

Unpaid carers roundtable event

19 November 2025

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We used the points set out in the Annex as a structure for the discussion, but participants were free to talk about the issues that mattered to them.

We are very grateful to the carers for sharing their experiences with us.

We are also grateful to Carers Wales and Carers Trust Wales for facilitating the session.

Group 1

Participants in this group were adult carers and parent carers.

Session 1: Identification as a carer, assessment and support

“Change is a necessity. None of us have asked to be in this position, and anyone could find themselves in our shoes.”

General comments about being an unpaid carer

- Carers told us that “the system is broken” – there is legislation in place but it is not being acted upon.



- Carers described feeling **guilty** about asking for help for themselves. They said they were used to asking/begging for help for those they care for, but they find it hard to ask/beg for help for themselves.
- They also said they feel **fear** as well as guilt – they are frightened to say they need help because it makes them look like they can't cope, and they don't want to be judged/ridiculed for this.
- They also described feeling **ashamed** to ask for help, and said they are *"invisible until crisis"*.
- Carers often don't realise that they are carers. Often they have multiple caring roles, for people with complex needs.
- They are reliant on informal groups and word-of-mouth to find out about support.
- As 24/7 carers, their social circle shrinks and eventually collapses, leaving them isolated and desperate.
- Carers have to deal with all aspects of the life of the person they care for, including their financial affairs, looking after their home and managing their medication.
- The pressures are so great that sometimes unpaid carers *"just want to run away"*. One carer told us that she often felt so overwhelmed by her responsibilities that she would sit in her car and cry.
- Carers said they felt they live **in solitude**. They told us that they can't see any light at the end of the tunnel. That they hope for the end of day so they can get some sleep ready to fight the next day.
- Carers told us their *"exhaustion is extreme"*.
- Carers described having to *"fight for everything"*, to *"fight the system"*. Some had found organisations like Bridgend Carers through word-of-mouth. They said they wouldn't have been able to manage without these organisations.
- They said that data sharing between relevant organisations was inadequate, and meant they had to tell their story over and over again to different people. This was very tiring and frustrating.

- They felt they were always having to look for information for themselves. There is no signposting, and no advocacy.
- Neurodivergence – carers with lived experience said this was being recognised, but not understood. They reported a lack of training about neurodivergence – in schools, social workers, and the health service. They felt that doctors often don't understand the needs of their neurodivergent patients.

Carers needs assessments

- Carers felt that very few assessments were taking place. They also felt that an assessment required lots of work from them for very little return. One carer told us that she had requested an assessment and had been told to complete her own. She had subsequently never received a form to do this.
- One adult carer told us she had received an assessment but did not know that she had, and that nothing had come of it.
- One adult carer applied for an needs assessment but had to issue a complaint because it took so long for the assessment to be undertaken (over six months). Has not heard anything following that assessment, which was two years ago.
- Carers felt that assessments should be part of an on-going process, rather than a one-off exercise which is no re-visited. They told us that someone should be checking-in on them, but that there was no follow-up and no advice given.
- We heard that the system was complex to navigate and that carers are put off requesting an assessment because there are no services available at the end of the process to refer on to.
- Carers told us that when they were sign-posted to services by local authorities/social services, these were usually charities/third sector services which already had long waiting lists. Charities themselves have very little money.
- One parent carer told us that local authorities are so understaffed and stretched that they can't cope with the level of demand. She reported having been sent, in error, a copy of another person's needs assessment,

containing personal, identifiable information. She said this demonstrated there was a problem in the system, and led to a lack of trust in her social worker (who had sent the document to her in error) as a result.

- Carers said that assessments had been based on assumptions rather than face-to-face interviews, and that those carrying out the assessments lacked any lived experience of caring.
- Carers felt the assessment was a tick-box exercise which did not take account of family circumstances. They felt that, following an assessment, the local authority would signpost as much as possible to community services (which were already stretched) in order to save money. One adult carer said she was told by her social worker that her mother had to be 'kept at home for as long as possible', rather than going into a care home. She felt this was to save the local authority money. One parent carer said that, despite providing medical letters to the local authority about her own health problems and those of her husband, no support was offered and the family was told that the children could be taken into care.
- Carers also felt that, following assessment, local authorities would start to "rip away" at any services that had been identified in the assessment.
- They argued that, although services are stretched, **early intervention** is crucial. They felt the system only 'acts on crisis'.

Session 2: Access to breaks and respite, and solutions

"If no one is looking after us, who will look after our loved ones?"

Access to breaks and respite

- Carers told us they **worried about being unwell themselves**, and what would happen to the person they cared for:

"We care out of love, but we need someone to care for us sometimes". "If nobody helps us, we will come to a halt. And what happens then to our loved ones?"

- Carers described a **lack of respite** care.

- They said the cost of formal care far outweighed the little bit of support they needed. They said that the system needed to recognise how much was being saved by the work of unpaid carers, and that investing in supporting those unpaid carers would pay for itself.
- Carers called for **practical support**, saying this was crucial to enable them to do every-day tasks.
- Carers said that respite was offered for one person being cared for, but not the other(s). A parent carer told us that she was given three hours a week of respite for one child, but not the other two children. This meant the respite offer was of limited value.
- Carers said they left their own needs (including health needs) until the very last because of their caring responsibilities. They felt that without unpaid carers, local authorities would have far more complex cases to provide care for.
- Carers reported having to find their own solutions to requests for respite. One carer said he was going to ask the cleaner to sit with his wife for a few hours rather than approaching the local authority for support, which felt very difficult. One parent carer said that, when she approached her local authority for support with her children, the social worker asked “*can’t your mother help more?*” Another parent carer said that her local authority had interviewed her elderly parents and siblings to ask why they were not able to offer more help.
- Carers said they **do not know what services they can access**; they are reliant on word of mouth and informal groups.
- Carers welcomed the support offered by charities, especially the opportunities to meet others in a similar position and share experiences. They said that, often, these carers charities/organisations had been set up by people with lived experience. They were far more helpful than local authorities.
- They told us that “*respite*” is not the right term.
- One parent carer described **interventions as short term**. She said they were good services when they were provided, but they don’t last.

- Direct payments were described as “*good when you can get them*”, but carers reported having to do all the work themselves, including vetting suitable staff. Concerned about need for enhanced DBS checks and how to arrange that. They suggested that local authorities could have a ‘bank’ of vetted individuals for carers to select from. They said that most carers would like to interview the person who will be looking after their loved ones, but they don’t have the time and they are already likely to be using any respite to do their admin.

What carers want

- Carers felt that the system was in place, but was not being carried out. There are “*lots of cracks*”.
- They felt that **no one is “governing” the system** – they want someone to be responsible for ensuring needs assessments are offered and carried out, and that carers have support as result of those assessments.
- Carers told us they want:
 - Access to a carers needs assessment, and they want someone to offer them appropriate advice and support;
 - Their assessment to be undertaken by professionals who will understand their needs, and that assessments should be done by an experienced team, rather than an individual;
 - To be supported to have **choice** – what the carer feels they are willing and able to do;
 - Action as a result of the assessment. That the people who undertake the assessments not to tell *them* “*you won’t meet the threshold for support*”, “*you will be on a waiting list*”, etc;
 - To be signposted to the appropriate support, and for that support to be **appropriate for their own particular needs**. Carers have diverse needs – it is important that the system recognises this.

Annex

The following points were used as a structure for the discussion, but participants were free to talk about the issues that mattered to them

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- Can you tell us about your caring role, and roughly how many hours a week you spend caring.
- From your experience, what are some of the day-to-day challenges carers typically face? Are there any challenges that are specific to your situation, for example your age, ethnicity, or who you are caring for?
- At what point did a service (like a carer service, school, local authority or health service) first identify you as a carer?
- Have you had a Carer's Needs Assessment from social services? If so, what support (if any) did you receive as a result, and how has it helped? Have you been offered any other support to help you manage your caring responsibilities?
- Overall, what kinds of support would make things easier for you, or improve your quality of life and well-being as a carer?
- What are the main barriers that can make it difficult for unpaid carers to get the support they need

Session 2: Access to breaks and respite, and solutions

- What is your experience of getting a break or respite care as a carer?
- What impact does access to breaks have on you as a carer, and on the person you care for? And how does it affect you both if you're unable to take breaks?
- If you've had a Carer's Needs Assessment, were breaks or respite discussed as part of that process? If yes, is respite care included in your own support plan, or in the care and support plan of the person you care for?
- In your view, how easy is it for carers to access support services like respite care, both in your area and across Wales?

- What are the main challenges/difficulties to taking a break as a carer? (e.g. cost, availability of replacement care, lack of suitable options)
- How can carers be better supported? What action is needed at a national level to improve access to support for carers, including breaks from caring? What more could the Welsh Government do to address the challenges faced by unpaid carers?
- What would make the biggest difference/improvement to your experience as an unpaid carer?
- Is there a key message you'd like to leave us with?

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Group 2

Participants in this group were mostly young carers (ages ranged from 12 to 16). There was also a carers' officer from a high school, a representative of a carers' charity; a support worker; two adult carers (one who is the carer representative on a RPB)

Discussion about school

- One young carer told us:

The main drawback for me is the lack of free time. I'm not able to access breaks or have any time to myself. School is the main outlet to see my friends, it's the only chance I really get to see other people my age.



- Another said “It sounds a bit sad but the main break I get is when I revise”
- We heard there is mixed support in school, some positive examples.
“I’m lucky my school (Radyr) is proactive and I was identified as a carer from year 7. Radyr has an identified carers officer.”
- Other schools don’t have the same support.
- Another young carer said
“My school doesn’t have set staff to support young carers. My form tutor tried to help as best they can.”
“All teachers need a better understanding of young carers.”
- Another young carer told us: “I still get punished for being late.” “There’s no support for young carers at all in my school.”
- There was agreement that we need more training for teachers to recognise and support carers; it should be a core part of whole staff training, and young carers should be involved in the training. It needs to be regular and systematic.
- The school carers’ officer said – *“we need whole staff training to improve identification, support and signposting.”*
- There was a suggestion that a young carers school council branch would help, supporting carers in all schools.
- The support worker said they had offered all schools in the area training on young carer awareness, and only 8 teachers came.
- Some schools are better than others. Some schools are reluctant to engage.
- Adult carer who is a carer representative on an RPB said:
Education is not involved in RPBs, it should be health, social care and education. Young carer support should be mandatory in schools like ALN.
- Part of mandatory education should be about caring roles. There was agreement that ‘caring’ should be on the curriculum, taught in schools

Young carers told us:

- Awareness of being a young carer is not high. People don't know what it is.
- Nothing is taught on young carers in my school.
- Young carers should be involved in teaching about being a carer; some would listen more if peers were delivering the messages.
- Young carer – *"I struggled with exams and concentrating"*. Young carers should be given extra time in exams if needed – there were mixed experiences in the group; some received this support, others did not.
- Young carers agreed that the 'no phone policy' in schools is making things harder. They are not allowed to check-in with what's happening at home and they are constantly worrying which makes it hard to concentrate:

"I don't want to have to explain the situation each time I need to phone home"

- A young carer said – *"We should have the right to a quality education and the opportunity to go to University, but it's difficult"*.

Mental health struggles

- Young carers told us:

"There are so many worries in my head about what will happen when I'm away."

"I am worrying about my mum at home all the time, it's the mental aspect of being a carer, we need wellbeing support."

- Mental health is a key issue

"We are all going through the same mental health challenges and pressures"

No choice but to care

- Young carers said:

“We feel we have to do it (caring), it’s not really a choice.”

“It’s not like we were given a choice.”

“It’s not like we can give it up, it’s a necessity.”

“For us it’s a necessity to see change. We didn’t choose this.”

Stigma and becoming invisible

- An adult carer told us:

“Becoming a carer you become unseen, you’re forgotten. There’s a stigma attached to being a carer.”

“There is zero support and zero sense of self worth”

“I came to caring later in life and I’ve suddenly become invisible.”

“It is a job, it needs respect, not to be looked down upon. Being invisible is awful.”

“As carers we slip under the radar and become invisible.”

- A young carer who cares for her sister who has autism said: not all disabilities are visible, need more awareness and understanding.

Identification of carers and lack of support

- Adult carers told us that the lack of identification of unpaid carers is a big issue, carers are often not identified until they reach crisis point.
- They said there should be more effort made to identify unpaid carers earlier – the GP surgery provides an opportunity to identify carers.
- They wanted a national campaign on ‘what it is to be an unpaid carer’, then more people might come forward.
- There was agreement that we need better awareness for all carers, and more funding to give carers breaks.
- Adult carer: *“when the person you care for is admitted to hospital, some are better than others at recognising carers. Some won’t tell me*

anything, there's huge variation. We need more focus on making hospitals recognise unpaid carers."

- Young carer:

"I hadn't heard of a carers needs assessment. Credu has helped me."

- Adult carer:

"I had an assessment but I didn't recognise myself in the report. The assessments often result in little to no support. I asked for support with falls prevention and I was told to go and watch a YouTube video."

- Carers needs assessment should be an important tool for support but it's not if there's no support available.
- When needs are identified, there should be a plan put in place to meet them.
- There's a postcode lottery for support.
- No funding is available for support services.
- Respite is not easy to access and there is a lack of replacement care.
- For elderly carers there is little to no support. There is very little statutory provision funded by local authorities.

Finances

- Adult carer:

"We are called 'economically inactive', implies we're benefits scroungers, we need to reframe the conversation around caring."

"I am struggling financially, I'm going to drown in debt."

- Adult carers – there needs to be more flexibility in jobs for caring
- Young carer: "I noticed my parents are struggling for money though they try to hide it from us. I noticed my parents missing meals as they can't afford to buy more." "We are really struggling and the financial support isn't there."

Young carer ID cards

- Young carer:

“The young carer ID card used to be valuable for me, I could use it the pharmacy, school etc.”

Another young carer - “Young carer ID cards are not a thing in my school, it hasn’t been implemented.”

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Group 3

Participants in this group were adult carers.

Feedback from the Adult Carers

- Carers told us: there is no time off from caring. Some said they had not had a real break for over 20 years, as no support was available for the person they care for, especially if that person needs 1-2-1 care and support, and if their condition means they can't or won't be able to take up the 'standard' respite offer. They felt there was no one they could leave the person with safely, which meant they were unable to have a break themselves.



- Carers are intelligent, able people who could be in good jobs, want to be able to participate in society, and want to have a healthy active life, but this life journey has been cut short. They felt they had been left to struggle, with limited help, which had resulted in illness (including mental and physical exhaustion) and often ended up with long term and serious health conditions.
- Their situation “*costs us our life*” - their jobs, their pension and their future.
- One carer stated -if someone would just take time to listen/ come in and assess the situation in their house and their actual needs, then there could be ways of supporting her son to learn to adapt and live independently – giving her hope for his future – especially as she now has health issues herself.
- Carers are prevented from contributing to society and having any interests – they want to be part of society and be able to volunteer / support others facing their situation—they are the experts now. It is never a life choice to live as a carer on benefits.
- They get into debt due to the cost of living and paying bills – sometimes extra costs due to health conditions, e.g. specific dietary needs.
- They are not accumulating debt from having material things or treats they do not need or should not be buying. Their debts come from just coping with normal living costs- food /bills / fuel/ rent/ special adjustments in the house.
- Online support mechanisms are great as carers can get to the computer (in the house), but they also need ‘face to face’ interaction with other adults and communication / visits. They feel invisible – sometimes no visits for years - feels isolating / just a statistic.
- One woman told us that had fought for years to get simple support and financial help for changes /devices in the house to support her parents’ conditions, including a wet room downstairs.
- Communication and connecting of available support services is extremely poor.

- Carers said they feel they have to be the nurses / GPs as there is not enough attention to detail. They become the experts for caring for their children/young adults, which puts extra pressure on them.
- Social service support is non-existent and often disjointed.
- When other family members in the house are in employment, it affects their benefits. This is not fair, as they are not caring for the person who is working.
- Carers Allowance—limited to one person only – what about those who care for more family members. One lady cared for two children with needs plus both her parents, in different properties.
- “When you do not fit the criteria, there’s less chance of ongoing support”.
- There is a need for simple, clear guidance for all carers. Carers need to know where to get help/ how/ whatever your situation.
- There should be a link with GP services / Social Services – these should be joined up and connected.

Solutions

- Schools should recognise the signs of someone being a carer and ensure correct support in place, offering help/signpost and follow up when concerns.
- Better training and information available for all carers – a link up— knowing where free local support groups/ information can be found – online and in person signposting.
- Getting the basic things right would help, as it reduces time taken to find information/ support/ which adds to stress / anxiety.
- Helping with simple chores/ food bank trip/ cleaning- domestic support for exhausted carers who get no break. Maybe a domestic support person on hand when needed for chores/ tasks/ admin/ shopping/ collecting medications.
- This is more important than the offer of day trip – you have to still return to the mess/ chaos / upset child/ adult / house situation / chores etc even if you go out for a few hours.

- If caring for a person younger than 18 years old, the focus is on the child, not the carer. But the carer needs support too at each stage, and the carer's emotional / mental health suffers - their future is uncertain and they have the constant worry of each life change. They had no warning this is the path their life would follow - no time to plan/ reflect—they find themselves coping and trying to get through each day/ night.
- There should be priority appointments with GPs for carers.
- 'Carer status 'services and support' should kick in for all who need support whatever their age and situation, and whatever the reason they find themselves as a carer.
- Third sector parties/ charities give the best consistent and real support—they need more funding and more recognition to keep this going.
- Carers themselves help to set up the support groups using their real-life experience to support others. All voluntary - again saving tax payers and the government, but no recognition for this. It helps the carers themselves as they feel they are doing something positive and connecting / sharing with others in same situation.
- There will always be a need to support carers, but carers want to see changes to policies which will have an impact, not lost promises or just words that do not go anywhere.
- Support groups often can be too far away. Many have no car or limited funds or time to be away from the house.
- Direct payments not explained and too complex.
- Carers need support for coping and managing their financial situation. It should not be so complex to claim or find out the correct information about what you can claim.
- Carers know they are carers, yet they are often stuck in catch 22 - they just need to know how to manage and where to get support. It is simply unfair that carers don't realise they are carers and so fail to get the right help. Nobody chooses to be stuck and unable to get a better life situation.
- You have no choice, but Welsh Government Ministers have a choice to change policy and ensure more funding and the right support system.

- Most carers only look for help when in crisis, when things have gone too far and they themselves are suffering mentally and physically. Carers have been left carrying their 'now young' adult' son or daughter down the stairs to get out of house to an ambulance, or appointment as they were unable to find support from someone willing to help. They often suffer day-to-day from having to carry the burden (physically and mentally) of being a carer, but they will carry on as they love the person and they have no other choice.
- Carers forums are the most useful, and have really helped and offer vital connections.
- 'Soft support' from those who genuinely understand helps them get through each day/night/week.

Improving the support/communications

- Education settings – recognising needs and signposting.
- Social Workers -better understanding and training in all areas of caring and carers' needs too.
- Peer to peer groups really help – they need support.
- Assessments – need to be more regular and need to 'check in' to the property/ home to understand everything about that carer's life situation.
- Hospital discharge process – carer should be given all the information and be clear what to do, how and when – not left feeling isolated and unsure on what support is local and how to claim.
- Carers Allowance should be improved and 'UK wide' – not specific to Wales.
- All the 'touch' points—should be clear in process/ support and guidance to signpost in the same, clear way.

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