



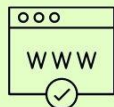
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Cymunedau Gofalu o Newid

Cost of Living Crisis and Learning Disability Families in Wales

The All Wales Forum
of Parents & Carers of People with Learning Disabilities



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Who We Are

- The AWF was set up by a group of parent carers across Wales who want to have 'voice and control' over the way in which services for their sons & daughters with learning disabilities are planned and delivered.
- We represent learning disability carers at a local and national level to ensure that issues directly facing family carers are heard and given proper consideration by both local and national government.



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Statistics

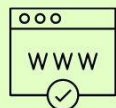
Carers Wales 'State of Caring in Wales 2022' Report:

- Carers in receipt of Carer's Allowance were more likely to be struggling to make ends meet (39%).
- Carers who were struggling to make ends meet were more likely to be cutting back on spending. More than a quarter of carers (26%) said they were cutting back on essentials such as food or heating, nearly twice as many compared to 13% last year.
- The majority of carers (72%) said they were 'extremely' worried about managing their monthly costs. 87% said that the rising cost of living was one of the main challenges they would face over the coming year. Both are 10% higher than the UK average.
- 26% cutting back on essentials such as food or heating

https://www.carersuk.org/images/State_of_caring_in_Wales/Compressed_Carers_Wales_State_of_Caring_in_Wales_2022_report_English_final.pdf



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Case study #1

- Big family with several loved ones with additional needs, two of whom are wheelchair users means they live in a bigger house which requires more energy
- Long waits to access specialist equipment means the family have had to buy some of these themselves
- One of the children with a learning disability is prone to catching chest infections and another of their children is having heart surgery soon and they will have to keep the house warm during the recovery
- The family feels abandoned and blamed for being parent carers





Case study #2

- Family with several loved ones with learning disabilities
- One of the children is at high risk of chest infections and suffers the cold more than the average person.
- The family has installed a smart meter and is in communication with the energy provider but has received very little clarity about Government help and have only seen their bills increasing
- The family has also received different readings and cannot get in contact with the provider over these
- They are estimating that to warm up the house for a half an evening it costs them around £30 and are extremely worried they won't make it financially through the winter





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Quotes

“We use more fuel as my young adult needs baths.. They has a progressive condition which means their hands and feet get extremely cold.. we layer up but this doesn’t always help.. they often can’t feel to tell me either .. so heating is on more and they have to take baths regularly.”

“My young adult has two hoists, a lift, a profiling bed, Gerberit toilet, electric powered chair and can't keep their body temperature constant. They might be in college during the week, however the house has to stay at a constant temperature as I never know when they are being sent home due to illness or their cp/epilepsy. That's without the washing - have to change the bed twice a week on a good week, on a bad day we've had 6-7 changes in a night, add into that the extra showers and towels we use then. So far the highest amount I've spent in a day is £11 (whereas this time last year my direct debit was just under £200 a month, it's now £330)

My young adult is eligible for the £200 from WG fund you apply for from the local authorities however we can't get warm home discount any longer as they are an adult who lives at home with me and isn't the bill payer.”



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Quotes

“2 of my children don’t currently have any education. I can’t expect them to sit in a cold house day in day out. It would be different if they were in school during the days. We had so many obstacles to accessing education for my children. Zero mental health support. An ALENCO who doesn’t know their job. No accountability. Disability discrimination. Medical discrimination. Cahms inadequacy I could go on and on and on”

“My loved one is incontinent so have to wash and dry multiple loads every day, also uses powerchair and doesn't have understanding to turn taps and lights off when leaving a room or after playing with water.”

“Incontinence requiring washer and dryer running all day. Through-lift running, electric bath platform running. Electric adult sized changing table. Sensory room and potable sensory unit running. 4 iPads., 2 iPods communications devices charging daily. Large two story DFG extension to heat.”



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Quotes

“Disabled children have to be kept warm to keep them healthy . Hoists have to be charged at all times , electric wheelchairs need charging , feeding pumps need charging , hot water needs to be available , profiling bed , multiple washing loads due to incontinence , electric feeding pumps need to be charged , lifts in houses have to be kept in at all times . Please remember people with shared care that have one person keeping the child’s benefits, so the other parent have even more financial hardship”

“my profoundly disabled loved one needs the room to be very hot when bathing or they will start to turn blue. you can't wrap someone in blankets when you're bathing them.”



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How can we Improve things for families...

- Support available for unpaid carers- what happens when there are huge waiting lists? What's next? Many services are already overwhelmed, we can still signpost families but is there anything to help them in the meantime
- Look to provide Carers Assessments locally through local carer organisations
- Ensure the funding of the preventative services within the community & constituency areas to avoid further crisis build up
- The UK Chancellors Statement and what it means for Wales- Welsh ministers will have £1.2bn to spend over two years. This needs to be used wisely to support the most vulnerable in our societies and communities such as carers to avoid crisis in other services such as the NHS.
- Continue to raise awareness of the right of unpaid carers to access support



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Resources for Families

- Warm Wales - <https://www.warmwales.org.uk/>
- Citizen's Advice Adviceline Cymru – Check your benefits and any support available - <https://www.citizensadvice.org.uk/about-us/our-work/advice-partnerships/advicelink-cymru/>
- Nest Scheme - <https://nest.gov.wales/>
- C.A.L.L. Helpline - <https://www.callhelpline.org.uk/>
- Carers Support Fund Wales Programme - <https://carers.org/around-the-uk-our-work-in-wales/carers-support-fund-wales-programme>



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Thank You

If you want to get in contact, you can find us
at caringcommunities@allwalesforum.org.uk

or contact us on social media



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