

Llais Gwent Region

Carers Survey – Report Summary

September 2023



Accessible formats

This publication is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us. You can ask for a copy by contacting our office:

01633 838516

gwentenquiries@llaiscymru.org

Llais Gwent Region,
Raglan House,
William Brown Close
Cwmbran
NP44 3AB

www.llaiswales.org

www.llaiscymru.org

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INTRODUCTION



Llais is an independent statutory body, set up by the Welsh Government to give the people of Wales much more say in the planning and delivery of their health and social care services – locally, regionally, and nationally.

We hear from people in different ways such as, online surveys, local engagement events, direct contact to our offices, our complaints advocacy, and enquiries services, and through face-to-face visits to health and social care sites.

As part of our annual plan, Llais Gwent Region wanted to find out from Carers in Gwent, their experience of accessing and using health and social care services for their own needs.

To do this, we created an online survey for people to give their feedback. We circulated our survey to external stakeholders, caring companies, published on our social media accounts and when we attended engagement events, we handed out copies of the survey.

The survey went live in June 2023, and concluded in August. In total we received 29 responses.



SUMMARY



In total we received 29 responses to our survey, and we mostly heard from people who lived in Caerphilly or Newport.

We heard from different types of carers - mostly from those who are unpaid carers. Being an unpaid carer means that the person you care for might be a partner, family member, friend, or neighbour. The care they provide may be temporary or permanent.

We also heard from a small number of people who were young carers, volunteer carers or micro carers. A micro carer is a self-employed carer worker, providing flexible, personalised support and care to citizens who live in their local area.

Un-paid carers told us they estimated that they spend between 10 – 50 hours a week, caring for someone.

Young carers told us they spend between 10 – 30 hours a week caring for someone, these hours are also like those who are micro carers. One person who is a volunteer carer told us they spend over 50 hours a week caring for someone.

We understand that being a carer is a demanding but reward job, and the care people provide to others is important, however, this can sometimes put a strain on those who provide care. People told us that being a carer can affect their ability to access NHS services, and when we asked for further information, people put the needs of the person they care for, first.

When carers want to access NHS services, they told us they find this difficult when needing to work around a time that they are not caring for someone.

Those who were waiting for NHS treatment, or an appointment said this was impacting the care that they were providing. Most people who gave this feedback were either an unpaid or volunteer carer.

Nineteen people told us they had not yet completed a carers assessment, five of whom were not aware they could have one. Those

who told us they had completed a carer assessment; most had not received any further support since.

Twelve people of the 29 respondents knew what support services they could access in their area, such as:

- Diversity Day Centre
- Headway
- Direct Payments
- Shared Lives
- ALN Groups
- Carer mailing list & Facebook group
- Care package
- Barnardo's Young Carers
- Housing options
- Adult Mental Health Services
- Alzheimer's Connect

Others were unsure on what support services were available to them in their area.

There was a theme identified from people in Caerphilly who gave feedback about day centre's which closed during the pandemic, and never re-opened. This affects their access to respite.

Positively, most people knew who they could contact if they needed to access social care support services.

Most people rated their access to social care support services as *“very difficult (8)”*, *“difficult (11)”*, or *“ok (7)”*.

Majority who accessed respite care services, told us that they needed to give a period of notice, in advance. One person from Caerphilly told us they needed to give *“as much [notice] as possible, due to the availability of placement.”*

There was a mixed response from people when we asked, *“are the support services you access, suitable for you?”*

Yes: 6

No: 9

Partially: 8

It is important that carers receive support to be able to look after their own well-being, especially as most people who filled in our survey were caring for someone between 10-50 hours per week. Unfortunately, more than half of the people who gave feedback on our survey, told us they felt their well-being needs were not being supported.

Only a small number of people told us they had received carers support which met their needs. Others told us they had received “some” support, but this did not meet their needs or, they were unable to access the support.

People should be able to access health and social care services that they need when they need it. However, fifteen people told us that there were health and social care services they needed that are not available to them. For example:

- Day Centres
- Transport
- Carers going into homes.

Most carers felt that the Covid pandemic has had a lasting impact on their access to health and social care support services. Again, day centres were mentioned throughout people’s responses to this question. Other examples from people’s comments, include:

- Harder to access services due to backlog.
- Face to face support has lessened.
- Day services have been reduced “drastically.”

COMMENTS



These are the comments received from carers:

Question: “Does being a carer affect your ability to access NHS Services? If “yes” or “sometimes,” please explain what services you struggle to access and why:”

“Getting an appointment at a convenient time when my husband is not with me.” (Torfaen)

“I don’t feel able to book or chase appointments for me when I’m prioritising the people I care for in my family.” (Caerphilly)

“Seeing my father’s medical needs, I sometimes forget my own medical issues.” (Caerphilly)

“I’m on my own with no family support and my husband works away.” (Caerphilly)

“Can’t have operation done due to no or little care cover.” (Monmouthshire)

“I have had to cancel appointments or going to A&E so I can take my mum to my appointment.” (Blaenau Gwent)

“My GP Practice, I cannot always wait for them to answer when I ring for an appointment. Sometimes I have waited up to 40 minutes for the call to be answered!”. (Torfaen)

“I have to priorities my care for health and appointments.” (Newport)

Question: “Any comments regarding carers assessments?”

“Carer support worker hardly contacts me.” (Caerphilly)

“The facilities in Monmouthshire for care are deplorable.” (Monmouthshire)

“Day to do is ok, but having moved from Newport to Torfaen, our respite has been cut from 42 to 28 nights. I am struggling!” (Torfaen)

“After my knee surgery I will not be able to look after my sister for 6 weeks as my knee heals. Her son is looking for day centre respite care for her for these 6 weeks as she will get ill again alone in her house not drinking or eating”. (Blaenau Gwent)

“I feel Blaenau Gwent Social Services are neglecting me.”

Question: “Should you need to access respite care services, are you required to give a period of notice in advance? If "Yes" to the above question, please tell us what respite care provider you use, and how much notice you must give:”

“We use Shared Lives and I have to check with the people my husband usually stays with. They also care for other people so can't always fit him in.” (Torfaen)

“We now use direct payments and even before at respite centre, dates were given many months in advance.” (Caerphilly)

“Caerphilly Borough, Montclair, Blackwood. Apply quarterly.” (Caerphilly)

“As much as possible due to the availability of placement.” (Caerphilly)

“Caerphilly CBC. Not sure on notice but when I knew I needed it I gave them notice asap.” (Caerphilly)

“Council run. Usually a week.” (Caerphilly)

“Home carers visit twice daily, was 3 times daily but I have my sister up my house between 9.30 to 4pm daily to look after her so she's not at home for 12.30 visit”. (Blaenau Gwent)

“I don't receive respite care; I care for my wife at home and for two nights respite away I have to have a live in carer costing around £800”. (Monmouthshire)

“Was told to ask family members for help as respite is not available unless desperate.” (Newport)

Question: "Are the support services you access, suitable for you?
Comments, please give more detail, good or not so good:"

"Respite with direct payments is fine but there are no day services that meet my daughters needs and wants." (Caerphilly)

"My partner is 58 and has MS not seen much for anyone in the same case". (Caerphilly)

"Care call times problematic, plus we need 3 calls a day but only have agency call long for one at present while we support the other times. We also care for a second relative with no care package." (Caerphilly)

"Can't employ a pa during the holidays due to council restrictions." (Caerphilly)

"Poor availability" – Caerphilly

"First respite my mother went into before she passed away was local and good. Next one I didn't find do good." (Caerphilly)

"Suitable for my needs." (Newport)

"Knowing who to go to and sometimes its lack of resources." (Newport)

"Day centres were closed during covid and have not reopened. This has had an enormous negative impact." (Caerphilly)

"I need assistance with her for all her hospital appointments and GP check-ups collecting her meds. I do not have a break on weekends, it's a 7-day job caring for her". (Blaenau Gwent)

"Insufficient, no good whatsoever and told by social services and local county councillors 'sorry there's nothing we can do about it!' So how do I care for my wife on my own? We are 78 years old. I was a member of the Community Health Council." (Monmouthshire)

"Not long enough hours and doesn't see their friends." (Caerphilly)

"I don't have any access to support services." (Blaenau Gwent)

"Our situation was ignored by social services for well over 12 months. It was only when we went to see a Torfaen Borough Councillor about the extremely poor state of a local road that the conversation began about how my mother-in-law was unable to go for a walk because of the road. Once the councillor became involved with our situation there was a call

from social services, and we were put on a waiting list for a social worker! We had to wait several months before we were contacted.”
(Torfaen)

Question: “Do you feel supported with your wellbeing needs?”

“Day to day, my needs are met but having 1/3 of our respite cut just because we moved is having a detrimental effect on my mental health”.
(Torfaen)

“In our area we are being forced to take on many more care hours due to day centres no longer being accessible to many and the community support isn’t suitable for many, so some aren’t using anything. Those that do use it are now only able to have a few hours a day or weekly instead of the full days we accessed before covid.” (Caerphilly)

“No one really bothers about the carer... it’s the person unwell priority and NHS have me chasing appts and arranging them over and over again.” (Caerphilly)

“Very poor.” (Caerphilly)

“I have a mental health support worker and try to get to groups when child is in school.” (Caerphilly)

“Good social worker and access to carer information.” (Caerphilly)

“I’ve never been asked about my well-being needs.” (Caerphilly)

“Impact of closure of day centres means I have little time to look after my own well-being as I am fully committed to caring.” (Caerphilly)

“Supported through Barnardo’s.” (Newport)

“I support myself.” (Newport)

“Not at all. In reports done by GP, District Nurses, Social Services, Occupational health etc I don’t feature, there’s nothing mentioned about an unpaid carer.” (Monmouthshire)

“My sons and my needs as a carer are not being met at all as of yet.”
(Newport)

“I rely on my neighbours to do my shopping.” (Blaenau Gwent)

“I have good support from my work and family; however, I don’t think there is enough support or knowledge of support available to myself in our area.” (Torfaen)

“My mum in law was diagnosed with dementia about 3 years ago. I have asked for information about this disease and been directed to web sites or given leaflets but to be frank none of them give the detailed information we need. For example, a fear of water on her face, or the fact that she lives on sweet foods but somehow has lost 2 stone in weight in less than 12 months”. (Torfaen)

“Social services won't support me to access the community, so I am unable to leave my bungalow on my own.” (Blaenau Gwent)

Question: What is your overall experience of accessing carers support?

“I'm a parent carer, I don't really know what support there exists for me, and to be honest, I don't have the emotional energy to go looking for it myself. I suspect many carers who are family members just "get on with it" and probably don't self-identity as "carers" so don't know about support available or consider asking.” (Caerphilly)

“Now I have found a suitable placement for independent living skills for my daughter, there is no help with transport as she is no longer under 19. I have disabilities myself and it's difficult to transport her there and back. This would make a massive difference to my health.” (Caerphilly)

“No carers assessment carried out.” (Caerphilly)

“Not all above options fit into category I need.” (Caerphilly)

“Our local authority claims to be open and transparent, but I have found them to be underhand and evasive. They appear to have set out a course of action to achieve their aims, claim they are involving carers, but in reality, our voices are being stifled.” (Caerphilly)

“I don’t drive and have no access - I need a car.” (Newport)

“The Social care system in Monmouthshire is either imbalanced or needs a complete overhaul of the system including the building of the ‘new’ care home at Crick (planned in 2017) and closer inspections of all

care homes in Monmouthshire including Monmouthshire County Council own care home in Chepstow". (Monmouthshire)

"I have contacted many services and social services but no support as of yet." (Newport)

"Still looking for care for my sister during my knee surgery and afterwards for 6 weeks daycare". (Blaenau Gwent)

"At first glance it seems like there is a lot of support for carers but when you scratch the surface there is very little practical help. I don't particularly want my nails done or a cup of coffee and a "chat"! I want practical help such as showering my mum in law, getting help with her garden, making sure that the correct bins are put out for the refuse collection, getting her to eat decent meals. More importantly help trying to understand whether what she is telling me actually happened, so really more help in understanding the progress of the disease." (Torfaen)

Question: Are there any health and social care services that you feel you need, that are not available to you now?

"Massive improvement for children's AAC services (augmented and alternative communication)." (Caerphilly)

"Help with transport when we find alternative day services activities now that the day centres aren't available and not be forced to use community support or have no services." (Caerphilly)

"Supported holiday schemes for our disabled children. This allows the child to go without me, stay in some sort of routine and I get some respite." (Caerphilly)

"No day centre services." (Caerphilly)

"I have never been told what is available and if I require them for my dad. To clarify I was my mother's primary carer until she passed away 3 years ago and now, I'm my father's since he's had health issues". (Caerphilly)

"Day centres." (Caerphilly)

"In my language I speak Punjabi - I don't speak much English." (Newport)

“Respite Care and Childcare.” (Newport)

“Day Centre.” (Caerphilly)

*“Look at previous answer’s, the system in Monmouthshire is broken, not my word’s, social workers, doctors, county councillors etc.”
(Monmouthshire)*

“Whatever is out there. Mental health support, counselling, respite, support worker etc.” (Newport)

“Carers break as I have no respite care for myself.” (Blaenau Gwent)

“Carers to come into my mum’s home to make sure she gets up, washes herself and gets some breakfast. My mum in law refuses to go out anywhere. We struggle to get her to medical appointments so going to lunch clubs or social clubs is not possible anytime we have tried to do that she feigns illness, such as stomach upsets.” (Torfaen)

Question: Has Covid-19 affected your access to health and social care support services?

“Headway day centre shortened the hours that it is open. It used to be 10:00 - 16:00 but now it closes at 15:00 which most taxi companies can't do. Therefore, my husband has to leave at 14:00”. (Torfaen)

*“There have been some delays in ophthalmology and children's mental health services, but the provision of some online appointments for CAMHS has benefited us, these worked to our advantage for the child.”
(Caerphilly)*

“Day services have been reduced drastically! People are having to give up work or place their loved ones into residential care because of the extra hours of caring that are being forced upon us due to day service reductions.” (Caerphilly)

“No day centre services.” (Caerphilly)

“Face to face support groups lessened and not accessible.” (Newport)

“All services. Mainly day centre.” (Caerphilly)

“It is harder to access services due to backlogging.” (Newport)

“Don’t know who to turn to.” (Newport)

Other comments about your experiences of accessing health and social services support:

“Social services have made the drastic cuts to day services but are not helpful. In our particular case my daughter was left alone in the community while out for a couple of hours with a support worker. She cannot be left alone! I do not trust the service anymore and will never use it understandably. Social services will not offer anything else and just keep repeating that she can have it again when I’m willing to send her. I’ve enrolled my daughter on a very safe independent living skills course at a college but need help with transport and an escort only to be told they won’t help with that as she is over 19. She needed that help to get to school and her needs haven’t changed. It’s wrong that new policies haven’t been made to help those that need alternative day support to be more accessible. I thought it was supposed to make day services more person centred. My daughter is not using money from the day service pot, so why can’t it be put towards her transport which in turn will help with my own disabilities and health?” (Caerphilly)

“Despite working as a social worker, myself it has been quite difficult navigating the social care system. I totally underestimated the impact of being a carer on family and work life. I have had to take time off work to meet relative’s needs.” (Caerphilly)

“No day centre services have an extremely detrimental impact on both the Carer and the individual cared for.” (Caerphilly)

“Everything has become more difficult to access and this leaves a suspicion that many services are being changed and this has been done covertly under the cover of covid.” (Caerphilly)

“Not knowing where to go and who can help. LA don’t do enough signposting and lack of trust with LA and negativity and its system fails the very social workers it needs to support sw - using power and exploitation of the most vulnerable children that they need to have the best interest in. The system fails the children.” (Newport)

“Social care in Monmouthshire is a disgrace. As an unpaid carer for over 5 years if I was paid £11 per hour for 24-hour care which is what I’m

doing, I have saved the local authorities in excess of £443,000”.
(Monmouthshire)

“Social worker goes against hospital care report saying she can be left alone even though her GP and nursing staff have said she unsafe to be left alone.” (Newport)

“As stated previously it took a Borough Councillor before anyone became interested in our problems. The fact we have two other relatives that we have also ended up looking after, one has vascular dementia, but social services have deemed that person competent and the other has educational learning difficulties just makes me feel that social services don’t have a clue about organising help for these people. I appreciate money is an issue but Torfaen waste so much money which could go into social care. Also, leadership is lacking there needs to be a change of culture within social services to ensure that the department is run more efficiently and effectively. Regarding health services, apart from problems getting a GP appointment, and the delay with cataract operations, to the extent my mum in law could lose her sight in her eye permanently, the doctor diagnosing dementia in patient’s and then doesn’t have follow up appointments to monitor the progress of the disease. I could go on. Again, we all know the NHS has been underfunded for years but where is the leadership that gets people to think outside the box in dealing with these issues, so the system works more efficiently and effectively for patients.” (Torfaen)

“I understand the pressures as I used to work in the sector, but I feel I have been neglected by health and social care services.” (Blaenau Gwent)

HIGHLIGHTS



Overall, people's feedback to our survey suggests that they would like more support in their community whether that's day centres or respite services. Throughout this report there were themes identified that we would like to highlight:

- a) Reoccurring comments were given regarding day centres in the community, being impacted by the pandemic, particularly in Caerphilly.
- b) Nineteen people had not completed a carers assessment, five of whom did not know they were able to receive one.
- c) People not feeling supported with their well-being needs.
- d) People's comments with their individual experiences of being a carer, and how accessing services, impacts them.

Appendix 2 – Equality and Diversity Survey Results

The number of people who filled in the Equality & Diversity questions: 16

What is your preferred language?	
English	Other
15	1

Which gender do you identify with?				
Man/boy	Woman/girl	Non-binary	Other	Prefer not to say
2	11	1	1	1

Do you consider yourself to be a trans person?		
Yes	No	Prefer not to say
	15	1

What is your sexual orientation?			
Asexual	Bisexual person	Gay	Lesbian
	1		1
Heterosexual/Straight	Pansexual	Other	Prefer not to say
11	1	1	

Month and Year of Birth

Jan 1960 – 90	Feb 1940-50	Mar 1950-80	Apr	May	Jun
3	1	2			
Jul 1950-2010	Aug 1970-90	Sept 2000-10	Oct	Nov 1970-80	Dec 1970-85
2	2	1		1	2
Miscellaneous 1980-90					
1					

What is your ethnicity?

Asian or Asian British

Bangladeshi	Chinese	Indian	Pakistani	Other
		1	1	

Black or Black British

African	Caribbean	Other

Mixed

Asian and White	Black African and White	Black Caribbean and White	Other
		1	

White			
Welsh/English//Scottish/Northern Irish/British	Gypsy or Irish Traveller	Irish	Other
12			

Another Ethnic group		
Arab Any other	Prefer not to say	Other
	1	

What is your religion or belief?				
Buddhism	Christianity	Hinduism	Islam	Judaism
	2		1	
Sikhism	Atheism	No religion	Prefer not to say	Other
		6	1	3

Do you consider yourself to have a disability?		
Yes	No	Prefer not to say
9	7	

Do you look after, or give any help or support to a family member, friend, or neighbour because of long term physical disability, learning difficulty, mental ill-health, or age-related problems?

Yes	No	Prefer not to say
14	1	

Are you currently pregnant or have you been pregnant in the last year?

Yes	No	Prefer not to say
	16	

Which of the following best describes your financial status?

I have more than enough for necessities, and a large amount of disposable income, that I can save or spend on extras or leisure	1
I have more than enough for necessities, and a small amount of disposable income, that I can save or spend on extras or leisure	4
I have just enough for necessities and little else	7
I do not have enough for necessities and sometimes run out of money	3
I do not know/prefer not to say	1

Appendix 3

Equality Impact Assessment

Please complete the following table to state whether the following groups will be adversely, positively, differentially affected by Llais' policy/activity/report or that it will have no affect at all.

Impact	None	Negative	Positive	Comments
Protected characteristics				
Age	X			
Disability	X			
Sex	X			
Race	X			
Religion/Beliefs	X			
Sexual Orientation	X			
Gender reassignment	X			
Marriage and civil partnership	X			
Pregnancy and maternity	X			
Other characteristics to consider				
Welsh Language			X	Reports & surveys are available and published bilingually
Other Languages		X		Reports & surveys can be published in a required language on request
Human Rights	X			
Poverty level	X			
Persons with dependents	X			
Rural residence	X			
Gypsy, Roma, and traveller communities	X			
Digitally vulnerable	X			

Risk assessment

Are there any risks arising from the implementation of this policy?

N/A

What measures are in place to manage or remove these risks?

N/A

Welsh Language

This document/policy/report has been assessed in line with our Welsh language requirements for standards:

37,38

69,70,71

In coming to our impact determination, we can evidence that:

All Llais public facing documents are available in Welsh & English.

Llais undertakes an Equality Impact Assessment for all public documents and identify them as positive for Welsh translations.

Outcome

Positive impact –

Standards 37, 38 – All public documents are produced and published bilingually in Welsh and English.

Standards 69-71 - We undertake Equality Impact Assessments for all public documents and identify them as positive for Welsh translations.

Negative Impact – None