easy read

Senedd Cymru
Welsh Parliament

Making access to support better for unpaid carers

What people told us

What this booklet is about

We are the **Health and Social Care Committee**.

This is an **easy read** summary about what **unpaid carers** told us about their lives.

Unpaid carers are people who give care but don't get paid.

We listened to what unpaid carers told us across Wales.

We did this in

- one-to-one interviews
- focus groups

We wanted to find out what unpaid carers think.

We did this in a safe and supportive way.

The next pages tell you what people told what mattered to them the most.

What people told us

Confused

1. Carers not knowing about support

People told us they

x **did not** know if they were a carer or not

x **had not** had a Carer’s Assessment

They told us they were stressed and tired.

They told us they felt lonely and everything was too much.

People told us they did not have enough time to care for themselves.

What people told us

2. People not seeing carers as having different needs

People told us they **did not**

- get the support that was right for their needs
- know where to find support

Some carers look after more than one person.

This made it hard to take a break from caring because they couldn't find another carer.

Solo carers felt

- alone
- not supported

Support group meetings were at a time that unpaid carers couldn't go to.

What people told us

3. Unpaid carers not getting enough support or money for carers

People told us they

Did not think other people know what they do – this was to do with getting **Carer's Payment**. This makes it seem like they are getting paid.

Carer's Payment is not enough to live on.

Carer's Payment is not enough money for what carers do.

People told us they think the government should pay more to carers.

Having more money would make the most difference to carers.

What people told us

4. People said Carer's Assessments and support are not accessible.

People told us

Carers Assessments were hard to understand

One person said they didn't know what a Carers Assessment was

Many people said they

- hadn't been offered an assessment or
- were turned away from an assessment

People didn't find the assessment was useful.

What people told us

More about this theme

Some people didn't see a copy of the assessment.

People were confused about who could get a Carers Assessment.

People told us

- social workers didn't do enough to let carers know about the assessment or about other support.

- some carers were in crisis because they didn't get an assessment earlier.

What people told us

5. Carers not thinking they will get a proper break

Taking a break from caring is called **respite**.

We spoke to a lot of people but only a few had been able to take a break.Very few people could take a break overnight.

One carer said her husband was left in a very poor state when she took a break.

The carer she left him with did not treat him well.

One person said when she took a break the person she cares for got worse.

A lot of carers don't have time to look after their health.

They put the person they care for first all the time.

Even when they got a break, they worried if the person they care for would be OK.

What people told us

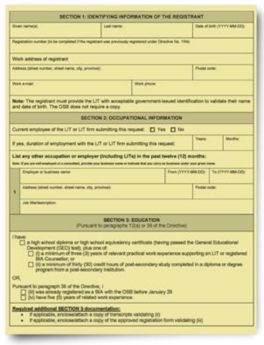
6. Carers finding systems hard

One carer said they needed more **accessible systems**. They said it was hard to communicate in health matters when you are a carer.

One group told us they wanted more easy read and Plain English information.

One person needed a translator at all their appointments – this only happened sometimes.

When people asked for support they felt like it was too much to do this.



One person was sent a long form to fill out so they could ask for a Personal Assistant.

Applying for **Disability Living Allowance** was very hard.

What people told us

Respite care for unpaid carers

We talked to carers from all **5 Senedd areas**.

Many people said they **could not** get respite care to take a break.

Carers found it very hard to find respite care for someone with a lot of needs.

Some carers said they

✓ **could** get respite care but there was a lot of issues about paying for this

x **could not** get respite care – even in an emergency

People who lived in rural areas found it hard to find someone to cover them if they took a break.

What people told us

Respite care for unpaid carers

People who cared for more than one person found they could only get respite from caring for **one person.**

This meant they never got a full break.

Carers with disabilities could get respite but it wasn't always accessible or right for them.

Carers told us that getting respite care depends on where you live.

People told us it was hard to find emergency care. For example, if they needed urgent health care.

Social care didn't give enough support.

It was hard to find good Personal Assistants across Wales.

What people told us

Personal Assistants and respite care

It was hard to find good Personal Assistants across Wales.

Carers said that not enough people wanted to be a Personal Assistants because it is

- not well paid
- short hours with a lot to be in charge of

Charities often helped to find respite care.

Carers said they got a lot of support from other carers.

People told us charities were good at getting it right. But this was hard for unpaid carers.

Carers said they liked to talk and share their life with other carers.