health and wellbeing. For example, by acknowledging that a cost of living crisis is a public health crisis and by working with local partners to co-ordinate a multi-agency response which ensures people who are struggling with the cost of living can access support.

5. Health and care service providers must address the impact of poverty on people's health and wellbeing in their everyday work

Health and care providers should centre poverty when designing models of care to make sure the people who most need care free at the point of delivery are able to access it. For example, by considering costs for transport to appointments, or by offering choice around phone or in-person appointments. Health and care providers should work to ensure people are aware of their entitlements to benefits, free prescriptions or support through the NHS Low Income Scheme. Health and care providers should make full use of social prescribing to support people experiencing poverty.

¹https://www.ons.gov.uk/economy/inflationandpriceindices/bulletins/consumerpriceinflation/february2022

² https://fairbydesign.com/whats-the-poverty-premium/

³ https://www.resolutionfoundation.org/press-releases/increasing-food-price-inflation-will-disproportionately-affect-low-income-families/

⁴ https://www.health.org.uk/evidence-hub/money-and-resources/poverty/relationship-between-health-and-poverty

⁵ https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/

⁶ https://www.versusarthritis.org/news/2021/september/hidden-cost-of-covid-19-bbc-panorama-nhs-wait-or-pay/

⁷ https://www.kidneycareuk.org/news-and-campaigns/news/rising-costs-living/

⁸ Ibid..

⁹ Ibid.,

¹⁰ https://committees.parliament.uk/writtenevidence/1680/pdf/

¹¹ https://www.mentalhealth.org.uk/statistics/mental-health-statistics-poverty#:~:text=A%20growing%20body%20of%20evidence,and%20experiencing%20mental%20health%20problems.

¹² https://www.mind.org.uk/coronavirus-we-are-here-for-you/coronavirus-research/

¹³ https://www.ageuk.org.uk/latest-press/articles/2022/three-quarters-of-over-65s-admit-theyre-worried-about-rising-cost-of-living/#_edn2

¹⁴ https://groundswell.org.uk/benefits-for-health/

¹⁵ https://cpag.org.uk/news-blogs/news-listings/organisations-call-for-minimum-7-benefits-rise