

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl](#)

This response was submitted to the [Health and Social Care Committee consultation on Improving access to support for unpaid carers.](#)

UC30: Ymateb gan: Young Lives vs Cancer| Response from: Young Lives vs Cancer

Improving Access to Support for Unpaid Carers - Evidence submission from Young Lives vs Cancer

This submission to the Health and Social Care Committee inquiry on support for unpaid carers is provided on behalf of Young Lives vs Cancer, the charity supporting children and young people (0-25) with cancer and their families. We are happy for our evidence to be published associated with our organisation. All lived experience quotes have been provided on an anonymised basis.

Cancer in Children and Young People

Every year in Wales around 180 children and young people under the age of 25 are diagnosed with cancer¹. Despite medical advances, cancer remains the leading disease-related cause of death for this age group.

Cancer in children and young people brings with it a vast range of unique impacts which are distinct to this age group and their clinical and psychosocial experiences. This includes the impact on their wider family and loved ones, who often immediately become unpaid carers as soon as they are diagnosed with cancer, throughout their treatment and beyond.

Throughout their experience with cancer, children, young people and their families can go through what is likely the most difficult time in their lives and live with enormous disruption and unexpected challenges, including practical, physical, mental and financial. Adequate support for those caring for children and young people with cancer is therefore vital.

Caring and financial impacts

When a child or young person is diagnosed with cancer, one or more of their parents frequently give up work, or at a minimum must reduce working hours or alter their employment arrangements, to care for their child. This has a significant impact both financially and on their long-term career prospects (see later).

To try to meet their caring needs, parents pull on every source of leave and time off they possibly can (frequently using combinations of these), until these are exhausted, which ultimately leaves the only option as unpaid time off or leaving employment. Young Lives vs Cancer's research² shows that this includes:

- taking unpaid leave (30%)
- taking additional holiday leave (29%)
- taking sick leave (40%)
- taking compassionate leave (35%)
- changing to more flexible working arrangement (35%)
- reducing working hours (31%) – however those with variable incomes lose out by not being able to work their usual hours

For almost a third of households with someone employed prior to the diagnosis (32%), at least one of the adults stopped work just to be able to travel to treatment with their child, however our experience suggests that this figure is higher when taking into account a broader range of caring activities than

¹ Children and Young People's Cancer Statistics, Cancer Research UK (Accessed November 2024)

² Running on Empty, Young Lives vs Cancer (2023)

travel to treatment alone. Previous Young Lives vs Cancer research³ found that two in three parents struggled to manage their child's cancer and treatment alongside their work.

Being forced to take the actions described above results in reduced income - 71% experience a loss in income, which on average is £6,000 annually, but for one in three this reaches over £10,000^{2,4}. Income losses appear to be more common in those with younger children and those where treatment takes place over a longer period of time².

These losses come alongside the significant additional costs that come with being diagnosed with cancer as a child or young person. Children and young people with cancer and their families also experience additional monthly costs due to living with cancer of £700 on average⁴, for essential, unavoidable costs including travel to treatment, accommodation, and increased household expenses amongst others.

The biggest of these costs is the cost of travel to treatment, which alone for those in Wales averages £280 every month, to travel over 530 miles every month – the highest costs and longest travel distances in the UK. As a result, 71% report struggling with the costs of travel, and one in 10 miss or delay treatment because of the cost of getting there².

These additional costs are experienced on top of their usual expenditure, which persists throughout their experience with cancer. This results in an average financial penalty of over £14,000 a year (combining income loss and additional costs).

Barriers to support – welfare benefits

Current benefits support for carers of children and young people with cancer are insufficient in supporting the direct financial costs they face at the point their caring need arises.

Our research shows that whilst almost three in five (58%) report receiving some new or increased benefits following the cancer diagnosis, and despite the significant caring needs of children and young people with cancer, only 28% of these are awards of Carer's Allowance^{2,4}.

Further research⁵ shows that on average, children and young people with cancer experience delays of seven months following their diagnosis before receiving a decision (and if awarded, their first payment) on their disability benefits (DLA or PIP). This has a knock-on impact on parents receiving Carer's Allowance, which is dependent on the award of DLA or PIP to be confirmed. This is leaving parents without vital support for months during their child's cancer treatment, despite the need to care for them arising at (or in some cases, prior to) diagnosis.

Carer's Allowance is also paid at only £81.90 a week, which when compared to the additional, unavoidable costs faced by carers of children and young people with cancer, does not meet the additional financial and caring costs of an average £700 a month that they face.

Caring and bereavement

The data from our research⁴ indicates that bereaved parents report around £200 higher additional costs than non-bereaved. This indicates that additional costs may be higher or felt more acutely for those who become bereaved when their child dies, after caring for them until that point and could be attributed to an increased care need towards the end of life.

However, when a child or young person with cancer dies, their family no longer receives any previously claimed disability benefits (PIP and DLA) or carer's benefits, which are stopped immediately on the death of their child. This is a sudden cessation of essential support for the additional costs that have mounted throughout their child's treatment and time caring for their child – costs and impacts which persist well beyond treatment or the point of bereavement. It is therefore essential that parents receive support at and into bereavement.

Despite this, there is no equivalent of the Bereavement Support Fund (for when you lose a partner) for families who lose a child. Families that we support express concern and challenges around the

³ Hard Work, Young Lives vs Cancer (as CLIC Sargent) (2020)

⁴ Cancer Costs, Young Lives vs Cancer (2023)

⁵ Cost of Waiting, Young Lives vs Cancer (2025)

immediate withdrawal of financial support and the lack of alternative financial support in place post-bereavement.

As a result of these financial impacts, lack of financial support, and other factors, parents can feel pressured to return to work sooner than they feel ready following their bereavement. As noted above, three out of five parents went back to work before they felt ready - over half said this was because they needed the money, and one in four parents returned because they felt pressure from their employers³.

It is vital that parents who lose a child to cancer are supported to grieve and process the impacts, especially on their mental health, of losing a child and are not pressured to return to work due to financial or other reasons. This requires sufficient bereavement leave, pay and other associated support – especially financial support (including improved support during caring for their child).

Caring and employment

The significant financial impacts carers of children and young people with cancer face results in them not being able to fully contribute to economy, giving them less spending power and seeing them take on additional debt. Leaving employment or making significant changes to working patterns also results in carer's careers stalling, progressing more slowly, or halting all together.

These issues are exacerbated by a lack of support from employers. For example, the type of leave available to parents can vary significantly, often depending on the Human Resources policies of their employer, driving significant variances in experiences. And although parents and carers are entitled to take time off work after a cancer diagnosis, there is no legal obligation for their employer to pay them³.

Nearly half of parents of children with cancer have never accessed flexible working arrangements. Of those, three out of five would have liked to. One in 10 parents felt their employer wasn't supportive when they told them about their child's diagnosis. This increased to 16% during treatment and one in four (27%) once treatment was finished. This suggests that support can be time-limited and that patience and good will of employers "can wear thin"³.

There are also wider impacts on short- and long-term employment felt as a result of caring for a child or young person with cancer. For example, over one in four parents have felt unfairly treated at work or when applying for a job because of their child's cancer³, which damages trust in employers, motivation to seek employment, and limits career progression for parents.

Ultimately, financial pressures and lack of support is resulting in parents returning to work before they are ready to do so. Three out of five parents went back to work before they felt ready, and over half of parents said this was because they needed the money. One in four parents returned to work even though they didn't feel ready because they felt pressure from their employer³.

Recommendations

To address the barriers and challenges noted in this submission, consideration should be given to the adequacy of carer's support for parents and carers of children and young people with cancer, and in particular the suitability of qualifying criteria and periods, for both disability benefits and carer's benefits.

Young Lives vs Cancer propose the following recommendations are considered:

- remove the qualifying period for disability benefits for children and young people with cancer where there is sufficient medical evidence of daily living impacts and care need, expediting the process (which would also impact on Carer's Allowance awards)⁵
- de-coupling the award of Carer's Allowance and other forms of support from the award of disability benefits, and basing this on when the care need arises not when the disability benefit has been awarded
- increasing statutory support to better reflect the true costs of caring, particularly for families facing the sudden onset of the costs of cancer and loss of income
- introducing a Young Cancer Patient Travel Fund so carers taking their child to hospital can receive support for the significant costs of travelling to treatment and care
- extend payment of welfare benefits support beyond the death of a child with cancer
- introduce a specific Bereavement Support Payment for families who lose a child

- improve support for and from employers to better accommodate carers' needs, including flexible working arrangements and leave arrangements, and recognition of the impact of caring for a child or young person with cancer

Lived experience quotes

The following quotes from parents of children with cancer, which were provided as part of Young Lives vs Cancer's research and policy evidence, further articulate the challenges that unpaid carers of children and young people with cancer face:

"I had to stop working while she [daughter] was having treatment. My employers weren't able to pay me, I had to take unpaid leave."

"Since he was diagnosed, I'd say we probably had a few thousand in savings, and now we've maybe got like £100 in savings."

"We fell behind with our gas and electric payments because we had to use the money for travel and extra costs of living in hospital."

[in response to their wait for benefits] "Six months with loss of income, no help, and extra costs meant we used all our savings. This could have been avoided."

"I had to take a year's unpaid leave from my job to care for my son as after my sick leave was used up I was advised I would be sacked if I didn't return to work which meant my already reduced wage became £0."

"We struggled with additional costs of getting to hospital for treatment, and living costs while staying for a week at a time, and loss of my income due to taking unpaid leave to attend appointments."

"I am currently signed off sick and will be leaving employment following a period of sick leave, so that I can care for my son. It is impossible to plan / predict our finances. We are having to reduce our outgoings and go without any luxuries / things that improve your quality of life which causes additional stress."

"More awareness on assistance available when parent is unable to return to work due to appointment schedule and emotional distress. Knowing where to start and go for support and what is out there."

"Financial support - there is no way a parents can work and care at the same time, and be able to give enough to both."

"By the time he was assessed, he had completed treatment, and I had to borrow over £1,000 to fund transport and living expenses. No PIP award meant that I am continuing to pay this back now, having taken on extra work, while still trying to support my son with monthly follow up appointments and ongoing health issues."

About Young Lives vs Cancer

Young Lives vs Cancer is the charity supporting children and young people (0-25) with cancer and their families. Each year we support around 220 children and young people with cancer and their families in Wales.

We do this through our specialist social care teams who provide practical and emotional support and work closely with primary healthcare professionals as an integral part of care teams. We also provide free accommodation near hospitals across the UK, and financial support and welfare advice to help tackle the additional costs that come with cancer.

No matter what, we stand alongside children and young people with cancer and their families, working in partnership with UK governments, the NHS, and our partners, to transform the system to ensure they can access the care and support they need, and their voices are heard.