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# Introduction

This Charter for Unpaid Carers sets out the legal rights of unpaid carers in Wales under the Social Services and Well-being (Wales) Act 2014. These rights are the same for all unpaid carers, whether they are an adult, a young person or a child. It also references relevant human rights and principles. Raising awareness of rights can empower unpaid carers to take control and recognise when their rights are being compromised, but it is equally important to raise awareness of rights amongst professionals.

This Charter uses practical examples to show what good practice looks like and should be read by unpaid carers and any professional involved in designing, delivering services or supporting unpaid carers. Supporting unpaid carers is everyone's business.

## Key Principles

The Social Services and Well-being (Wales) Act was introduced in 2014 to reform social services law with a key focus on improving the well-being outcomes for people who need care and support and carers who need support.

An unpaid carer is a person who provides or intends to provide care for an adult or disabled child.

This could be caring for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

The principles on which the 2014 Act is based are:



**Voice and control** – giving people voice and control over the outcomes they want to achieve.

**Prevention and early intervention** – increasing support services in the community to help individuals as early in the process as possible.

**Well-being** – promoting the wellbeing of those who need care and support and carers who need support.

**Co-production** – encouraging individuals to become more involved in the design and delivery of services.

**It introduced new rights for unpaid carers which are:**

- **The right to well-being** – your local authority, local health board and Welsh Ministers must promote the well-being of people who need care and support, and carers who need support.
- **The right to have information, advice and assistance** – your local authority must provide information, advice and assistance about support services so you can find and access them.
- **The right to an assessment** – your local authority must offer you a carers' needs assessment. This assessment is to find out what support you need and how your local authority can help if you do need support. Your right to an assessment is not affected by how much money you have, but you may be asked to contribute to the cost of your support.
- **The right to have your voice heard and have control over decisions about your support** – during your assessment your local authority must ask you what matters to you as a carer or a young carer. You must be involved in all decisions about your support. Carers have a choice over whether they provide care and the type of care they may wish to provide.
- **The right to advocacy if you are unable to fully take part in discussions yourself** – An advocate is someone who can help make your voice heard when decisions are made about your support.

## Human Rights

**All of the rights contained within the Human Rights Act 1998 apply to everyone however the following are particularly relevant to unpaid carers.**

- Article 8: Right to respect for your private and family life
- Article 2 of Protocol 1: Right to education.

**All rights contained within the UN Convention on the Rights of the Child apply to young carers under the age of 18 but the following are particularly relevant:**

- Article 12 (respect for the views of the child). Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.
- Article 31 (leisure, play and culture). Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.
- Article 29 (goals of education) Education must develop every child's personality, talents and abilities to the full.

## Language needs and an “Active Offer” of Welsh language

**Wales is a culturally diverse country and the Social Services and Well-being (Wales) Act 2014 emphasises the importance of knowing an individual’s preferred language from the outset. The guidance supporting the implementation of the Social Services and Well-being Act states that carers’ needs assessments should be carried out in the individual’s language of need and preferred communication and in a style and manner appropriate to their age, disability and cultural needs.**

**The Act’s Code of Practice states:**

‘This means that the local authority should be proactive in its approach and the individual should be asked which language they would prefer at the beginning of the process.

This will ensure that they are able to receive services in their own language throughout the process of identifying and meeting care and support needs’.

Communicating in the individual’s language may require the use of interpretation services but this should not prevent an ‘Active Offer’ being made. This includes providing an “active offer” of Welsh language to individuals – the offer must be an integral part of the care provided.

This might be something as straightforward as answering the phone in Welsh, or using interpretation services to ensure effective communication.

## The UN Principles on Older Persons

**Raising awareness of rights can empower older people to take control and recognise when their rights are being compromised, but it is equally important to raise awareness of rights amongst professionals. The Social Services and Well-being (Wales) Act requires local authorities to have due regard to the United Nations Principles for Older Persons.**

Due regard means more than simply being aware of the UN Principles. It means that local authorities must actively consider how the duties impact on the decisions they make.

## The Well-being of Future Generations Wales Act 2015

**The Well-being of Future Generations (Wales) Act places duties on named public bodies, including local authorities and health boards to embed a preventative approach by considering the long-term impact of their actions.**

They must also work in partnership to involve and engage with individuals and communities as they seek to improve the social, cultural, environmental and economic well-being of the area.

Public bodies are required to adopt five ways of working which include taking a more joined approach to integrating service design and delivery.



# How these principles and rights look in practice

## Coproduction

**Unpaid carers should be equal partners in the creation of policy and services. This means being given a voice in policy and service development, planning and delivery, but also in the development of research and training. Organisations should ensure unpaid carers are involved from the early stages of the process through to final decisions.**

This could be achieved by having unpaid carers represented at all levels of decision making bodies led by local authorities or health boards, but also on government advisory and working groups.

Public bodies should make sure a culture of coproduction is embedded within the organisation and understood among staff at all levels to ensure that unpaid carers are supported to engage in the creation of policy and services.

## Community Based Preventative Support

Early intervention and prevention can help unpaid carers and the people they care for to continue with their caring role and avoid reaching a crisis point before accessing vital support services. Preventative activities can include a break from caring, receiving information and advice or the chance to work or learn.

The need for activities to support unpaid carers to look after their health and well-being should be considered as part of a carers' needs assessment to help a carer do what matters most to them.

## Unpaid carer's story

The Small Grant Scheme (SGS) is an initiative developed by the Gwent Carers Strategic Partnership to support life alongside caring. It uses a preventative approach to support unpaid carers who say it has improved their health and well-being, reduced isolation, improved their financial situation and given them more time for themselves.

Carer S provides care for her 9-year-old autistic daughter D. D requires constant supervision and relies on S for all her needs. She has sensory and behavioural issues which resulted in S having to give up work to look after her.

D has great difficulty adapting to any change throughout the day and relies on S to regulate her emotional responses. S has shoulder, back, knee and hip problems and used the Small Grant Scheme to pay for gym membership. Taking part in aqua-fit, yoga and dance classes helped keep S mobile and strengthened her muscles; she has met new friends and the gym helps her to focus on her own needs.



## Access to Information, Advice and Assistance

**Local authorities and health boards must make sure unpaid carers can get information and advice about what care and support is available and how to access that support. Information, advice and assistance must be provided in a way everyone can understand and should take account of language needs.**

Providing appropriate information, advice and assistance therefore provides the vital first steps of a preventative approach.

All sectors including health, social care, education and community based organisations have a role to play in supporting unpaid carers and staff should be trained so they can provide the correct information about carers' rights and local services. They can achieve this by providing information and assistance, or signposting to relevant support such as a local authority carers' service.

Contact with a health professional at a local pharmacy or GP surgery is often a key entry point for an unpaid carer to get information, advice and assistance, as well as most importantly, an individual recognising they have caring responsibilities and are therefore an unpaid carer.

Advocacy support can also play an important role where an unpaid carer, or the person they care for, is unable to clearly discuss their care and support needs as part of their discussions with social services or other services.

### Unpaid carer's story

A gentleman was referred to NEWCIS who had a very intense caring role. His wife had multiple health conditions and he had been providing round the clock care to her for years. During this time, the pressure and stress that he was under had taken a toll on his own mental and physical health.

NEWCIS worked with the carer to explore what would help him cope better with his own mental health difficulties. He expressed the need to speak to someone about the trauma of the last ten years caring and an urgent referral was made to their counselling service. NEWCIS also referred the carer to Citizens Advice for a full benefits health check as money was causing a lot of worry.

NEWCIS also worked with the carer to create an emergency plan for the future. Looking at friends/relatives/community and ensuring he had a plan for when he felt he needed support or could not cope.

NEWCIS and the surgery applied for health respite funding as the wife needed medical treatment. NEWCIS also gave a carer grant for the husband to purchase a new washer/dryer.

This was a situation where a carer needed both emotional and practical support. He was finding it very difficult to identify the things that would help. It took time to break down barriers and build trust before the carer would talk through what a day looked like for him. Once this had been done it was clear the support he needed. He was resistant to accept help, but when he saw the practical things that could be done he opened up and was willing to talk.

## Carers' Needs Assessment

**Under the Social Services and Well-being Act, “where it appears to a local authority that a carer may have needs for support, the authority must assess whether the carer does have needs for support (or is likely to do so in the future), and if the carer does, what those needs are (or are likely to be in the future)”.**

Unpaid carers have a right to have a carers' needs assessment and, where eligible needs are identified, to have them met to help them achieve the outcomes they need. Such an assessment is separate from any assessment of the needs of the person they care for.

The statutory Codes of Practice which accompany the 2014 Act detail what needs to be considered to ensure the carers' needs assessment identifies what the carers' needs are and this must include establishing whether a carer is able and willing to continue caring.

Unpaid carers can expect all aspects of an assessment to be delivered in practice and service managers should put monitoring systems in place to ensure this.

Unpaid carers can expect staff delivering assessments to be aware of their legal obligations under the Act. Staff should use clear language when engaging with an unpaid carer because it is important that the terms used are consistent and the carer can understand the process, its purpose and the outcome.



## Direct Payments

**Direct payments are a way that local authorities can help to meet an individual's eligible need for care and support, or an unpaid carer's need for support. They are a way for people to arrange their own care and support.**

Direct payments are not a form of income but are paid specifically to buy services or equipment. This means they do not affect benefit entitlement or income tax.

Direct payments are intended to improve choice, control and independence for people. Individuals can work with the local authority to decide how their care and support needs will be met using direct payments. The individual or unpaid carer can decide who provides that support and control how, where and when it is delivered.

You can find out more about direct payments and how they can help you in our dedicated resource hub:

<https://socialcare.wales/service-improvement/direct-payments-a-guide>

## Hospital Discharge

**When the person being cared for requires admission to hospital it can be a stressful and uncertain time for their unpaid carer. Apart from the concern for the health of the person admitted to hospital, they may also face a set of processes which are unfamiliar.**

Unpaid carers should be identified and meaningfully consulted with from the start of the hospital discharge process and their entitlement to a carer's needs assessment should be explained to them.

Unpaid carers should be treated as someone who has relevant and important knowledge about the person they care for and they should also be reminded at this stage that they have a choice over whether to begin or continue caring.

Healthcare professionals should ensure they clearly inform the unpaid carer about the likely changes to the condition of the person they care for, avoiding jargon.

Professionals should consider whether support has been put in place before the discharge, such as care plans, home adaptations, equipment, or a new carers' needs assessment.

If a support package is not in place on the day of the discharge, professionals should consider whether the discharge is able to take place.

## Unpaid carer's story

Fiona felt unsupported and undervalued as an unpaid carer. She was calling the hospital each day to check on her father and was frustrated with the lack of consistent information and communication, as well as medical updates/progress not being forthcoming. On one occasion Fiona had spent several hours trying to locate her father when he had been moved to another ward without her knowledge.

Fiona was referred to the Carers' Officer who helped Fiona to liaise with the ward sister and facilitated ongoing communications for her with hospital staff.

Fiona felt that a massive pressure has been alleviated and now she feels better supported and valued as an unpaid carer. The Carers Officer also advised Fiona about her entitlement to a Carers Needs Assessment and replacement care as part of the discharge support plan.

As a result, Fiona felt fully involved in the discharge planning process and the care plan which was put in place to support both herself and her father.

### This included:

- Daily support for personal care
- Access to a 24 hour 'careline'
- Replacement care and 3 weeks of residential care for her father to enable her to take holidays and breaks from her caring responsibilities throughout the year.
- Benefits advice to review entitlement to Carer's Allowance and Council Tax reduction.



# Unpaid carers in education and employment

Unpaid carers should be enabled to access different forms of education, learning and training. This should apply to carers in employment, carers looking to find employment or return to education, and young carers. (A young carer is usually considered to be a child or young person up to the age of 18). Under the Social Services and Well-being (Wales) Act, there is a clear requirement for education and employment to be considered as part of a carers' needs assessment.

The assessment should consider whether the unpaid carer works or wishes to do so; whether the carer is participating in or wishes to participate in education, training or any leisure activity, and in the case of a carer who is a child, their developmental needs and whether it is appropriate for the child to provide the care (or any care) in light of those needs. The statutory Codes of Practice Parts 3 and 4 detail these requirements.

## Unpaid carer's story

Key to support for young carers is helping them be recognised and supported in education settings including schools. The Young Carers in School Programme encourages schools to show they are meeting the needs of young carers. Schools then receive accreditation based upon the level of support and advice they have on offer.

### Aspects of this programme include:

- staff training offered every 6-8 weeks;
- assembly videos that can be shared with students and staff of all ages;
- letters sent to families with information on how to access young carer services and carers' assessments locally, and
- information, advice and assistance provided to any school that makes contact with the provider or the programme.

## Financial Support

Unpaid carers should have easy access to specific financial and benefits advice or guidance services such as Citizen's Advice Cymru who offer advice on any additional financial support that an unpaid carer may be entitled to. In addition to giving advice regarding benefits they will be able to signpost any other avenues of support that are available to you.

Citizen's Advice can be contacted by telephone on: 0800 702 2020.

<https://www.citizensadvice.org.uk/about-us/our-work/advice-partnerships/advicelink-cymru/>

## Carer's Allowance

Carer's Allowance is a UK Government benefit for unpaid carers who could get £69.70 a week if caring for someone at least 35 hours a week who is receiving certain benefits. Unpaid carers do not have to be related to, or live with, the person they care for but do not get paid extra if caring for more than one person. If someone else also cares for the same person only one person can claim Carer's Allowance. Further information and advice are available from the Carer's Allowance Unit:

Phone: 0800 731 0297

<https://www.gov.uk/carers-allowance>

## Unpaid carer's story

Susan is an unpaid carer for her brother, Colin. Her brother has been in hospital for many weeks. She has been referred to Citizen Advice Bureau for Carers for help with issues she is currently facing.

Susan's nephew has been helping her to prepare for Colin's discharge from hospital. Her nephew did not understand how many issues Susan was experiencing until he started to help her prepare for Colin's discharge.

Susan was classed as a 'Jobseeker' and was claiming Job Seekers Allowance (JSA). This was her only income. She was receiving help paying her rent through Housing Benefit. She was also receiving Council Tax reduction. As Colin was living with her, the Housing Benefit was being reduced as he was a non-dependant.

The CAB4Carer adviser looked at both Susan and her brothers' income and was able to secure £73 a week for Colin through State Pension Credit.

Susan's Housing Benefit increased to cover all the rent. Susan was also helped with her own health and well-being. She was signposted to her housing association for an assessment for aids and adaptations and advised on support she could get from her local authority, including a carers' needs assessment.

Susan was advised about other services for carers available to support her well-being.



## Making a complaint

**Public bodies and organisations involved in the provision of support and services for unpaid carers will have a complaints process.**

In the health sector, NHS trusts and bodies will have specific processes in place and these should be easy to find and understand. The same applies to local authorities.

In situations where an unpaid carer is unsatisfied with the support they have been offered, or feel that their legal rights are not being upheld, there are routes available to them to challenge decisions and raise complaints. Service providers should provide information to unpaid carers explaining their right to challenge decisions, relevant complaints processes and sources of advocacy or representation.

Unpaid carers may also wish to investigate these options if they feel their situation has fallen short of the expectations set out in this Charter.

## NHS Wales – Putting Things Right

If you have concerns about your care or treatment, it is recommended that you talk to the staff involved with your care or that of someone you care for, as soon as possible. They will try to resolve your concerns immediately.

If this does not help, or you do not want to speak to the staff, you can contact the health board or trust's complaints team.

For further information and advice about the different ways of raising concerns or complaints about your NHS care or treatment you can find this at [NHS Wales complaints and concerns: Putting Things Right | GOV.WALES](#)

## Local authority complaints process

Local authorities in Wales are expected to provide effective support which makes a positive difference in people's lives, and to have formal processes in place for when there is dissatisfaction or concern about the standard of service provided.

The Complaints Officer for the local authority will provide advice and support and will help to determine, through discussion with the complainant, if and when the complaint should move from local resolution to formal investigation.

If you are unhappy with the social services department, you should raise a complaint through the council social services complaints procedure. The local authority must always offer to discuss a complaint to try to resolve matters in the first instance.

If a resolution is not reached, a formal stage will follow where the complaint will be considered by an independent investigator.

Details of the complaints process can be found on the local authority website for each of the 22 local authorities in Wales, or can be requested by telephoning the council.

A list of information and council contact telephone numbers and their website addresses can be found in the Welsh Government's carers' rights information leaflet: <https://gov.wales/sites/default/files/publications/2021-10/carers-rights-a5-leaflet.pdf>

## Public Services Ombudsman for Wales

If you do decide to pursue a complaint directly but remain dissatisfied with the outcome, you may consider taking your complaint to the Public Services Ombudsman for Wales: **Public Services Ombudsman for Wales, 1 Ffordd yr Hen Gae, Pencoed, CF31 5LJ. Phone: 0300 790 0203 Email: ask@ombudsman.wales www.ombudsman.wales**

## Care Inspectorate Wales

Providing feedback about care services and raising a concern about care services.

These can be submitted online at <https://careinspectorate.wales/providing-feedback-about-care-services> and <https://careinspectorate.wales/contact-us/raise-concern>

## Community Health Councils

Each local health board area has a community health council. They provide free confidential advice and support to patients who have a complaint about NHS services. You can obtain more information at:

**Community Health Council Telephone: 02920 235558 Email: enquiries@waleschc.org.uk https://boardchc.nhs.wales/your-local-chc**

From April 2023, the Citizen Voice Body (CVB) will represent the voices and opinions of the people of Wales in respect of health and social care services.

## Representation and advocacy

If you are unable to fully take part in discussions yourself as a carer, an advocate is someone who can help make your voice heard when decisions are made about your support. An independent advocate must be arranged if you are unable to speak up for yourself or do not have someone to support you to express your views, wishes and feelings.

## National carers' organisations and independent commissioners

### **Carers Wales:**

Provides advice and information to carers and the professionals who support carers.

#### **Advice line – Monday to Friday:**

0808 808 7777

[www.carersuk.org/wales](http://www.carersuk.org/wales)

### **Carers Trust Wales:**

Committed to improving support and services for unpaid carers.

0300 772 9702

[wales@carers.org](mailto:wales@carers.org)

<https://carers.org/around-the-uk-our-work-in-wales/our-work-in-wales>

### **All Wales Forum:**

Provides a national voice to empower parents and carers of people with learning disabilities.

029 2081 1120

[admin@allwalesforum.org.uk](mailto:admin@allwalesforum.org.uk)

[www.allwalesforum.org.uk](http://www.allwalesforum.org.uk)

### **Age Cymru:**

Information and advice for matters affecting over 50's in Wales.

0300 303 4498

[advice@agecymru.org.uk](mailto:advice@agecymru.org.uk)

[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

### **Older People's Commissioner for Wales:**

Protects and promotes the rights of older people throughout Wales.

03442 640670 / 02920 445030

[ask@olderpeoplewales.com](mailto:ask@olderpeoplewales.com)

[www.olderpeoplewales.com/en/home.aspx](http://www.olderpeoplewales.com/en/home.aspx)

### **Children's Commissioner for Wales:**

Protects and promotes the rights of children throughout Wales.

01792 765600

[post@childcomwales.org.uk](mailto:post@childcomwales.org.uk)

[www.childcomwales.org.uk](http://www.childcomwales.org.uk)

This charter was coproduced with unpaid carers, their representatives and professionals delivering services to unpaid carers.