

Wales Carers Summit

2022 Report



Introduction

With society still reeling from the effects of the pandemic, the Wales Carers Summit aimed to identify positive solutions and policy changes that could be made by statutory authorities, carers support organisations and communities to make life better for unpaid carers.

Hosted by Carers Wales and funded by Welsh Government, the online Summit took place the week beginning 7th February 2022. Throughout the week focus group sessions were held on a variety of topics, co-facilitated with a range of organisations. During the sessions, carers shared their experiences, evidence was gathered and carers articulated how services should and could respond to their needs now and in the future. Key points raised during the week were presented in the form of questions to a panel of health and social care experts in the Friday plenary session.

This report summarises the focus group sessions, plenary and the powerful testimonials and feedback that carers shared with us throughout the week.

The report will be shared with policy and service decision-makers throughout Wales and will be used as the basis for Carers Wales policy and campaigning work. Carers Wales will run a follow-up session to the Summit during Carers Week 2022, where an update will be provided on progress achieved so far.

A short film has also been created summarising the plenary session which can be viewed on the Carers Wales YouTube channel.

We would like to sincerely thank all the organisations who co-facilitated the focus groups and the expert panel who joined us at the plenary session. Above all, we want to give huge thanks to the carers who took part to share their expertise, their very personal experiences and their insights into what needs to change and why.



Setting the scene

At the height of the Covid-19 pandemic, the number of unpaid carers across Wales increased from 487,000 to as many as 683,000¹. Services available to carers were limited before the pandemic, however many of these were closed during the pandemic and have not re-opened or are significantly pared back.

Since the start of the pandemic, thousands of carers across Wales have been under immense strain. They continue to bear the burdens of an overstretched and under-resourced health and social care system struggling to deal with the aftermath of the pandemic. Their contribution saved public services an estimated £33 million each day during the pandemic². Despite this huge contribution, often to the detriment of their own health and well-being, carers feel that they have been overlooked by politicians and decision-makers at local, regional and national levels.

Carers have rights enshrined in Welsh legislation, but those rights are not a reality for far too many carers across Wales. Our State of Caring in Wales briefing 2021 found that 37% of carers did not know what a Carers Needs Assessment was. This is despite the Social Services and Well-being Wales Act having come into force in 2016. This legislation gave all carers a right to an assessment of their needs. Many reflected to us in the State of Caring survey that they had struggled to find the support they needed. 76% said their ability to take breaks from caring has been reduced and 60% reported that their physical health had deteriorated while 71% said their mental health has worsened.

In the latter part of 2021, six out of the seven Local Health Boards, in conjunction with their local authority counterparts, issued statements asking unpaid carers to step up even further to provide care and support to loved ones. This was due to the increased pressure on hospitals to discharge patients and the lack of social care workers to provide support in care plans.

If carers are expected to provide this additional support as the third pillar of the health and social care system, then they must be properly supported and must not feel that they are being forced or pressured to take on caring duties that they may not be willing and able to do. With so few carers having carers needs assessments, they are taking on caring responsibilities without the necessary support in place to enable them to care safely and look after their own health and well-being.

As we emerge from Covid-19 restrictions, Local Authorities and Local Health Boards must re-establish and fully reinstate carers' services to meet the backlog of carers' needs. Carers are exhausted from providing the bulk of care during the pandemic and their needs must be properly considered in the short-term service recovery planning process and in the longer-term resourcing and planning of the health and social care system. This should happen alongside meaningful communication with and involvement of unpaid carers in the day-to-day delivery of services.

It is totally unsustainable for statutory authorities to rely so heavily on unsupported unpaid carers and the consequences of doing so will be far-reaching for health and social services, for carers themselves and for the most vulnerable people in our society.



¹ Carers UK 2020 – Caring behind closed doors forgotten families in the Coronavirus outbreak p17-18

Carer Focus Group Sessions



The sessions were held in the morning, afternoon and evening from Monday to Wednesday during the Summit week. They covered a range of topics as outlined below.

Across the sessions, carers expressed frustration, anger and upset at the way they have been treated for many years. They shared very personal and desperate experiences with us. Overall, carers stated that the pandemic had worsened an already precarious situation and that the past two years had been challenging on several levels.

Key themes from the discussions covered the need for:

- Improvements in carers accessing and benefitting from their rights within the Social Services and Wellbeing Act
- improvements in the recognition and understanding of the role of carers
- greater respect for the knowledge and experience unpaid carers have
- improvements in meaningful communication with and involvement of carers across statutory services
- improvements in service provision to support carers to care safely and confidently.



Day 1

A National Care Service

This focus group focused on the proposed National Care Service which features in the Co-operation Agreement between the Welsh Government and Plaid Cymru and was co-facilitated by Rhys Ab Owen, MS for South Wales Central.

Due to this being in the early stages of development, proposals for a National Care Service in Scotland, which are at a more advanced stage, were shared and carers were asked to share their thoughts about a proposed service for Wales. We asked carers what a National Care Service should do for unpaid carers, how they think carers should be prioritised in the design of the service and whether they had any concerns.

Key points that carers made were:

- There were several comments that there needs to be a cultural change in the way that carers are valued, recognised and treated for any new service to deliver meaningful change for carers.
- More resources need to be made available for carers' services, with clear integration across services and agencies.
- Unpaid carers should be the backbone of any National Care Service and their central role must be properly recognised with carers listened to throughout the design process. Carers need to be properly valued, represented and have a voice on governing boards.
- A common sentiment was that a National Care Service for Wales should ensure national frameworks, eligibility criteria and service standards for carers to ensure equity of services across Wales.
- It was felt that the National Care Service should be built on current good practice.
- There were concerns that a National Care Service would result in more bureaucracy and that carers may only benefit from indirect initiatives.
- Concerns were raised about how a National Care Service would be governed, monitored and managed. Carers suggested there needs to be greater national accountability for the delivery of carers services, such as through a Carers Commissioner.



- ☞ **A standardised framework for carers that is run and maintained by a local, dedicated Care Centre whose remit is specifically to support unpaid carers.** ☞
- ☞ **Clear and meaningful involvement of third sector and unpaid carers in planning.** ☞
- ☞ **Totally support the principle of core funding for carers services. This should be integral to the National Care Service.** ☞
- ☞ **Take it out of the local authority – too much disparity between local authorities with regard to resources that are available to unpaid carers (e.g. respite).** ☞
- ☞ **We should have unpaid carers on national boards from all regions – our representation should be the majority, not the minority.** ☞
- ☞ **There's a huge waste of pre-existing talent among carers. It's so difficult to get professionals [away] from calling us 'Mum and Dad'.** ☞

Direct Payments



This focus group focused on Direct Payments and was co-facilitated by Audit Wales, due to their inquiry into Direct Payments. We asked carers what they liked about Direct Payments, what could be improved and what would encourage increased take-up of Direct Payments.

There was a consensus that carers did not know what they could be used for or how to access them and that there is a disconnect between policy and lack of understanding on what you can use direct payments for.

Key points that carers made were:

- There needs to be guidance for carers and social workers about what Direct Payments are and what they can be used for.
- Social workers need Direct Payments training.
- Carers mentioned inequality in the system as local authorities manage direct payments in different ways, with some better than others. There needs to be uniformity of rates and consistency in policy across Wales.
- It was mentioned that the care market is controlled by external organisations and carers need to be able to offer an attractive wage to enable recruitment and retention of Personal Assistants (PAs). This is especially the case with the difficulties recruiting and retaining paid care workers. It was mentioned that agencies charge substantially more, and Direct Payments fell extremely short of their hourly rate, with carers expected to pick up the shortfall. When carers are on benefits this is just not possible.
- Carers in receipt of Direct Payments generally felt they were good when they work well and enable flexibility and more person-centred support.
- Some barriers identified to taking up Direct Payments were concerns about being an employer including all the administrative tasks without adequate support, a fear of what the money can be spent on and having to seek advance permission which can take a long time, the time spent in managing administrative tasks, not being told about Direct Payments in the first place, difficulty recruiting and retaining staff.
- A question was also asked about how many carers receive Direct Payments in their own right for support for them rather than the person they care for.
- Assessments should be 'carer blind'. Social workers should not be assuming that the carer will cope; if the carer has eligible needs, then they must be addressed.

- ☞ ***It feels as though Social Workers are sometimes the gatekeepers...*** ☞
- ☞ ***There's not a uniform rate for how much LAs get for social care, so it's not a level playing field from the beginning.*** ☞
- ☞ ***I'd like there to be a more trusting approach regarding how a carer uses direct payments. We're trusted to save the Council tens of thousands of pounds every year but not trusted to allocate £10 for a trip to the cinema.*** ☞
- ☞ ***Make the whole process of applying for Direct Payments easier.*** ☞
- ☞ ***I have been caring for my husband 9 years, only heard of DP in the last 6 months.*** ☞
- ☞ ***We were awarded them for respite needs, but unfortunately not been able to find anyone.*** ☞



Putting things right - Complaints

This focus group focused on raising a concern and was co-facilitated by the Older People's Commissioners office. It explored carers' experiences of taking forward a concern or a complaint, the process, whether carers felt that there is adequate support and information and what would help them to pursue redress if they felt that they had been treated unfairly.

Feedback was that their experience of raising a concern or making a complaint had been completely unsatisfactory. Generally, carers in the focus group wanted concerns to be addressed and lessons learned rather than making a formal complaint. From the experiences of those in the focus group they felt that when they raised concerns, they were not taken seriously which resulted in having to make a formal complaint.

Key points that carers made were:

- Complaints' timescales are not being honoured – the excessive length of time it takes for statutory services to respond to concerns or complaints was noted.
- There is a lack of advocacy or support to make a complaint.
- There is a lack of accountability and responsibility. It was felt that the complaints system exists to protect professionals and because there are no consequences, complaints are dismissed.
- There was worry that by raising a concern or making a complaint, carers would be penalised in some way by 'the system', that the close relationships between public bodies can make trusting the complaints process a challenge and that statutory services' account of what happened is the truth.
- Carers felt making a complaint to a statutory service is a David v Goliath task.
- Many carers shared how the process of taking a complaint forward was stressful, traumatic and had an impact on their health and well-being.

We asked what would help carers to seek redress.

They made several suggestions including:

- Clear information about the difference between how to raise a concern and how to make a complaint.
- Support from an independent advocate.
- Some carers felt that an independent conciliatory body to provide advice, information and support to take forward concerns may help reach more constructive outcomes.
- There needs to be a focus on getting it 'right first time'.

☞ **The Ombudsman should not be used as a dumping ground as Health Boards cannot get their act together.** ☞

☞ **We approached all kinds of organisations: Care Inspectorate Wales, our Senedd Member, no-one responded at all.** ☞

☞ **We started trying to raise concerns about abuse and no-one wanted to know.** ☞

☞ **Access to legal aid because they have solicitors, and we don't. We can't pursue legal routes because it will cost us money we don't have.** ☞

☞ **With social services, you have to complain to the same people that you're complaining about, and they generally close ranks.** ☞

☞ **We are not waiting 2 years for a resolution.** ☞

Day 2

Home adaptations and aids

This focus group focused on home adaptations and aids and was co-facilitated by Care and Repair Cymru. Given the current pressure on the health and social care system, we explored how aids and adaptations could support individuals to manage more independently in their own homes, what equipment and adaptations would be beneficial to support carers in their caring roles, avoid injuries and enable them to look after their health and well-being.

Key points that carers made were:

- Before discharge from hospital (where carers will be expected to undertake a variety of tasks), they should receive equipment and support. Support should include how to use lifting equipment, manual handling training, medicine management training etc.
- Carers need to be identified and properly consulted about what the needs are. One carer cited five separate cases of unsafe discharge from hospital due to lack of adequate consultation.
- There is a disconnect between hospitals and other agencies that should be putting services including adaptations/aids in place before discharge.
- Cost can be prohibitive, especially in the case of more substantial equipment and adaptations needed.
- Lots of carers shared their experience of not meeting eligibility criteria for the provision of equipment and despite being on benefits and unable to afford things, were expected to self-fund costly equipment to the detriment of their own health and well-being.
- Any adaptations/aids need also be provided in a timely manner so that carers are not left struggling and unable to manage.



- The types of aids/adaptations available can be a postcode lottery depending on where you live. There needs to be equity in provision.
- A carer's needs assessment should consider what equipment is needed to care and the social worker should be experienced enough to guide carers through ways to access equipment.

☞ **Carers have enough to do caring, without having to FIGHT for everything that the cared-for need. I just gave up in the end and funded what my mother needed myself which put me in debt, but it was essential so that I could continue to care for my mother.** ☞

☞ **We bought our own electric wheelchair, rise and recline chair, perching stool, walker etc.** ☞

☞ **A paid care worker has to follow HSE guidelines on using equipment...unpaid carers aren't considered. For example, you require 2 staff for using a full hoist. Every time we use a hoist it's a safeguarding concern...** ☞

☞ **Our local council has "Ask Sarah". It shows aids and adaptations that can be purchased.** ☞

Skills for Carers

This focus group focused on skills for carers and Social Care Wales had helped to prepare for the session. Carers have told us that they want to learn and develop skills that can help them with their caring role as well as enable them to care safely. Carers have told us that they would benefit from specific training including, but not limited to, manual handling, dressing wounds, medicine management, nutrition, hydration, infection control, and emotional and mental health support.

The pandemic has meant that carers are providing increased levels of care that would normally be undertaken by health and social care professionals. Carers have enquired about more formal training to support them. We asked carers what sorts of skills they thought they needed and how they would be best supported to get them.

Key points that carers made were:

- Interest was expressed in technological solutions and support, as well as practical solutions such as manual handling training.
- Carers questioned why they were not getting the training that paid care workers receive and suggested that carers should also be offered that training.
- Learning could be provided in diverse ways including in person, video calls and factsheets. Online training portals could be open to carers and other resources could also be shared.
- It was felt that paid professionals and unpaid carers would benefit from being in the same training sessions to increase awareness.

- Training should also be offered at the point of a specific diagnosis and a training path developed as the condition worsens.

We asked how carers could be supported to enter the paid care workforce should they wish. Comments were made that skills acquired through periods of caring should be recognised in application forms to explain employment gaps. It was felt that the practical skills developed as an unpaid carer would be highly relevant to paid care work, but also skills such as empathy and understanding.

☞ **Unpaid carers can't train unless a sitting service is arranged to facilitate opportunity** ☞

☞ **Perhaps at diagnosis, there could be training for new carers.** ☞

☞ **Often don't know where to go for help because we don't know what is out there. This should be done at diagnosis so all skills needed can be offered in a timely manner.** ☞

Working Carers

This focus group focused on working carers and was co-facilitated by the Wales Hub of Employers for Carers and Cardiff Council. Employees in every industry are balancing their jobs with unpaid caring responsibilities. This focus group explored what good practices existed around working carers and what more could be done by employers to benefit carers in their workforce.

There was a consensus that many managers were insufficiently aware of what constitutes a 'carer' even when organisational policies are in place. Many carers in employment also do not recognise their caring role and for those who do, many feel that there is a stigma attached that stops them from speaking up. Carers also spoke about struggles to get organisations to agree to flexible working and said this was the case pre as well as post-pandemic. Carers also explained the challenges of working, caring and balancing other responsibilities with very little support from statutory services as well as employers. The focus group then explored whether any additional arrangements had been made by employers to support carers as we emerge from the pandemic.

Key points that carers made were:

- Carers stated that employers were under the impression that they needed to spend large amounts of money to support carers or make additional changes in policies, but that small things like information on staff intranet etc could provide valuable support.
- Structures need to change to accommodate carers whose situation can change overnight and requests for flexible working should be taken seriously.
- Employers should be raising more awareness of carers in the workplace; there should be representatives of carers in the workplace and a cultural change is needed in the way that carers are perceived by colleagues, peers, and line managers. Employers should raise awareness in newsletters and other communications with staff with discussions in review meetings on what support carers need.
- Line managers need support, training and awareness on how carers may need to be supported and the understanding of the economic benefits of retaining or employing carers.



☞ **Well before the pandemic started my employers were very good. They were willing to let me have flexible hours and when possible, let me make up hours that I lost. I was stressed but they did listen and met me halfway whenever possible.** ☞

☞ **I feel it's all about awareness...info stands in workplace and training from carers services to a member of the workforce or staff to be a rep for carers.** ☞

☞ **Some carers will look forward to the opportunity to go back to work as it will be an opportunity for them to 'escape' their caring role for a while. I know carers who have told me that their work gives them a break - sometimes the only break they get.** ☞

☞ **The fight to get the carer package that my mam deserves, is harder than caring and working full-time combined. It is mentally exhausting.** ☞

Day 3

Hospital Discharge

This focus group focused on hospital discharge and was co-facilitated with the Welsh NHS Confederation, Head of Therapy and Occupational Therapy in Powys Teaching Health board. We know that carers have been facing unprecedented challenges and pressure to help the NHS discharge loved ones from hospital, against a backdrop of huge pressure on the social care sector as demand cannot currently meet the supply issues with the recruitment and retention of paid care workers.

The pressures on both the health and social care system have meant that many carers have had to step in to help fill the shortfall in services. From Carers Wales research we were aware that many carers have been providing the bulk of care during the pandemic and that without adequate support they will be unable to sustain the additional responsibilities without having an adverse impact on their own health and well-being.

We explored with carers what should happen before discharge takes place, what needs to happen to ensure carers are properly considered in the process, what is needed to be considered from both health and social care prior to discharge and what would help and support carers to manage their caring responsibilities safely at home.

Key points that carers made were:

- Carers need to be identified by the hospital as soon as possible after the admission pathway is started. There was recognition that this may not be immediate but that it should happen as early as possible.
- Carers commented that health care professionals should be identifying carers as being 'not just next of kin' and paperwork needs to be amended to prompt professionals to consider whether the person already has or will be likely to have a caring responsibility when the person is discharged.
- Paramedic handover should also include paperwork that includes the word 'carer' and not just 'next of kin'.
- Carers need to have information and advice as soon as possible and know where they can go and who they can turn to for help.
- Ward nurses, discharge nurses and care co-ordinator nurses should at a very minimum be trained to be carer aware.
- There needs to be a specific hospital liaison person/expert to speak to carers in advance of discharge to ensure that everything has been considered and is in place. Where things are not in place and the person is medically fit for discharge, there needs to be adequate provision for step-down facilities to not just alleviate pressure on the NHS but also alleviate the pressures placed on carers.
- Carers felt that there should be a specific department in hospitals to deal with any post-discharge issues.

☺ **It needs a toolkit, a discharge coordinator whose sole role is this - hence accountability** ☺

☺ **It needs a Hospital Discharge Champion at Welsh Government level where it is driven by quality and value-based health care.** ☺

☺ **I asked for a carer's assessment prior to my mam's discharge but was told that it wouldn't happen until she was home, because I wouldn't know what my needs were until then!** ☺

☺ **We are told at times my dad is medically fit to leave hospital, but there is no thought or question as to how we will manage at home with him or what aids are in place.** ☺

☺ **My husband with challenging behaviour came home to only me...the crisis team came in twos because they needed to ensure safety.** ☺

☺ **Put information on Local Health Board websites, a dedicated page explaining the discharge pathway, including how carer fits into the discharge.** ☺

☺ **Don't use jargon such as D2A. General public don't know what this stands for.** ☺

Post-pandemic local government: May 2022 and beyond

This focus group was held in partnership with the Welsh Local Government Association (WLGA).

Local Council elections will take place in May 2022, and we explored with carers what new council administrations need to do to better meet the needs of carers. In particular, how to ensure that the ethos of prevention and person-centred services, as well as the key statutory duties within the Social Services and Well-being (Wales) Act, are properly planned for and delivered for carers.

Key points that carers made were:

- Carers felt that local authorities should ring-fence carer funding and be accountable and transparent where the money is spent. Carers felt that bureaucracy costs money, which could be diverted to front line services.
- There was a consensus that there needs to be more integration with health, with less bureaucratic processes.
- What worked well for some carers during the pandemic were short, frequent calls with the social worker which didn't happen before. This seems to be more cost and time-efficient and carers felt better supported.
- It was felt that the Regional Partnership Boards focus on finances which impedes the transformation agenda. There need to be genuine links between local and national government to drive the meaningful change needed for carers.
- There should be independent external monitoring.
- Training needs to be provided to staff and local councillors.
- Carers felt that emergency planning should be a key part of the assessment process with carers being given an out of hours contact number.
- Carers felt there should be specialist carer officers employed across each local authority in Wales. There are some officers, but carers need to know who they are, how to contact them and what their remit is.
- Carers commented on the post-code lottery of services and wanted to see universal respite services across Wales with eligibility and service standards, better needs assessment processes and emergency provision for carers.



“ Social care and health problems would be improved if the two budgets were merged and if the services could act as one!! ”

“ As soon as you are identified as a carer, an individual information session or carers pack as a start. ”

“ We need to plan for the next generation. There is no evidence that this is happening as it is the same people working in a system that is not fit for purpose without system change. ”

Co-production – Nothing about us without us

This focus group was held in partnership with the Co-Production Network for Wales. Co-production is one of the main principles embedded within the Social Services and Well-being (Wales) Act.

The Act aims to give people a say in the development of services, transforming the way that social care is delivered across Wales to promote people's independence, give them a voice, choice and control. Co-production is where a relationship develops to enable professionals and for the purposes of this focus group, carers to work together to plan and deliver services by recognising that carers are assets to be used and consulted with. Many carers do not get involved in the planning process and the group explored what the barriers are and what is needed to engage carers.

Key points that carers made were:

- Professionals needed training at the highest levels to understand what co-production means in practice.
- Co-production is defined differently by different organisations and there needs to be a definition of what equal partnerships are.
- One representative is not enough to represent a whole community, anything less than 30% representation in a meeting is not enough.
- The balance of power in meetings is unequal and carers often felt intimidated and undervalued by paid professionals. Attendees said that when they attend meetings it feels adversarial, and carers felt co-production was just a tick box exercise.
- Being remunerated for their time is a key consideration so that carers feel properly valued.
- Statutory services need to recognise carers' skills, properly listen and realise that they do not always know best and that one size doesn't fit all.
- There should be mechanisms to evaluate, monitor and measure the impact of co-production.
- Have dedicated officers to support carers to get involved in co-production in public bodies.
- Promotion of opportunities could be better communicated using multiple channels.

- Feedback and co-production progress should be provided in a timely way.
- Remove accessibility barriers to enable carers to be more involved - such as accessible venues, hybrid meetings etc and ensure that replacement care is provided.
- Ensure meeting papers arrive well in advance with adequate support available.



☞ **Working with us will produce a better care and support plan and probably save them money.** ☞

☞ **On the question of sustaining co-production, if it makes a difference and people feel they are being listened to, they will keep being involved.** ☞

☞ **Show us we make a difference, so we keep trying.** ☞

☞ **Keep in touch and not just make contact when you need a carer's input.** ☞

☞ **Recognise that carers have something to offer.** ☞

Day 4

On Day four, Carers Wales ran a session for carers interested in being involved in Carers Wales' policy, influencing and campaigning work.

If you would like to find out more about becoming an Insight Volunteer, please visit the Carers Wales website.

During day four, feedback, input and comments made throughout the week were collated and summarised into a set of key questions for the Friday plenary session.

Day 5: Plenary

The Plenary session was held online and broadcast live over Facebook. Those in attendance were able to respond via the online 'chat' facility.

Welcome

Julie Morgan, Minister for Health and Social Services

The Minister said that she remained absolutely committed to putting the voice of carers at the heart of health and social care policy. She recognised that carers face considerable pressure and that pre-pandemic as well as currently, carers' contributions have been invaluable.

Working in partnership with the Ministerial Advisory Group for carers, carers engagement group and carers themselves led to the Strategy for Unpaid Carers being published in March 2021. The delivery plan for the Strategy was launched in November 2021. This represents a new commitment and sets out the priorities to improve recognition and support for carers. She outlined the additional funding Welsh Government had provided to local authorities and the extension of funding for four key carer projects within Carers Wales, Carers Trust Wales, All Wales Forum of Parent Carers and Age Cymru to provide a range of support for carers and to work with the health and social care sector to improve awareness of issues affecting carers and how carers can be better supported.

Overview of the Summit

Claire Morgan, Director, Carers Wales

Carers don't want or need platitudes about how important they are. Carers need practical help to care on a daily basis, carers need breaks and carers need money.

Claire likened the health and social care system to a three-legged stool, with each leg being health, social care and unpaid carers. Each leg of the stool is critical for the other to remain upright and stable and each element needs to work together as equal partners to sustain and get the support that each needs.

Claire reflected that the ethos and aims of the Social Services and Well-being (Wales) Act has not delivered its aspirations for better support for carers. The delivery has been impeded by financial austerity and the global pandemic but also ingrained attitudes dismissing unpaid carers in statutory bodies. She said that the Act itself remains sound and vital for the well-being of carers and the whole of the health and social care system in Wales and that there needs to be effective delivery, robust accountability for non-delivery, scrutiny and improvement where there is poor performance.

Claire reminded everyone that during the pandemic, carers saved £33 million a day for Wales and that many carers had changed their lives completely to look after vulnerable family and friends. Many of those carers gave up work and there are still countless carers caring more than they were at the start of the pandemic when services closed or were severely limited. Many carers have still not had any break and the health of carers has suffered. The cultural change that is needed is from top to bottom, with strong confident leadership by those who can make a difference, in the Senedd, in government, in local authorities and across health boards. The issues that have been raised by carers is now beyond urgent and cannot be kicked down the path any longer.

Expert panel

The expert panel members were introduced as follows:

Albert Heaney	- Chief Social Care Officer for Wales
Councillor Susan Elsmore	- Deputy Spokesperson, Health and Social Care for the Welsh Local Government Association and Cabinet Member for Social Care, Health & Wellbeing in Cardiff Council
Darren Hughes	- Director, NHS Confederation Wales
Sue Evans	- Chief Executive, Social Care Wales
Rhiannon Ivens	- Deputy Director with responsibility for carers, Welsh Government
Helen Walker	- Chief Executive, Carers UK
Rhian Thomas	- Former carer and Chair, Carers Wales Advisory Committee

Claire stated that the questions that were being put forward to the panel members were based on the issues that had been raised by carers throughout the week.

Question 1 – directed to Albert Heaney

“As mentioned in the introduction, unpaid carers need to be recognised as the third key element of the health and social care system in Wales. What assurances can you give carers that their needs will be addressed and prioritised in your workplan as Chief Social Care Officer for Wales?”

Albert responded by saying that since taking up his post he had undertaken a listening exercise with carers. He had heard first-hand their powerful statements about their experiences and recognised that things needed to change. In his top five priorities he confirmed that he would be looking at the issues that carers are facing and in particular would address issues in relation to carers’ assessments and direct payments. He hears the frustration and commits to working with carers and with Ministers to seek improvements to care and support.

Question 2 – directed at Darren Hughes and Councillor Susan Elsmore

“We heard from many carers that more effective and meaningful integration between health and social care would help. How is this being addressed through your work?”

Darren responded by acknowledging that without carers the NHS would collapse and paid tribute to the enormous contribution that carers make. He recognised that the health and social care system needed to work together to do more to ensure carers’ needs are taken into account during planning, ensuring a more joined up approach to support people. Councillor Elsmore commented that she could see the anger and frustration in the chat, acknowledged that and as a Cabinet Member for Cardiff City Council that their own targets could be better. She made a

commitment on behalf of WLGA to raise issues at meetings and decide on three top actions to take forward. She also stated that the health and social care system needs to be better integrated and that carers should be treated as professionals, so they are kept informed and information is shared.

Question 3 – directed at Sue Evans and Rhiannon Ivens

“Carers have told us that they are often ignored or seen as unimportant by health and social care professionals, despite providing the majority of care in Wales and having rights under the Social Services and Wellbeing (Wales) Act. How do you think we can achieve the cultural change needed to ensure the role of unpaid carers is better understood so that carers can access their rights and receive the support they need to care safely and confidently?”

Sue paid tribute to carers and explained that the role of Social Care Wales is to consider the learning and development needs of the workforce. They have rewritten vocational qualifications framed on a rights-based approach emphasising carers and those who need support. She recognised that the implementation of the Act is challenging and said a programme of work is also underway on strength-based approaches and person-centred planning to try and embed the aspirations of the Act. The Carers Strategy has provided the tools and implementation now needs to take place. There is a need for leadership from Welsh Government, local authorities and local health boards as well as Social Care Wales. Sue stated that she had been an unpaid carer herself and committed to being an ambassador for carers and to have a conversation about training the workforce.

Claire then asked Rhiannon about her thoughts on how cultural change can be achieved by decision-makers and policy professionals.

Rhiannon is an unpaid carer herself and joined Welsh Government in April 2021. She stated that Welsh Government were providing funding to Carers Wales and other carers organisations through their grants but also commented that a lot more still needs to be done and that she was absolutely committed to supporting carers. The Carers Strategy includes four national priorities including identification and valuing carers.

Question 4 – directed at Darren Hughes

“Since the repeal of the Carers Measure in Wales, carers are not being routinely identified at hospital discharge. As a result, many are not being made aware of their rights or the support available. This has implications for them in their ability to care and ultimately health and social care services. What assurances can you give carers that improvements will be made in hospital discharge processes?”

Darren noted that people feel strongly about these issues, and it was fair to say that communication is not good. He committed to take back the frustrations of unpaid carers to the members of his organisation and highlight the areas for improvement. He acknowledged that communication and engagement with carers across all sectors are key to ensuring that vital support and advice is available to carers. He also made a commitment that there needs to be a lot more work done with carers around hospital discharge and he would have a follow up discussion with Carers Wales.

Question 5 – directed at Councillor Susan Elsmore

“There remains a postcode lottery for carers across Wales in what support and services they can access. We know that there are different rates of direct payments, for example some local authorities offer better respite packages than others and there is often little understanding or transparency about the eligibility criteria for accessing support. The Welsh Local Government Association is in a unique position of bringing together local authorities from across Wales. What more do you think can be done to overcome this postcode lottery?”

Susan responded by saying that the term postcode lottery is interesting but we should remember that each local authority is a statutory organisation able to make its own decisions. She acknowledged the anger of carers and said that each local authority must ensure that the respite offer is serious. She said that she will take back to local authority colleagues that carers have been contacting them and that they were being told that they knew nothing about the respite funding.

Question 6 – directed at Albert Heaney

“Much of the support provided to carers comes via a fragmented and disjointed care system provided by a

multitude of providers. What are your thoughts about how this can be improved?”

Albert responded that he was at the Summit because it matters and that the panel care passionately about getting things right. He also acknowledged again the strength of feeling from the chat and that there is a journey needed to change things. He commented that the Act itself is largely sound but that the implementation needs to be re-looked at. He committed to be part of an opportunity to do things differently going forward and to work with the statutory bodies responsible for delivering the Act.

A supplementary question was then directed at Rhiannon Ivens about more robust performance management when things aren't working and the opportunities to share both good and bad practice.

Rhiannon responded by saying that she could see how passionate carers were feeling and as a carer herself felt passionate about her role. She said that there were complaints processes in place and that carers should raise complaints concerning their dissatisfaction with services. She also mentioned the Ombudsman's role to look into complaints. Claire responded by saying that in the focus group this week we heard what a minefield the complaints process was and multiple examples from carers about complaints not being responded to promptly or in an effective way which was putting it politely. Claire stated that Carers Wales may look to legally challenge certain situations where carers have had consistent complaints and had not been supported and even when taking a complaint to the Ombudsman carers have not had anything resolved. Rhiannon committed to discuss the examples carers had given in the focus group with a view to making uniform changes in the way that local authorities are dealing with complaints in Wales.

Councillor Susan Elsmore also committed to working with Carers Wales and have top actions to ensure that local authorities can be held accountable.

Question 7 – directed at Helen Walker, Chief Executive of Carers UK

“What do you believe are the key actions Welsh Government should take to support carers in employment?”

Helen said that the social care system needs to provide services to enable carers to return to work. Employers need to be more flexible and to agree to flexible working from day one. Governments and employers can support working carers through the Employers for Carers initiative and other tools that Carers UK have. There is also a gender imbalance that is a huge issue and Welsh Government should work with Carers Wales to ensure their employees can be properly supported.

Claire asked Rhian Thomas for her reflections.

Rhian Thomas commented that there had been a lot of discussion during the week about carers' assessments not being completed properly and that services are resource led rather than needs-led. She said the Social Services Act is fine but it is not being properly implemented and this results in ongoing disappointment and frustration for carers. She also stated that the postcode lottery is a long-term issue that doesn't seem to be getting any better.

Claire asked the expert panel to identify their key commitments from the Wales Carers Summit. These are summarised below.

Albert Heaney

In his role as Chief Social Care Officer for Wales, Albert stated his commitment to unpaid carers as one of his top priorities. He committed to working collaboratively with Government, organisations and carers to achieve improvements. His will aim to start with improvements to Direct Payments and Carers Assessments and he undertook to be an ambassador/champion, to listen, respond and seek the improvements that everyone wants. He acknowledged the pressures on carers and their frustrations. He will aim to drive forward the work with partners.

Cllr Susan Elsmore

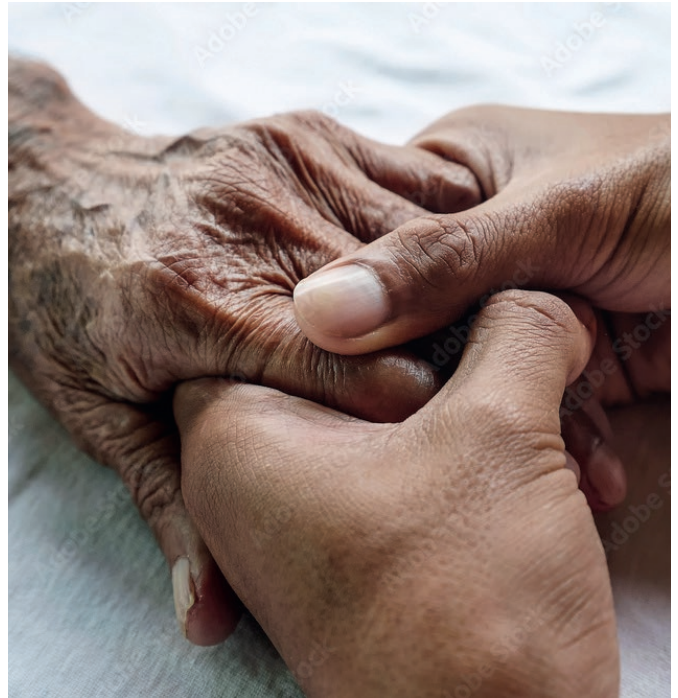
Councillor Elsmore committed to working with the Chief Social Care Officer, Welsh Government and other organisations to devise a non-bureaucratic way of identifying carers and ensure that they are sufficiently valued and respected by social care professionals. She stated that there should be robust performance measures to be in place and committed to reporting back to the Welsh Local Government organisation to review the complaints process failures.

Darren Hughes

Darren acknowledged that carers are integral to the system and that carers want change and not platitudes. He said that care should be provided at the right place, the right time and with the right support and there needs to be better joined up work between the NHS, local authorities and the voluntary sector. He acknowledged that more needs to be done to identify carers, especially around the hospital discharge process. He confirmed that he was more than happy to have a follow-up conversation with Carers Wales to consider solutions.

Sue Evans

Sue committed to checking Social Care Wales' own employment policies and practices to support carers in the workplace. She committed to re-evaluating whether their rights-based approach in relation to carers was strong enough and whether they needed



to be strengthened. She said that Social Care Wales would continue to listen to the voice of unpaid carers and keep using evidence captured by Carers Wales to inform improvements. She committed to being a champion for unpaid carers and through the Carers Strategy hold each other to account.

Rhiannon Ivens

Rhiannon committed to investigating the complaints system, especially the time taken to resolve complaints. She will continue to work with Carers Wales, and through the Ministerial Advisory Group for Carers to tackle issues via the Carers Strategy and Delivery Plan.

Helen Walker

Helen was pleased to hear a genuine commitment to make a difference to unpaid carers and made a plea that we learn from one another across the nations, including good and bad practice. She said we need to share learning from the pandemic and how we support carers more effectively across the UK.

Rhian Thomas

Rhian said she would work with the Carers Wales team and Advisory Committee to push forward the commitments from today. She said that the most important thing was that unpaid carers want to feel valued for their wealth of knowledge and skills.

Claire closed the Wales Carers Summit by thanking everyone for their involvement during the week. She committed to following up with expert panel members, key decision / policy makers across Wales and more importantly with unpaid carers to ensure positive change happens.

Our mission is to make life better for carers



We give expert advice,
information and support



We connect carers so
no-one has to care alone



We campaign together
for lasting change



We innovate to find new ways
to reach and support carers



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