

STATES OF JERSEY



PROPOSED GOVERNMENT PLAN 2024- 2027 (P.72/2023): FIFTEENTH AMENDMENT

INCOME SUPPORT (SPECIAL PAYMENTS) FOR CARERS OF CHILDREN WITH LIFE-THREATENING, LIFE-LIMITING ILLNESSES, OR COMPLEX HEALTHCARE NEEDS

Lodged au Greffe on 27th November 2023
by Deputy L.V. Feltham of St. Helier Central

STATES GREFFE

PROPOSED GOVERNMENT PLAN 2024-2027 (P.72/2023): FIFTEENTH
AMENDMENT

1 PAGE 3, PARAGRAPH (h) –

After the words “Appendix 2 – Summary Tables 5(i) and (ii) of the Report” insert the words –

“, except that, in Summary Table 5(i) the Head of Expenditure for Customer and Local Services should be increased by £600,000 to enable special payments to be paid to any household in which a member of the household is a child who has been diagnosed with or recognised as having a life-limiting condition, a life-threatening condition, or a complex healthcare need, by a healthcare professional”

2 PAGE 3, PARAGRAPH (l) –

After the words “as set out at Appendix 3 of the Report” insert the words –

“, except that, on page 90 after the words “benefits for many years to come.” there should be inserted a new paragraph as follows –

“Funds have been allocated for 2024 to support a non-statutory scheme, equivalent to the child personal care benefit, for children diagnosed with or recognised as having a life-limiting condition, a life-threatening condition, or a complex healthcare need. During 2024 the Government will undertake a review of the relevant legislation in order to extend this provision in legislation for future years.”

DEPUTY L.V. FELTHAM OF ST. HELIER CENTRAL

Note: After this amendment, the proposition would read as follows –

THE STATES are asked to decide whether they are of opinion –

to receive the Government Plan 2024 – 2027 specified in Article 9(1) of the Public Finances (Jersey) Law 2019 (“the Law”) and specifically –

- (a) to approve the estimate of total States income to be paid into the Consolidated Fund in 2024 as set out in Appendix 2 – Summary Table 1 to the Report, which is inclusive of the proposed taxation and impôts duties changes outlined in the Government Plan, in line with Article 9(2)(a) of the Law;
- (b) to refer to their Act dated 30th September 2016 and to approve the application of existing resources for work on the development of ‘user pays’

charges in relation to all aspects of waste, including commercial and domestic liquid and solid waste;

- (c) to approve the proposed Changes to Approval for financing/borrowing for 2024, as shown in Appendix 2 – Summary Table 2 to the Report, which may be obtained by the Minister for Treasury and Resources, as and when required, in line with Article 9 (2)(c) of the Law, of up to those revised approvals;
- (d) to approve the extension of the use of the existing Revolving Credit Facility to include the provision of funds that would otherwise be implemented through bank overdraft or bank overdraft facilities under Article 26 (1)(a) of the Law, should they be needed, subject to the limits outlined in that article;
- (e) to approve the transfers from one States fund to another for 2024 of up to and including the amounts set in Appendix 2 – Summary Table 3 in line with Article 9(2)(b) of the Law;
- (f) to approve a transfer from the Consolidated Fund to the Stabilisation Fund in 2024 of up to £25 million, subject to a decision of the Minister for Treasury and Resources based on the availability of funds in the Consolidated Fund as at 31 December 2023 in excess of the estimates provided in this plan, or from budgeted underspends identified before 31 December 2024;
- (g) to approve each major project that is to be started or continued in 2024 and the total cost of each such project and any amendments to the proposed total cost of a major project under a previously approved Government Plan, in line with Article 9(2)(d), (e) and (f) of the Law and as set out in Appendix 2 - Summary Table 4 to the Report;
- (h) to approve the proposed amount to be appropriated from the Consolidated Fund for 2024, for each Head of Expenditure, being gross expenditure less estimated income (if any), in line with Articles 9(2)(g), 10(1) and 10(2) of the Law, and set out in Appendix 2 – Summary Tables 5(i) and (ii) of the Report, except that, in Summary Table 5(i) the Head of Expenditure for Customer and Local Services should be increased by £600,000 to allocate funds to enable special payments to be made to any household in which a member of the household is a child who has been diagnosed with or recognised as having a life-limiting condition, a life-threatening condition, or a complex healthcare need, by a healthcare professional;
- (i) to approve the estimated income, being estimated gross income less expenditure, that each States trading operation will pay into its trading fund in 2024 in line with Article 9(2)(h) of the Law and set out in Appendix 2 – Summary Table 6 to the Report;
- (j) to approve the proposed amount to be appropriated from each States trading operation’s trading fund for 2024 for each head of expenditure in line with Article 9(2)(i) of the Law and set out in Appendix 2 – Summary Table 7 to the Report;

(k) to approve the estimated income and expenditure proposals for the Climate Emergency Fund for 2024 as set out in Appendix 2 – Summary Table 8 to the Report; and

(l) to approve, in accordance with Article 9(1) of the Law, the Government Plan 2024-2027, as set out at Appendix 3 to the Report, except that, on page 90 after the words “benefits for many years to come.” there should be inserted a new paragraph as follows –

“Funds have been allocated for 2024 to support a non-statutory scheme, equivalent to the child personal care benefit, for children diagnosed with or recognised as having a life-limiting condition, a life-threatening condition, or a complex healthcare need. During 2024 the Government will undertake a review of the relevant legislation in order to extend this provision in legislation for future years.”.

REPORT

Purpose

The purpose of this amendment is to ensure that parents and carers of children with life-threatening or life-limiting conditions, or a complex healthcare need, can access financial support to assist them with the additional expenses and financial pressure experienced due to the additional care needs associated with the illness.

Background

Currently, there are many families that include a child with a life-limiting or life-threatening condition, or a complex health care need, that receive no financial support from Government. This is despite the additional costs of providing care, the loss of income from only being able to work reduced hours, or the need for a parent or carer to take a break from work entirely due to their caring requirements. This results in families being put into undue emotional and financial stress at an incredibly difficult time, and places them into a situation where they are reliant on the support of charity. The issue is exacerbated because many of the children are required to travel off-island for periods of treatment and/or maybe the only child on the Island with their condition.

As outlined in the Health Minister's answer to [WQ. 422/2023](#) a care pathway for children with complex care needs was launched in 2016 based on the principles set out by the UK charity 'Together for Short Lives' that is considered to reflect best practice in the UK. This pathway is managed jointly by the HCS Paediatric team and Family Nursing and Health Care (FNHC). Up to the end of 2022, there were 58 children managed on this pathway.

Together for Short Lives identifies four groups of life-threatening or life-limiting illnesses, which I include as an example of the types of conditions that this amendment relates to:

Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail , where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. <i>Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.</i>
Category 2	Conditions where premature death is inevitable , these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health. <i>Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1.</i>
Category 3	Progressive conditions without curative treatment options , where treatment is exclusively palliative and may commonly extend over many years. <i>Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.</i>
Category 4	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death . Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care. <i>Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.</i>

These conditions are also recognised by Children, Young People, Education and Skills which provides some support services via the Children and Families Hub ([WQ.421/2023](#)).

Access to benefits is also recognised within the [Together for Short Lives Core Care Pathway for Children with Life-threatening and Life-limiting Illnesses](#). The Minister for Social Security confirmed in her answer to [WQ.420/2023](#) that the only financial support offered to families with children with chronic health conditions is the Child Personal Care Benefit, Home Carer's Allowance, and Income Support. However, there is currently no recognition of many life-threatening or life-limiting conditions, or the complexity of care need, within the income support or social security legislation because the nature of the conditions mean that many of the children do not meet the impairment criteria set out in the [Income Support \(Jersey\) Regulations 2007](#). Therefore, many families cannot receive the Child Personal Care Benefit or the Home Carer's Allowance despite children requiring complex or continuing care. Further, families with a mortgage are most likely not to meet the income support means test due to mortgage payments not being included in household expenditure for income support claims. This leaves families with no financial support from Government despite financial stress due to the increased costs associated with health care, and loss of income if a carer is unable to work in their usual employment.

Currently, the Child Personal Care Benefit is available to families with children who have a high level of long-term illness or disability, but not for families with life-limiting or life-threatening conditions. This is at odds with the best practice outlined within the Together for Short Lives Guide to Children's Palliative Care, which states:

Many children with life-limiting or life-threatening conditions need the same good quality universal services as disabled children. However, the increased likelihood or certainty of death in childhood or young adulthood for a child with a life-limiting or life-threatening condition adds a degree of complexity and urgency to the care that is needed for the child, and the increased support that is needed for the family. These children often need additional planning to meet their fluctuating, unpredictable and sometimes urgent need for dedicated children's palliative care services.

There should be close working between services for children with life-limiting or life-threatening conditions and those for disabled children to achieve joined-up provision which enables them to maximise their potential and live life to the full.

P.10, *The Guide to Children's Palliative Care, Together for Short Lives*

Child Personal Care Benefit is paid at a rate of £175.28 per week if a child is assessed at level three of the Personal Care Component of the [Income Support \(Jersey\) Regulations 2007](#). In consideration of the need for increased support outlined above I believe it would be proportionate to realign the criteria so that children with life-limiting and life-threatening illnesses are assessed at this level. However, this amendment will enable the Minister for Social Security to work with the Minister for Health and Community Services, and the Minister for Children and Education, to get professional assessments to inform definitions and criteria ahead of making legislative changes.

Conclusion

The financial element of this amendment ensures that funding is available so that families can get the equivalent of Child Personal Care Benefit through a non-statutory benefit in 2024. The amendment also requests the Assembly to agree in principle to the Minister for Social Security bringing forward updates to the relevant legislation so that life-threatening and life-limiting illnesses, and complex care needs, are acknowledged and assessed for financial support.

Financial and staffing implications

It is estimated that 50 – 60 families may meet the criteria for support at any given time. Therefore, it is estimated that the cost of the non-statutory benefit will not exceed £550,000 in 2024. There may be some administrative costs associated with establishing the benefit and drafting legislation for future years, therefore I have included £50,000 to ensure that this is accounted for.

I have left the source of funding to Ministers' discretion. If they are unable to identify a suitable source within current Heads of Expenditure the additional draw on the consolidated fund would not lead to a negative balance.

Income Support for carers of children with the recognition or diagnosis of a life-limiting or life-threatening condition - A Case Study		
Background/Insight	Impact for family members	Professional Reflections
<ul style="list-style-type: none"> There is a cohort of local children who have the recognition or diagnosis of a life-limiting or life-threatening condition, or a long-term chronic health condition. Some children may be given a named diagnosis whilst others don't – which can leave the family in 'limbo' and without access to appropriate services if appropriate supports or interventions are not put into place. It is acknowledged that the financial cost of illness and disability is significant, (Contact a Family, 2012) however, 'Together for Short Lives' highlight that complex and/or rare conditions often require considerable supporting evidence from health professionals to convince benefit agencies (TFSL 2004). Families often lose one income to facilitate caring. There is the potential for unpredictable or potentially terminal events and parents/carers experience living with uncertainty. They value support that puts their child and family at the centre of care planning, and provides an integrated service in response to individual need and circumstance rather than disease trajectory - with an emphasis on 'Quality of life'. 	<ul style="list-style-type: none"> Parents were upset and frustrated following unsuccessful application, and fearful as to how they would financially cope. An appeal failed. Mum changed job and Dad took extra hours to manage financially and meet their child's care needs, ensure provision of medical supplies, and to facilitate both planned and emergency hospital admissions/reviews. Annual leave was quickly used up, and unpaid leave was not an option. The parents have experienced so many challenges, their mental health has been affected and their relationship strained. Both children have also required emotional support due to increased anxiety and the impact that the complex health care needs have had on them both. The child is so traumatised and needle phobic due to the level of medical interventions and treatments he has had to endure throughout his life he has required extra specialist CAMHS input and psychological support. UK hospital visits are frequent and costly. If unplanned, financial burden increases alongside the disruption, separation and emotional stress. For extended treatment episodes where accommodation is organised, there are the pressures of running of two households. Specialist medical equipment and feeds are prescribed for the child, and these need to be collected and paid for by the family. Infection control measures are recommended for within the home which the family also fund. 	<p>Tess Watson, Case Worker, CLIC Sargent Jersey: 'We help families by reducing stress over financial burdens and 'hidden' costs. This differs for each family depending on their circumstance, but we see first hand the frustrations and anguish they experience. We remove some of the pressure and embarrassment of asking for help. One Mum said: <i>'We are so grateful. We've already come across extra charges for things like pillows and duvets - even silly things like washing is not straight forward because we then need an extra set of everything!! All things that we hadn't even thought of.'</i></p> <p>Polly Axford, Community Children's Nurse (CCNT): 'We advocate for the child and their family, and in our practise we see many of the experiences within this case study replicated in other families whose children have complex health care needs.'</p> <p>Jess Paton, 'Family First': 'I am always sad to see the lack of financial support given to families through what is a very stressful and upsetting time in their lives. Charities step in to ease the financial burden faced - I hope change can be made to give parents the chance to focus solely on their child and family's wellbeing'</p>
Case Study	Parent Feedback	Recommendations/Considerations
<p>Born with congenital heart disease and renal disease this boy (8) and his parents and sister (10) have received support from the Community Childrens Nursing Team (CCNT) the Children's Palliative Care Pathway (CPCP) since his birth. He has required multiple admissions to UK hospitals and also in Jersey, and receives co-ordinated care from numerous specialist teams.</p> <p>There have been extended UK admissions (3-5months a time) for parents to gain competence and upskill so as to safely deliver his care at home. His parents became expert caregivers and responsible for the complex, day-to-day care of their child – e.g. home dialysis, blood sampling, central line cares. They are functioning as his care providers and advocate, alongside their parental role, and their lives are affected financially, socially and emotionally.</p> <p>Mum has changed job several times trying to accommodate maintaining the finances they need and being able to provide the care her son required over a 24hr period. She is frequently exhausted as she juggles this, which is exacerbated during episodes of illness and/or increased UK reviews. Unplanned admissions particularly impact the whole family, with hidden costs and sudden changes to routine alongside uncertainty and anxiety about what the future holds. 'Family First' have provided support through their journey so far to 'bridge some of these gaps'.</p> <p>Typically, school attendance this term alone only is 40% this due to episodes of illness requiring time at home or hospital admissions both locally or in Southampton.</p>	<p><i>'I was completely exhausted at times as up throughout the night then working a long day the following day.'</i></p> <p><i>'We felt completely let down and pushed to breaking point because we did not fit the tick box criteria.'</i></p> <p><i>'The form asked if he could use a spoon which he could - but he was feed through a gastrostomy tube.'</i></p> <p><i>'If things had not have changed when they did, I'm not sure where I would be now as it was not a sustainable way to live.'</i></p> <p><i>'I ended up on antidepressants just to try and keep myself functioning. At times I felt broken and didn't want to be here any more because of the pressure – trying to keep on top of my son's needs and working was breaking me.'</i></p>	<ul style="list-style-type: none"> Each child and their family is unique in their own disease trajectory and 'one box does not fit all'. With change, we can enhance and facilitate that this vulnerable group of children and their families have a better 'quality of life'. The current application form does not accurately reflect some children's level of need. The current application form does not capture the impact or challenges faced by many with chronic and/or acute complex health care needs. It is hard to predict the future and some children's needs may fluctuate and be unpredictable. Needs of those with degenerative conditions or at the 'end-of-life' will continually evolve and their needs increase, as well as those of the family.

Income Support for carers of children with the recognition or diagnosis of a life-limiting or life-threatening condition - 'Letter from a parent'

To whom it may concern,

Firstly, thank you for taking the time to read my letter.

Our son Liam was diagnosed on September 6th 2022 with high risk B-cell Acute Lymphoblastic Leukaemia at 13 years old. Less than 24 hours later myself, husband and Liam were flown to Southampton General Hospital where he started chemotherapy treatment. We were told we would need to be in Southampton receiving treatment for 4-6 weeks which was hard to imagine as we have other children, jobs, a mortgage and also our family dog. Liam's health was our main priority, so we focused on him and getting him better. Once we arrived in Southampton, we were then told that Liam would need to stay for 6 months in the UK to receive treatment. I was not too concerned regarding my outgoings as my sick pay would cover me for 6 months, but my husband however, is not paid for time off and as his income covers the majority of our monthly outgoings. This did leave us concerned as to how we would be affected financially, and as the government only cover the cost of four return flights and we had no idea how we would manage being apart for such a long period. We knew we could not afford to pay for regular flights for my husband and two other children.

All this whilst having to deal with the emotions and trauma of having a child with cancer. Charities such as 'Family First' and 'CLIC Sargent' reached out to offer support. This was welcomed but also overwhelming, and I had no idea at the time how much I would rely on them as time went on. I just wanted my child to be ok and us to be back at home as a family. I struggled to focus on anything other than my child. One Tuesday I was sat at work and the next day I was sitting in a kids cancer ward, with my world crumbling and I could not control it.

Liam treatment meant he had to have a portacath inserted into his chest to receive treatment, and after 6 days he became extremely unwell and was moved to PICU. Liam had Stage 4 Septic Shock. He was ventilated and put onto life-support. His life was not guaranteed, and it was extremely difficult watching our child connected to so many machines, not knowing whether we would hold or talk to him again. As a parent having to make the choice of who will stay and who will go back home to Jersey was extremely hard – what if it was the last goodbye? The emotional torture was hard on us both as parents and being by his side, and each others, felt the right thing to do. Fortunately, Liam pulled through and after a few weeks in hospital we were provided with a flat as Liam was now an outpatient. Because of the Jersey charities available to families with sick children, our two other children were able to join us for a week at the end of October before returning home with my husband.

Myself and Liam were we were alone in a strange city. There was the real worry and extra stress of knowing if Liam got a temperature or became sick we would need to pack up the we were staying as the government would only cover the costs of accommodation whilst he was an out-patient. We did not know anyone who could help us, so even on Liam's worst days we needed to go out as we needed to eat. We could not afford to buy on-line food as we were penny watching and needed to ensure we only bought essentials. We now had two households to keep, and needed to make our money stretch as far as possible. Initially, we had been told to only pack to stay in Southampton for a couple of weeks, so we also had to find clothing suitable for the change in season as the weather became cold. Liam was on high dose steroids which meant he was hungry a lot more than normal. Our budget was tight! Apart from Family First and CLIC Sargent charities, we have been offered no support or help with finances from Social Security as we own our own home. We were advised we would need to sell our home and only then could they look at our case. We have basically been relying on the amazing charities to help cover the costs for my husband and two other children to visit us and with any other extra expenses and monthly bills.

Six months on and Liam was still no closer to returning home. The treatment was not working as well as we had hoped it would, and we were advised that Liam would require more treatment in the UK followed by a bone marrow transplant. Our youngest was a match to be Liam's donor, which meant more time off work for my husband so as he could attend hospital appointments at Great Ormond Street Hospital whilst I stayed with Liam. This put more financial strain on us and our priorities started to shift from our children's health and well-being to how we would financially cope. My wages had also stopped by this point, so we were managing on one income and supporting two households. I looked into applying for carers allowance as my son had cancer, but the assessment requirements leaned more towards him not qualifying. I felt it was more of a tick box application, and although Liam did not respond well to the chemotherapy, he was physically coping and feeling relatively well, so I knew the likelihood of us qualifying was extremely slim. We had been through so much as a family already, I was not prepared to put us through more stress by reapplying – stress we did not need as we had already had so much to deal with, and I felt our own mental health and well-being was extremely low. I also feel the assessments are extremely judgemental, as the fact is regardless of whether or not the assessment criteria is met, if a child requires medical care or treatment in the UK, a parent is required to stay with that child by law. This law means that a parent cannot work!

We have now been in the UK for 15 months and still no closer to returning home. My son will turn 15 years old next month and should have started his GCSE's in September. Once we return home we will need to return to the UK for review and tests which means life will not go back to 'normal' for a while yet, and this includes financially. Thank you again for taking the time to read my letter. I feel it is important that I speak up not only to share my own story, but for other families past and present. I hope that positive changes can be made.

Lisa

References:

Contact a Family, 2012. *Counting the Costs 2012 – The financial reality for families with disabled children across the UK*. London: Contact a Family.

Together for short lives, 2004. *A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*. Bristol.