



Partneriaeth
Ranbarthol
Gorllewin
Morgannwg

West
Glamorgan
Regional
Partnership



POPULATION NEEDS ASSESSMENT
2022 - 2027

CARERS WHO
NEED SUPPORT

If you require this information in an alternative format, please contact the
West Glamorgan Transformation Office via email at
west.glamorgan@swansea.gov.uk

1. Carers who need support – Who are they why do they need support?

The Social Services and Well-being Act defines a “carer” as “**a person who provides or intends to provide care for an adult or disabled child**”. The term “carer” can be associated with paid professionals who provide care to people. Unpaid carers are usually family or friends that give their time to help a person who needs support. However, “unpaid” does not necessarily mean that they do not receive any financial support for carrying out this role. Some carers can claim allowances and benefits to support them.

Carers are listed as a community of interest under the Socio-economic duty ratified by Welsh Government. This means that there is an expectation on public bodies when making strategic decisions “to have due regard to the need to reduce the inequalities of outcome resulting from socio-economic disadvantage.”¹

Carers can be of any age, have different relationships with the person they care for, and different life situations. For example, carers may be Black, Asian or from other Minority Ethnic groups and in some languages the term “carer” doesn’t exist. Carers from Lesbian, Gay, Bisexual and Transgender + communities must also have their identity respected and supported to care in a way that respects this identity. These different dimensions to caring mean that carers are as different to each other as they are similar.

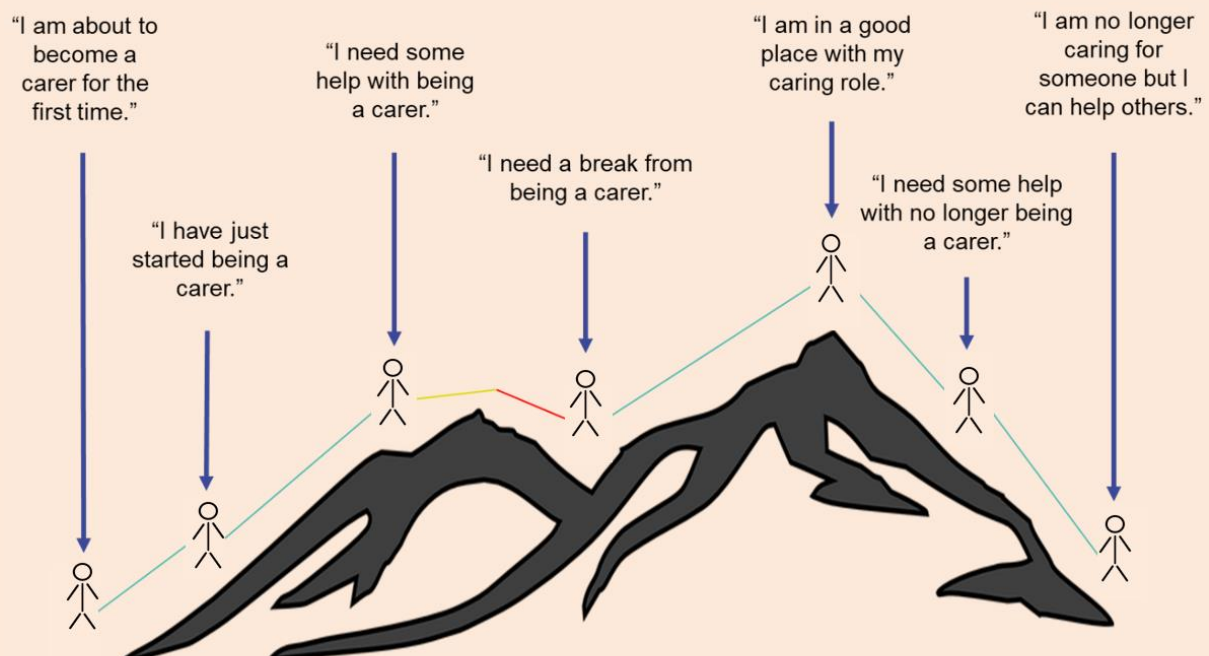
The West Glamorgan Carers Strategy outlines in more detail how we plan to meet the needs of carers over the next 5 years². Any new needs identified in the Population Needs Assessment will be included. We have chosen to think about carers in terms of stage of life, relationships and life situations, and how caring can change over time.

¹ Welsh Government (2021) A more equal Wales, The Socio-economic Duty Equality Act 2010, Statutory Guidance <https://gov.wales/sites/default/files/publications/2021-03/a-more-equal-wales.pdf>

² West Glamorgan Regional Partnership <http://www.westglamorgan.org.uk/carers/>

Caring scenarios are based on...						
Your age group <i>What stage of life?</i>	Child	Young Person	Adult	Older Adult		
Your relationship <i>Who are you caring for?</i>	Parent / Grandparent	Sibling	Child / Grandchild	Spouse / partner	Unrelated (e.g. neighbour)	
Your situation <i>What is your life like?</i>	Caring for multiple individuals	Working	Unemployed / retired	In education	Living separately to cared-for individual	Living with a disability or illness

The caring journey can be difficult and rewarding, just like climbing a mountain. It does not take place in a linear form, the path can undulate and the terrain can change. However, unlike a single mountain climb or short-term caring role, caring is frequently a long-term commitment.



Carers will begin the journey with varying levels of knowledge and experience. They may find that along the journey, they need help or need a break to get them to being in a good place, and they can move

between these parts of the journey continuously for the duration. There is also a need to consider the needs of carers at the end of the caring journey, including transition from their caring responsibilities, what their experience can offer other carers and how we can learn from their personal journey.

Carers show us through their actions that it is a role that people take on because of their commitment and tenacity to help the people they care about. Our aim is to ensure that the caring journey is made easier through working collaboratively with carers, health, social care and third sector organisations to create the right mix of services and support that meet the needs of carers in West Glamorgan.

The West Glamorgan Regional Partnership has recognised that carers are critical to supporting our health and social care services. We support Carers Wales' call for their recognition as the "third pillar" to this infrastructure³. We support this view because across Swansea and Neath Port Talbot there are over 50,000 carers⁴ (see also data tables below) in over 160,000 households⁵ who provide care and support that prevent the need for health and social care interventions. The Welsh Government Strategy for Unpaid Carers highlights that the care provided by Carers or all ages is worth £8.1 billion to the Welsh economy⁶. Since the pandemic began unpaid carers contribution has been valued at £33 million⁷.

Social Value is a term frequently used to describe added benefits to individuals and communities following an intervention. If we support carers in their role and they are able to participate in the communities in

³ Carers Wales (2020) Track the Act Briefing 5. Retrieved from:

<https://www.carersuk.org/files/section/6609/carers-wales-track-the-act-briefing-final-version-eng.pdf>

⁴ Office for National Statistics (2011) Provisions of unpaid care by general health by sex and by age. Retrieved from: <https://www.nomisweb.co.uk/census/2011/lc3301ew>

⁵ Office of National Statistics (2014) Number of unpaid carers in household – UA's in Wales. Retrieved from: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/adhoc/003305ct02762011censusnumberofunpaidcarersinhouseholduasinwales>

⁶ Welsh Government (2021) Strategy for unpaid carers <https://gov.wales/sites/default/files/pdf-versions/2021/3/2/1616489674/strategy-unpaid-carers.pdf>

⁷ Carers Wales (2020) Unpaid carers in Wales have saved £33 million every day of the pandemic <https://www.carersuk.org/news-and-campaigns/news/unpaid-carers-in-wales-have-saved-33-million-every-day-of-the-pandemic>

which they live, then we have been able to deliver additional social value for carers. The Wales Co-operative Centre⁸ have produced a number of tools to progress the development and commissioning of social value services. The West Glamorgan Social Value Forum will aim to drive forward our understanding and develop a regional approach to ensuring that we commission regional funding with a foundation built on social value.

Age Profile of Carers

Neath Port Talbot

Carer	All categories: Provision of unpaid care	Provides no unpaid care	Provides unpaid care: Total	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week
Age						
All categories: Age	138,682	118,322	20,360	10,379	3,273	6,708
Age 0 to 24	39,513	37,885	1,628	1,158	256	214
Age 25 to 49	45,565	38,580	6,985	3,890	1,171	1,924
Age 50 to 64	28,416	21,393	7,023	3,797	1,185	2,041
Age 65 and over	25,188	20,464	4,724	1,534	661	2,529

Swansea

Carer	All categories: Provision of unpaid care	Provides no unpaid care	Provides unpaid care: Total	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week
Age						
All categories: Age	234,363	204,083	30,280	17,290	4,489	8,501
Age 0 to 24	72,956	70,480	2,476	1,805	384	287
Age 25 to 49	76,359	66,357	10,002	6,147	1,514	2,341
Age 50 to 64	43,783	33,263	10,520	6,506	1,532	2,482
Age 65 and over	41,265	33,983	7,282	2,832	1,059	3,391

Source: Nomis - 2011 Census LC3301EW - Provision of unpaid care by general health by sex and by age

⁸ Wales Cooperative Centre (2020) Supporting care commissioners and procurers to promote social value models of delivery <https://wales.coop/supporting-care-commissioners/>

Whilst this data is helpful to help determine a minimum number of carers, we expect there to be many more. The 2021 Census will give an opportunity to identify how carer numbers have increased over time. Age groupings that are more comparative (e.g. increments of 5 or 10) would be preferable to enable effective tracking of what stage of life people are becoming carers so that interventions can be aligned to different cohorts more appropriately.

The Carers Week Research Report 2020⁹ broke down the age profile of carers in Wales as follows:

- 🌸 17% are aged over 65, 28% are 55-64, 19% are 44-54, 25% are 35-44, 5% are 25-34, 6% are 18-24.

Their research also revealed that:

- 🌸 57% are women and 43% are men
- 🌸 Half (50%) of unpaid carers are in paid work. 31% are in full-time work, and 19% are in part-time work.

Age Cymru conducted a survey of older carers where 14% of the respondents were from the West Glamorgan region. The survey results gave the following national profile for carers¹⁰.

- 🌸 57% were aged between 50-59, with 29% aged 60-69 and 14% aged 70+
- 🌸 44% live in the same household, with 56% living elsewhere
- 🌸 77% of respondents were female, 23% male
- 🌸 91% were looking after someone aged 50+
- 🌸 41% were caring for a parent, 25% a spouse, 17% caring for a child, 17% looking after another relative/friend/neighbour.

Despite the focus of this survey being on older carers it reveals that caring for someone is likely for most people at some point in their lives. The majority will care for a parent or partner but it's important to note

⁹ Carers Week Research Report (2020)

https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

¹⁰ Age Cymru (2021) For the Moment: Summary of findings from older carers

<https://www.ageuk.org.uk/globalassets/age-cymru/documents/carers-project/age-cymru-carers-report---english.pdf>

that 17% of carers over 50 continue to support to their child or children in later life.

Considering caring across households as well as carer numbers clearly shows that caring is a family affair and that people take on multiple caring roles within and external to their households.

The 2011 Census estimates that classify all households by number of unpaid carers are demonstrated in the following table.

	TOTAL: All households	No unpaid carers	One unpaid carer	2 unpaid carers	3 unpaid carers	4 unpaid carers	5 unpaid carers	6 or more unpaid carers
W92000004 WALES	1,302,676	1,022,239	203,324	67,938	7,153	1,655	312	55
W06000012 Neath Port Talbot	60,393	44,970	11,075	3,855	408	74	11	0
W06000011 Swansea	103,497	80,486	16,706	5,540	605	130	25	5

Source: Office of National Statistics – CT0276_2011 Census - Number of unpaid carers in household - UAs in Wales)

The data collected on carers is limited however we can build a picture of how many carers there are with similar caring scenarios by looking at data relating to patients and service users. We have provided an example of this for 3 different groups of carers but we recognise that further statistical work is required to give a more accurate picture. The 2021 Census information (which is due to be published later in 2022) will enable us to investigate more up to date data.

Parent Carers

We have estimated that there could be at least 12,000 parent carers in West Glamorgan. We have made this assumption based on the number of children with special education needs across the region. However, there are limitations, e.g. where there may be more than one child with special education needs in the household. It also does not account for co-parenting families, and of course wider family support.

	Wales	Swansea	Neath Port Talbot
Children with Special Educational Needs 2020/21	92,688	8,741	4,970

<https://statswales.gov.wales/Catalogue/Education-and-Skills/Schools-and-Teachers/Schools-Census/Pupil-Level-Annual-School-Census/Special-Educational-Needs/pupilssen-by-localauthorityregion-provision>

Young Carers

Similarly, the number of young carers known to Social Services is low and out of date (see table below). The true number of young carers is likely to be much higher. Taken in consideration with the number of children with special educational needs, we can make the assumption that there are some with siblings involved in supporting their needs and the number of young carers in the population is much higher. However, further work is required to determine an estimate.

	Wales	Swansea	Neath Port Talbot
The number of young carers known to Social Services during the year	782	29	31
The number of young carers known to Social Services who were assessed during the year	728	29	31
The number of young carers known to Social Services who were provided with a service during the year	684	28	31

Source: Statistics Wales - 2015/16 Young carers by local authority and measure

Dementia Carers

The prevalence of Dementia in the former Abertawe Bro Morgannwg University Health Board footprint in 2015 was between 7,200 and 9,500¹¹. Whilst this is out of date, the numbers of people living with dementia is likely to increase (see mental health chapter). People living with dementia are frequently supported by family and this can be provided by multiple generations. The nature of the condition means that

¹¹ Alzheimer's Research UK (2021)

<https://app.polimapper.co.uk/?dataSetKey=91cf47c5b8d542d28d8e0da9f3a67ed8>

at some point there will be an unpaid carer supporting most people living with dementia. We can from this figure estimate that at any one time there can be at a minimum 7,000 individuals supporting someone living with dementia. However, this is based on the lowest possible figures and only assumes one carer for each person. This figure is likely to be much higher and further analysis is needed to determine a more accurate figure.

To summarise the salient points:

- 🌸 Carers are critical to the delivery of our health and social care sector.
- 🌸 There are at least 50,000 carers living in West Glamorgan.
- 🌸 We need to make sure we engage with harder to reach groups of carers.
- 🌸 57% of carers are women and 43% are men.
- 🌸 Most carers are caring for an older person.
- 🌸 There are at least: 12,000 parent carers and 7,000 dementia carers, but we need to gather more information about young carers and other large groups of carers that may have specific support needs related to their caring situation.
- 🌸 Further work is needed to understand carers' needs at a population level.

2. What lifestyle factors affect a Carer's quality of life?

The lifestyle factors that affect the general population will also apply to carers. Caring for someone can be a rewarding and positive experience, however, taking on a caring role can have negative consequences for wellbeing. Caring can also exacerbate any existing lifestyle factors that can have negative consequences, such as living in poverty or living with a chronic condition.

The Joseph Rowntree Foundation Poverty Annual Report 2019/20¹² stated that you are much more likely to be in poverty if “you live in certain regions, live in a family where there’s a disabled person or a

¹² Joseph Rowntree Foundation (2020) Poverty Annual Report 2019/20 <https://www.jrf.org.uk/report/uk-poverty-2019-20>

carer, if you work in certain sectors such as accommodation and catering or retail, or if you live in privately rented housing.” They also suggest that in the UK around 7% of carers are living in poverty. However, given the poverty rate for West Wales and the Valleys is 26.6%¹³ we think that the number of carers living in poverty in West Glamorgan is higher than 7%.

The Carers Week Research Report 2020 found that the following challenges were the most prevalent for carers in Wales:

- 🌸 not being able to take time away from caring (78%)
- 🌸 managing the stress and responsibility (77%)
- 🌸 the financial impact of the additional care costs (72%)
- 🌸 the impact it has on other personal relationships (eg with family, friends, partners, etc.) (70%).
- 🌸 the negative impact on their physical and mental health (69%)
- 🌸 the negative impact it has on their ability to do paid work (63%)
- 🌸 not having anyone to talk to about the challenges of caring (52%).

The Carers Week Research Report 2021¹⁴ highlighted the impact of caring on wellbeing and emphasises the need for a break and the risks of carers reaching crisis point. .

- 🌸 63% are worried about continuing to care without a break
- 🌸 74% are exhausted as a result of caring
- 🌸 72% have not had any breaks in the pandemic
- 🌸 71% are stressed and anxious
- 🌸 35% say they feel unable to manage their caring role
- 🌸 65% feel lonely and isolated.

Many unpaid carers struggle to balance work and caring for someone. Carers Wales estimates that 149,812 people in Wales have had to give up employment to care. Of those who have been able to stay in

¹³ Office of National Statistics (2020) Poverty rate by NUTS 2 region, UK, financial year ending 2018 to financial year ending 2020.

<https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/adhocs/13572povertyratebynuts2regionukfinancialyearending2018tofinancialyearending2020>

¹⁴ Carers Week (2021) Breaks of Breakdown <https://www.carersweek.org/media/u4jby32a/carers-week-2021-research-report.pdf>

employment, 74,906 have had to reduce their working hours to support the people they care for¹⁵.

To summarise the salient points:

- 🌸 Caring can have a negative impact on health and wellbeing.
- 🌸 It can exacerbate existing and also cause the development of new health conditions.
- 🌸 Caring has an impact on participation in the workforce and carers who give up work to care can find themselves living in poverty as a result.
- 🌸 Carers are unable to take adequate breaks away from their caring role.
- 🌸 Many haven't been able to take a break since the pandemic began.
- 🌸 Carers are becoming more isolated and lonelier as a result of their caring role.

3. Services used by Carers

Carers use health and social care services as individuals themselves but also as advocates and supporters for the people they care for.

Carers services within the West Glamorgan region are listed below:

Organisation	Contact	Purpose
Swansea Carers Centre	104 Mansel Street, Swansea, SA1 5UE Tel: 01792 653344 www.swanseacarerscentre.org.uk	...provides a range of information, advice, support, services and events for carers in Swansea.
Neath Port Talbot Carers Service	Cimla Health & Social Care Centre, Neath SA11 3SU Tel: 01639 642277 www.nptcarers.co.uk	... to identify carers and to provide carers aged 18 and over in Neath Port Talbot with advice, information and support

¹⁵ Carers UK (2019) Juggling work and unpaid care
http://www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_0119_WEB.pdf







Organisation	Contact	Purpose
Swansea Parent Carer Forum	61 Pennard Drive Southgate Swansea SA3 2DN swanseapcf.org	...to work co-productively with local services to help bring about improvements in services for disabled children, young people and their families.
Hafal Swansea	Alexandra House, Alexandra Road, Swansea SA1 5ED Tel: 01792 816600 www.hafal.org	...offers daytime support and information for carers of adults with severe mental health problems and also a monthly support group.
YMCA Swansea	YMCA Swansea 1 The Kingsway Swansea SA1 5JQ Tel: 01792 652 032 www.ymca.org.uk/location/ymca-swansea	...provides support and information for young carers aged 8-18 in Swansea.
Neath Port Talbot Youth Service	Neath Port Talbot Youth Service Tir Morfa Centre Marine Drive Sandfields Port Talbot SA12 7NN Tel: 01639 763030 www.npt.gov.uk	...offers a range of support to children and young people up to the age of 25, who have a caring role at home. This could be because of illness, disability, mental health or drug and alcohol misuse.

4. What do we know about the needs of Carers?

The Welsh Government Strategy for unpaid carers¹⁶ sets out four national priorities for carers. These are:

1. Identifying and valuing unpaid carers
2. Providing information, advice and assistance
3. Supporting life alongside caring
4. Supporting unpaid carers in education and the workplace.

The West Glamorgan Carers Strategy was approved in January 2021. It explores the needs of carers further and sets out the following six themes where we need to focus our efforts:

-  Balancing priorities
-  Supporting each other
-  Information and advice
-  Identified and recognised
-  Dignity and respect
-  Support services.

Our mission

We will work together to improve the wellbeing of carers in West Glamorgan by listening, learning, being supportive and delivering changes through the Regional Partnership that meet the rights and needs of carers.

Our vision

Carers are identified, recognised and supported to care. They have a life alongside caring and have a feeling of well-being throughout their caring journey.





¹⁶ Welsh Government (2021) Strategy for unpaid carers <https://gov.wales/sites/default/files/pdf-versions/2021/3/2/1616489674/strategy-unpaid-carers.pdf>

Carers Strategy Evidence Review

During the development of the carers strategy, a review of evidence was conducted to identify key issues under each of the strategy themes. The evidence reviewed highlighted a number of issues and needs for carers and these were developed into a service of outcomes for inclusion in the strategy. Further information about this is available in the strategy document and the identified needs are outlined below.





Balancing priorities - Carers value having a break from caring

“Only one in five respondents (21%) agreed or strongly agreed with the statement “I am confident that I have a contingency plan in place in case of emergency”. This was lower in Wales where only 16% agreed/strongly agreed, but higher in NI (21%) and Scotland (26%)”¹⁷

-  Contingency planning support and services to deliver them.
-  “Me Time”, networking with other carers, workshops for wellbeing.
-  Respite – flexible to the need, booking, a variety of options and meaningful for people.
-  Support to ensure educational needs are met for young carers, parent carers and sibling carers.

Supporting each other - Carers value support from other carers

“Carers are receiving help from their friends and family who understand what they are going through and the importance of a good network of support so that they are able to have a break. Carers feel it is important to receive compassion rather than pity.”¹⁸

-  Creating opportunities for carers to come together.
-  Ensuring that a mix of virtual and face to face contact is possible.
-  Creating carers groups within other settings e.g. schools or work places.
-  Supporting carer led groups.

Information and advice - Carers value the right information and advice

“Over half of young carers and 43% of young adult carers want ideas of things to do at home.”¹⁹

¹⁷ Carers UK (2020) Behind Closed Doors <https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-report>

¹⁸ West Glamorgan (2021) Regional Carers Strategy, Appendix C Reference, evidence from Swansea Council

¹⁹ Carers Trust (2021) My Future, My Feelings, My Family <https://carers.org/downloads/what-we-do-section/my-future-my-feelings-my-family.pdf>

- 🌈 Practical advice and suggestions to help generate their own ideas on a variety of issues.
- 🌈 Contingency planning advice – what to think about.
- 🌈 Advice for carers at key points e.g. diagnosis, appointments, discharge, care packages.
- 🌈 Written information in plain English/ easy read and choice for Welsh and other languages.

Identified and recognised - Carers value being recognised for being a carer

“There are over 370,000 unpaid carers in Wales – around 1 in 10 of the population, with a large proportion of them working part time or full time. This number increases every year and Carers Wales estimate that these carers save the Welsh NHS about £8.1 billion every year.”²⁰

- 🌈 Involved in decision making, especially for young Carers.
- 🌈 Identify people as a carer even when they don't recognise themselves as one.
- 🌈 Should be everyone's job to identify carers.

Appropriate treatment - Carers value being treated appropriately for being a carer

“11% of young carers and 20% of young adult carers said they found it hard to access food and medicines.”

“66% of those going through an assessment process for extra help with their child's learning say it has been delayed by the pandemic. 43% of those entitled to an annual review say it has lapsed or been put on hold.”²¹

- 🌈 Consistent staff and approach, particularly for people with long term needs.
- 🌈 Raise awareness of carers needs for different types of carers, e.g. young carers, sibling carers, working carers, sandwich carers, parent carers, spousal carers.
- 🌈 Schools have approaches for identifying and supporting young carers.

²⁰ TUC (2020) Supporting older workers - A toolkit for trade unionists Wales TUC Cymru
<https://www.tuc.org.uk/news/wales-tuc-launches-new-guide-supporting-older-workers>

²¹ Disabled Children's Partnership (2020) #LeftInLockdown - Parent carers' experiences of lockdown
<https://disabledchildrenspartnership.org.uk/wp-content/uploads/2020/06/LeftInLockdown-Parent-carers%E2%80%99-experiences-of-lockdown-June-2020.pdf>





- 🌸 Employers are made aware of ways to support carers to stay in work.
- 🌸 Give consideration for people's socio-economic situation, carers may be living in poverty.
- 🌸 Consider people's mental health and wellbeing and understand this can change and fluctuate over time.
- 🌸 When making decisions, consider what impact this may have on carers.
- 🌸 Funding carer services means carers are enabled to keep on caring.
- 🌸 Carers assessments are offered and appropriately carried out.

Support services - Carers value help in understanding their rights

“75% of the public think the government should increase support for carers”

- 🌸 GPs are key to identifying and signposting Carers for support.
- 🌸 Carers' third sector support is appreciated and requires sustainable long-term funding.
- 🌸 Direct Payment systems are difficult to navigate and challenging to negotiate for carers.
- 🌸 Carers assessments need to be positive experiences.
- 🌸 Carers emergency card is a good prompt for carers to think about contingency planning but needs to be promoted with Carers.
- 🌸 Charging for services – should people pay? Can people pay?
- 🌸 Carers need respite, sometimes with and sometimes without the person they care for.
- 🌸 Mental health and wellbeing support is essential for carers to keep on caring.
- 🌸 COVID-19 specific:
 - Carers are providing more care than they were before (service limitations and/or choice to shield).
 - Reduction in business as usual and closure of therapeutic and support services have meant carers either replace or discontinue such interventions, with consequences for the person they care for.
 - Assessments and support services need to return to business as usual as soon as possible.



As part of the evidence review for the Carers Strategy, some cross cutting threads emerged that were found to permeate through all themes. These were:

-  Carer wellbeing,
-  Communication,
-  Co-production, and
-  Training.














Carers Liaison Forum Evidence












To support how we will deliver the Regional Carers Strategy the West Glamorgan Carers Liaison Forum was established. Its vision is to create a forum where Carers can create a collective voice, be heard, and help make positive change to health and care services in the West Glamorgan Regional Partnership.











The Forum were presented with information about the Regional Carers Strategy, its themes and outcomes. They then explored each theme using the following questions:

-  What actions need to be taken to enable these outcomes?
-  What are the roadblocks?



The table below outlines the needs they would like us to focus on improving for the future.

Theme	Outcomes	What Carers have told us
Balancing priorities	<ol style="list-style-type: none"> 1. Carers have flexible and responsive respite opportunities. 2. Carers have support with developing contingency plans. 3. Carers have access to wellbeing workshops. 4. Carers have workplace and educational support. 	<p>More work with carers is needed to develop a deeper understanding of this theme. It means different things to different people and priorities are different depending on the carers situation. There is need to pay particular attention to:</p> <ul style="list-style-type: none">  Information and advice at the right time, accessible and timely.  timely and holistic assessments,  flexible, responsive and innovative respite/breaks.  direct payments that deliver on supporting their wellbeing.  Adult carers would like interventions that enable them to get good quality sleep.  Adult carers would like a holistic approach to assessing needs but with options for it to be independent of the person being cared for.  Young carers would like support with tuition and homework clubs  Young carers would like help with choosing subject options and careers advice.
Supporting each other	<ol style="list-style-type: none"> 5. Carers have opportunities to meet each other. 6. Carer led groups are commonplace. 	<p>Peer support is one of the best kinds of support. Variety of support is needed – it doesn't always need to involve talking or sharing experience of caring. Knowing what's available regionally as well as locally and how do make sure carers have the same opportunities across the region.</p> <p>There is need to pay particular attention to:</p> <ul style="list-style-type: none">  rights information to support one another,  consistent and accessible information across the region.  variety of different ways to connect with each other and support services to refer into.  Time is critical – having a range of activities at different times is needed.  Young carers need support services where they can meet up with other young carers.

Theme	Outcomes	What Carers have told us
Information and advice	<p>7. Carers are informed of their rights.</p> <p>8. Carers have dedicated and tailored information and advice portals/places across all statutory providers.</p> <p>9. Carers have information and advice about contingency planning.</p> <p>10. Carers are informed about Assessments and how they can be of benefit.</p> <p>11. Easy read options and minority languages are catered for appropriately.</p>	<p>Carers need the right information at the right time and the right amount. There is need to pay particular attention to:</p> <ul style="list-style-type: none">  Clear and inclusive language, plain, easy, sign/visual and options for other languages.  Consistency of message and terminology is needed across statutory and third sector partners.  A central place with trusted independent information for carers would be valued by carers.  Diagnostic pathways could provide early information, but more work is needed to understand what information would be needed.  Training for staff on carers rights is needed because carers do get the wrong information sometimes.
Identified and recognised	<p>12. Carers are recognised even if they do not self-identify.</p> <p>13. Carers are actively identified by organisations and staff supporting them.</p> <p>14. There is shared responsibility across and within organisations for identifying carers.</p>	<p>Lots of carers don't identify themselves, they are spouse/partner, parent, sibling or friend first. There is need to pay particular attention to:</p> <ul style="list-style-type: none">  Carers are exhausted, they care 24/7 and we need to better understand what this means.  We need to better recognise the inequalities that exist within caring, e.g. women often don't have the options to develop careers and develop relationships outside their caring role.  Diagnosis can be a critical point where we could identify carers early e.g. asking patients "who supports you?".  Need to listen to carers experiences and identify the possible "recognition" points that they think would have prompted them seek help.  If rights are upheld and good care/support is provided for the person who needs it then the role of the carer becomes far easier.  Recognition for carers as experts by experience but that they need support to fulfil the role.

Theme	Outcomes	What Carers have told us
Dignity and Respect	15. Carers are recognised as experts by experience. 16. Awareness of Carers is commonplace. 17. Standard approaches across department's e.g. schools, IAA services, hospital discharge. 18. There are consistent approaches across and within organisations.	Human rights need to be the bedrock of how we meet carers' needs. There is need to pay particular attention to: <ul style="list-style-type: none">  Deliver a human rights-based approach across the region.  Providing clear, consistent, accessible and honest information enables Carers to make informed and dignified decisions about themselves and the people the care for.  Champion the role of carers in organisations and services.  Respect Carers as experts by experience, on their own needs and the people they care for.  Giving Carers a space to make their voices heard (Forums) is important to fostering dignity and respect for them and their needs.
Support services	19. New developments and changes are co-produced with carers. 20. Carers services are funded sustainably 21. Carers are actively offered direct payments. 22. Carers' positive and negative experiences are used to inform service improvements. 23. Carers have responsive and flexible access to mental health and well-being services.	Services need to be delivered and designed using co-production principles with carers. There is need to pay particular attention to: <ul style="list-style-type: none">  Lifelong approach to supporting the caring journey e.g support for dealing with life limiting illnesses and support with transitioning to and from being a carer.  Learning from complaints and compliments - Use more storytelling to learn and improve services based on lived experiences e.g. videos and other creative media.  Contingency services are needed to support carers contingency planning for emergencies.  More support at the end of the caring role e.g. bereavement support.  Carer's value third sector support – longer term funding is needed for sustainability.

In addition to the researched outcomes identified in the strategy, some clear needs emerging from the forum also include:

-  Information, advice and advocacy – good quality support is needed by carers to support their caring role.
-  Carers assessments – under used and under offered.

- 🌸 Short breaks/Respite - more innovative approaches are needed.
- 🌸 Direct Payments – difficult to navigate and under used for carers needs.
- 🌸 Communication – accessible information given at the right time.
- 🌸 Training – consistent training for staff on how to work with carers.
- 🌸 Funding – sustainable funding of carers services is needed.

Some of the qualitative information identified in the Carers Liaison Forum is reflected in other reports. They are summarised below, but the reports themselves contain useful insights on a number of key areas: upholding human rights, information and advice, carers assessments and respite/breaks for carers.

The ‘Measuring the Mountain’²² citizen jury concluded that the positive experiences shared with the jury showed the “unequivocal value of positive human interactions based on trust, respect, mutual understanding and a meaningful balance of power”. This supports the need to adopt a human rights and continuous improvement approach by better understanding carers’ experiences to help improve how we meet their needs.

The Social Care Institute for Excellence²³ (SCIE) undertook an evidence review into the needs of carers in 2021. They found a number of barriers to meeting the needs of carers. The last available data was for 2018/19, and they made the following findings:

- 🌸 Gathering data on the assessments for young carers as well as adult carers was insufficient.
- 🌸 Insufficient clarity on rights information for carers and staff. Terminology around what matters conversations and carers assessments needs to be clearer.
- 🌸 Stigma and self-recognition are barriers to being identified and being offered a carers assessment.
- 🌸 Lack of timely information and advice.

²² Measuring the Mountain (2020) Executive Summary <http://mtm.wales/resources>

²³ Social Care Institute for Excellence (2021) <https://www.scie.org.uk/wales/research/unpaid-carers>

- 🌸 Some carers are at greater risk of not accessing support, e.g. children with additional needs, sensory impairment, language barriers or lack of internet access.
- 🌸 Delays to assessment and not meeting the threshold for support were significant barriers.
- 🌸 Effective first point of contact services were an enabler to getting support at the right time.
- 🌸 The third sector play an essential role in identifying and providing support which has been pivotal when communicating with communities.
- 🌸 Numbers of carers have increased and it's been difficult to access assessments, but where there is direct contact, it is appreciated by carers.
- 🌸 Carers need to feel heard and treated with respect, conversations need to be private, creating a safe space for carers.
- 🌸 “The knowledge and attitude of people conducting assessments affect how well they are perceived by carers. Carers are also aware of time and resource pressures, and can feel under pressure to make decisions quickly or feel they have to fight for services.”

SCIE also highlight some gaps in our knowledge and suggest we better understand:

- 🌸 Information about young carers
- 🌸 Frontline identification of carers
- 🌸 Information about carers from hard-to-reach groups
- 🌸 Combined assessments
- 🌸 Role of third sector in assessments
- 🌸 Terminology and interpretation
- 🌸 Impact of COVID-19 and the changes in thresholds for support.

The report comments that the numbers of carers receiving an assessment are low compared to the population of carers across Wales (according to the most recent data available from Carers Wales in 2019/20). In West Glamorgan, 1.7% of its 50,000-carer population received a ‘what matters’ conversation or a carers assessment.

Public Health Wales and Cardiff University²⁴ conducted research into the needs of carers before and since the pandemic began. They made a number of findings and recommendations for action:

- 🌸 **Identities and relationships** – targeted information and advice for carers in multiple accessible formats. Carers assessments must be a priority, with an additional focus on identifying the impact of the pandemic and rebuilding carers well-being. Assessments should also focus on sustaining the caring relationship.
- 🌸 **Health and well-being** – gaps in social support opportunities must be filled. There is a need for young adult carer groups with dedicated support worker supervision. Carers assessments should be focused on whether the caring role is reasonable in terms of the carers human rights. Counselling services must be available free to carers to aid recovery of well-being.
- 🌸 **Employment, education and finances** – employment legislation must be reviewed, each school should have a young carers lead, universities should identify young adult carers in student population, Welsh Government needs to review the sustainability of the Carers Allowance.
- 🌸 **Services and systems** – local authorities and health boards should be proactive in identifying carers, a national register should be considered. Regional unpaid carers teams need to be established to co-ordinate a multi-agency approach including health, social services, education and available for direct carers enquiries. Mapping of third sector support services and identifying gaps. Government consultation is needed on the needs of carers during this crisis to plan for a better response in future emergencies. Unpaid carers should be prioritised on an equal footing with the person they care for. Schools providing care to disabled children should be consulted regarding their provision during the pandemic and whether it would be reasonable to expand services to sustain their education in future emergencies.

²⁴ Public Health Wales & Cardiff University (2021) The voices of unpaid carers during the COVID-19 pandemic: message for the future <https://phw.nhs.wales/publications/publications1/voices-of-carers-during-the-covid-19-pandemic-messages-for-the-future-of-unpaid-caring-in-wales/>

Carers Trust Wales and Age Cymru held a series of round table events with carers of people living with dementia, staff from care, statutory and third sector providers²⁵. The Swansea round table highlighted the issues for dementia carers, but there are similarities of experience which can be linked to what carers have told us in the forum:

- 🌸 Investment in prevention support for carers is needed to prevent more carers reaching crisis.
- 🌸 Telephone support is welcomed, but face to face needs to be available as well.
- 🌸 Cared for individuals conditions may have worsened, making carers roles more challenging.
- 🌸 Respite and short breaks are critical to supporting carers to recover their wellbeing.
- 🌸 Specialist advice and support to carers is needed.

The Age Cymru Survey¹⁰ of older carers also mirrored some of what Carers told us in the Carers Liaison Forum:

- 🌸 80% had not been offered a carers assessment.
- 🌸 48% said they needed support with the following things:
 - 25% said accessible advice and information
 - 25% said services at home (help with meals, shopping, gardening, cleaning and intimate care)
 - 22% said respite
 - 7% said emotional support
 - 5% said socialising and companionship
 - 3% said financial support
 - 13% made various comments re: family support, transport difficulties, or unspecified support needs.

Their detailed survey also gave us information about accessing support:

- 🌸 52% indicated that they did not know what was available
- 🌸 36% said that the person they care for did not want them to access support
- 🌸 22% of those who commented about accessing support said that the pandemic had limited the availability of services

²⁵ Carers Trust and Age Cymru (2021) Caring for someone with Dementia <https://carers.org/downloads/wales-pdfs/report---caring-for-someone-with-dementia.pdf>

- 🌸 19% said they were currently managing and didn't need support
- 🌸 32% of respondents said that it was either very or fairly difficult to access support
- 🌸 16% found it very or fairly easy to access support.

The report also outlined the priority needs for older carers. Whilst some of these needs have been reflected in the Carers Liaison Forum and other research, we need to investigate further about how we meet these needs for all carers across West Glamorgan:

- 🌸 51% said contingency/emergency planning
- 🌸 41% said accessing benefits
- 🌸 38% said health/welfare support
- 🌸 37% information about regular breaks
- 🌸 35% communicating with social services
- 🌸 31% wanted information on future planning needs.

The 2019 Audit Wales report: The front door to Adult Social Services²⁶ stated that “despite some progress, carers are still not getting equal access to services and support. We recommend that public bodies improve access to the front door to adult social care and increase carers’ awareness and understanding of their rights.”

There is also regional evidence that supports the need to review how we inform and advise carers and routes to obtaining a carers assessment. The data shows that there are too few carers receiving an assessment and not enough data to support a hypothesis as to why this is the case. The data below is only reflective of carers of adults over 18 years old. Figures exclude parent/guardian carers of children with additional needs.

Adult Carers Assessment Data (this data does not include parent carers of children under 18)	Wales	Swansea	Neath Port Talbot
1. Number of adults who received advice or assistance from the information, advice and assistance service during the year	60577	3224	1864
2. Number of assessments of need for care and support undertaken during the year	63662	3309	1518

²⁶ Audit Wales (2019) The “front door” to Adult Social Services
https://www.audit.wales/sites/default/files/Front-door-to-adult-social-care-english_11.pdf

2.1 Of those, the number that led to a care and support plan	24756	3070	1393
3. Number of assessments of need for support for carers undertaken during the year	7261	700	287
3.1 Of those, the number that led to a support plan	2748	516	6
4. Number of carer assessments that were refused by carers during the year	6876	838	88
5. Number of assessments of need for care and support for adults undertaken during the year whilst in the secure estate	218	3	0
5.1 Of those, the number that led to a care and support plan	49	3	0
6. Number of requests for repeat assessment of need for care and support and need for support made by an adult during the year	2610	0	0
6.1 Of those, the number of repeat assessments undertaken	2444	0	0
6.2 The number of repeat assessments in 6.1 that led to a care and support plan or support plan	1130	0	0
7. Number of care and support plans and support plans that were reviewed during the year	41215	8081	1439
7.1 Of those, the number of plans that were reviewed within agreed timescales	22786	5742	892
8. Number of requests for review of care and support plans and support plans for carers before agreed timescales made by an adult during the year	3642	0	0
8.1 Of those, the number of reviews undertaken	3384	0	0

(Source: Statistics Wales – 2018/19 Assessments by local authority and measure)

More recent data collected by Carers Wales shows that the numbers of Carers Assessments provided April 2019 to March 2020 were still relatively low given the size of the carer population and the number of people receiving care and support services across the region (10,000 adults and 2,000 children in 18/19²⁷).

²⁷ Statistics Wales (2021) <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Adult-Services/Service-Provision/adultsreceivingcareandsupport-by-localauthority-agegroup> and <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Childrens-Services/children-receiving-care-and-support/childrenreceivingcareandsupport-by-localauthority-agegroup>

County	Carer Population	Information Advice Assistance	Carers Assessments /What matters conversations	Support
Neath Port Talbot	20365	725	256	Unable to provide due to IT system
Swansea	30349	Not easily quantifiable	588	83

Source: <https://www.carersuk.org/files/section/6609/carers-wales-track-the-act-briefing-final-version-eng.pdf>

The Carers Week Research Report 2021 Break or Breakdown emphasises the need of a break for carers.

Carers are using the few breaks they have for the following things:

- 🌸 37% of carers were using their time away to take some exercise
- 🌸 33% of carers were using breaks to complete practical tasks such as housework
- 🌸 26% of carers had used time away from their caring role to attend their own medical appointments
- 🌸 26% of carers used a break from caring to focus on their own wellbeing
- 🌸 25% of carers had used a break to 'catch up on sleep'.

When asked what they would like to use their break for they stated:

- 🌸 Focusing on my wellbeing (e.g. reading a book, time to myself) (53%)
- 🌸 Taking some exercise (e.g. a walk, exercise class, run) (52%)
- 🌸 Spending time with other family and friends (50%)
- 🌸 Taking part in hobbies and leisure activities (49%)
- 🌸 Going away (40%).

Carers need a range of respite options to support their role, and also to enable them to have a break. Further work with carers in West Glamorgan is needed to develop a more varied range of respite and short break choices. Carers Trust have published a guide to support this work that can be used to develop new ways to deliver respite and short


breaks to carers. They have set out 12 principles to capture the vision for short breaks and respite across Wales²⁸.

1. See individuals and focus on what personal outcomes matter to carers and the people they support
2. Build on strengths in supporting and sustaining caring relationships
3. Be sensitive to caring relationships and work towards making breaks a positive experience for everyone
4. Provide accessible and timely information about break options
5. Offer supported choice of breaks and help with decision-making
6. Provide personalised, flexible and responsive break options, that reflect the diversity of the carer population
7. Identify and promote creative approaches to commissioning and other statutory funded and no cost breaks options
8. Build links with key sectors that relate to everyday life not just social care and health
9. Promote and support creative break options in the local community and communities of interest
10. Nurture the development of peer support
11. Ensure quality of break options with a particular focus on what matters to carers and the people they support
12. Capture outcomes arising from a break for carers and the people they support.




5. CONCLUSION AND GAPS IDENTIFIED

The evidence from this chapter highlights the considerable challenges experienced by carers who require support in our region.







The Carers Strategy has provided the framework for collating the needs of carers in West Glamorgan. We have used the cross-cutting threads to present some overarching needs:










-  **Carer wellbeing** – actions arising from the population needs assessment must focus on carer wellbeing and how the action contributes to the regional vision for carers.









²⁸ Carers Trust Wales (2021) Road to Respite Report <https://carers.org/downloads/wales-pdfs/carers-trust-road-to-respite-report.pdf>









-  **Communication** – consistent and accessible communication is needed across the region. Statutory partner communication teams should collaborate on a regional approach to communicating with carers. Developing common terminology and language that is inclusive and accessible to all.
-  **Co-production** – carers must be involved in co-designing services that meet their needs. Co-production must be embedded as per the Regional Co-production Framework.
-  **Training** – there must be extensive carer awareness training for all statutory partners, and beyond health and social care staff. Co-production training is also needed to ensure that carers are able to co-produce individual support plans and also services to meet their needs.

The Carers Strategy themes provides the framework for the needs of carers in more detail. The “needs to be met” column highlights the foremost requirements going forward.

	Needs to be met	
Theme	Strategy Outcomes	Population Needs Outcomes
Balancing priorities	<ol style="list-style-type: none"> 1. Carers have flexible and responsive respite opportunities. 2. Carers have support with developing contingency plans. 3. Carers have access to wellbeing workshops. 4. Carers have workplace and educational support. 	<ul style="list-style-type: none">  Choice of services for meaningful respite and short breaks.  Services that support the caring role and lightens the load (not necessarily replacement care).  Direct payments that can be used to access the above services.  Support to enable carers to stay in work or education.  Services for carers to maintain health and wellbeing.  Services to support contingency planning by carers.

	Needs to be met	
Theme	Strategy Outcomes	Population Needs Outcomes
Supporting each other	5. Carers have opportunities to meet each other. 6. Carer led groups are commonplace.	<ul style="list-style-type: none">  Carers have opportunities to meet together, share their experiences and understand their rights.  Carers have opportunities to engage with and influence the regional work stream on carers e.g. Carers Liaison Forum.  Carers are supported to engage in Carer Representative roles.
Information and advice	7. Carers are informed of their rights. 8. Carers have dedicated and tailored information and advice portals/places across all statutory providers. 9. Carers have information and advice about contingency planning. 10. Carers are informed about Assessments and how they can be of benefit. 11. Easy read options and minority languages are catered for appropriately.	<ul style="list-style-type: none">  Information that is targeted at key areas where carers might identify themselves e.g. mapped across the caring journey and public services  Carers' information is available at key access point to health and social care. e.g. GPs, diagnosis, hospital discharge and social services access points.  Human Rights information for carers and the people they care for.  Routes to carers assessments are clear and easy to navigate.  Information is consistent, accessible and available in a range of formats dependent upon need e.g. easy read, large print, language options.  Information is targeted at schools and employers about supporting the needs of carers.

	Needs to be met	
Theme	Strategy Outcomes	Population Needs Outcomes
Identified and recognised	<p>12. Carers are recognised even if they do not self-identify.</p> <p>13. Carers are actively identified by organisations and staff supporting them.</p> <p>14. There is shared responsibility across and within organisations for identifying carers.</p>	<ul style="list-style-type: none">  Carers need to be recognised as experts by experience and involved in meaning full discussions about their needs and the people they care for (including young carers).  Young carers need to be identified in schools for signposting to early support.  Carers don't have to say they are a carer before being directed to information, advice and support  Carers need the identification card to be recognised by partners across the region.  The ID card also needs to recognise their contribution and offer benefits to support them and their role.
Dignity and Respect	<p>15. Carers are recognised as experts by experience.</p> <p>16. Awareness of Carers is commonplace.</p> <p>17. Standard approaches across department's e.g. schools, IAA services, hospital discharge.</p> <p>18. There are consistent approaches across and within organisations.</p>	<ul style="list-style-type: none">  Carers need a human rights-based approach to meeting their needs.  Carer awareness training needs to be delivered to partners across the region.  Young carers need to be recognised in education settings, e.g. carers leads.

	Needs to be met	
Theme	Strategy Outcomes	Population Needs Outcomes
Support services	<p>19. New developments and changes are co-produced with carers.</p> <p>20. Carers services are funded sustainably</p> <p>21. Carers are actively offered direct payments.</p> <p>22. Carers' positive and negative experiences are used to inform service improvements.</p> <p>23. Carers have responsive and flexible access to mental health and well-being services.</p>	<ul style="list-style-type: none">  Carers need to be involved in co-producing and co-designing services that they use to support their caring role and the person they care for.  Carers need a range of different support services from a range of sectors.  Carers need direct payments services to work well and meet their needs.  Carers need new and innovative forms of respite and short breaks.  Carers experiences need to be learnt from and used to inform how services develop.  Carers need independent advocacy support to navigate systems (specialists may be needed for parent carers and young carers).  Young carers need services that support their educational and career goals/aspirations.  Support services in place for specific types of carers. e.g. dementia or special educational needs.

Using the Carers Strategy as a framework and engaging directly with carers through the Carers Liaison Forum, we will further identify needs and gaps regularly. The Carers Strategy Action plan will outline how we plan to meet those needs in greater detail. This work is underway and the action plan is currently being co-produced with carers.

Appendices:

Carers Liaison Forum – see below for meeting summaries for July and November 2021.

July 2021

Date: 19th July 2021 10am to 11.30am

Zoom Call

Co-Chairs: Frank Ramsay, Carer and Julia Nawell, Carer

Meeting Summary

Welcome and introductions

We welcomed everyone to the meeting and said that we were short on time so people could make introductions in the breakout groups. We asked for people to promote the forum and if working with carers to invite one to come along with them next time.

Presentation – Carers Strategy, themes and explanation (see overleaf for some information)

Lee Cambule gave an overview of the Regional Carers Strategy to help with the discussions in the breakout groups. A copy of the presentation can be opened by double clicking the icon at the bottom of this summary. The table at the bottom gives an overview of the Carers Strategy themes and the outcomes that we want to see for carers.

The information we discussed in the meeting will be used to help develop an action plan for the strategy and help us refresh the strategy. We also shared information about ways to get involved beyond the Forum and either work on developing the ideas and content for the action plan or become a Carer Representative. Carers interested in getting involved were asked to contact Johanna via carers@nptcvs.org.uk.

A question was raised about how our regional work was linking with the Welsh Government Carers Strategy and the Charter they planned to put together. Johanna explained that she was connected to this work and had made an offer to Welsh Government to involve this Forum.

A question was raised about Carers Representatives working with the region, we are actively looking for carers to become representatives. Contact Johanna for more information carers@nptcvs.org.uk

Prioritising themes – We want your views on which themes we discuss over the next few meetings.

We asked the group to vote for the 4 themes that were most important to them. This does not mean that any one theme is more important than another. People voted using this link <https://www.menti.com/9t95s5uy96>

We decided to talk about Information and Advice and Support Services in this meeting. Forum members not at the meeting can add their votes to help decide the next 2 themes to discuss.

Breakout session 1

Questions for the session.

Consider the outcomes for the “theme”:

- What actions need to be taken to enable these outcomes?
- What are the roadblocks?

Example given to help discussion.

“Carers are informed of their rights”

Actions – Dedicated carers pages on websites.

Roadblocks – keeping the web pages up to date, making sure people are aware of them.

Information and Advice – people told us:

- Carers don’t recognise themselves as carers and professional don’t routinely recognise carers as well.
- Range of providers need to promote and make people aware of carers needs and rights.
- Regional information for consistency.
- Carers rights to an assessment needs to common be knowledge.
- Clear concise information across Statutory providers and third sector.
- When someone who needs support is identified any carers needs to be identified at the same time and given information about carers rights.
- Guidance on reporting on carers assessments set out by Welsh Government needs to be followed.
- Importance of information for carers at key places where carers could be visiting e.g GP’s
- In some cultures, there isn’t a work for “Carer” and we need to target information to these groups.
- Accessible information that can be a central place to direct people.
- Information about support service easily available.
- Some Local Authorities have a page for carers and that there is a lot of information for carers already out there.
- Information needs to be correct and consistent from statutory partners.
- Accessible communications i.e. ensure that there is a range of print and background colours, easy read and compatible with screen reading software.
- PDF’s documents aren’t useable for screen readers and when we publish things online.
- Use of language is important, Carers Assessments can be interpreted as an assessment of ability the work “needs” is critical – Carers Needs Assessment should be the term

With agreement from the group we did not have a break.

Breakout session 2

Questions for the session.

Consider the outcomes for the “theme”:

- What actions need to be taken to enable these outcomes?
- What are the roadblocks?

Support Services – people told us:

- Bereavement support should be included as a support service.
- Joined up working is needed to achieve these outcomes
- Co-production is more than just engagement
- Funding needs to be longer than just 1 year – services need to be mapped to help plan for gaps in services.
- Direct payments need to be more widespread and easily available.
- Use storytelling to convey carers experiences – can be really powerful but emotional for the storyteller, feedback on what’s happened as a result is important.
- Contingency services are needed to support carers contingency planning for emergencies.
- Lifelong support on caring journey e.g. support for dealing with life limiting illnesses and transitioning to and from being a carer.
- Co-producing with service designers is needed.
- Forums like this are supported by managers and staff encouraged to attend.
- Co-production written into job roles and supported with training.
- Equality impact assessment for co-production.
- Engaging with digitally excluded people.
- Direct Payments sharing best practice and success stories for carers.
- Paying carers for their time.
- Funding comes and goes – how do we utilise existing funding.
- We have a 5 year strategy but funding is mostly annual.
- Support to navigate Direct payments is needed.
- Respite support can also be difficult to arrange and obtain without support.
- Bereavement support is available from NPT Carers Service.
- Identifying when funding is ending will help identify what we need to replace or support.

General discussion

People were asked if they would like to share information in this part of the agenda.

- Let’s Talk Campaign is being launched by NPT Council and they want to hear from People living in Neath Port Talbot.

Carers who want to get more involved in working with the Forum then please contact Johanna on carers@nptcvs.org.uk.

Next meeting is on the 16th August.

West Glamorgan Carers Strategy Information

Vision

Carers are identified, recognised and supported to care. They have a life alongside caring and have a feeling of well-being throughout their caring journey.

Theme	Outcomes
Balancing priorities	<ul style="list-style-type: none"> 6. Carers have flexible and responsive respite opportunities. 7. Carers have support with developing contingency plans. 8. Carers have access to wellbeing workshops. 9. Carers have workplace and educational support.
Supporting each other	<ul style="list-style-type: none"> 7. Carers have opportunities to meet each other. 8. Carer led groups are common place.
Information and advice	<ul style="list-style-type: none"> 12. Carers are informed of their rights. 13. Carers have dedicated and tailored information and advice portals/places across all statutory providers. 14. Carers have information and advice about contingency planning. 15. Carers are informed about Assessments and how they can be of benefit. 16. Easy read options and minority languages are catered for appropriately.
Identified and recognised	<ul style="list-style-type: none"> 15. Carers are recognised even if they do not self-identify. 16. Carers are actively identified by organisations and staff supporting them. 17. There is shared responsibility across and within organisations for identifying carers.
Dignity and Respect	<ul style="list-style-type: none"> 19. Carers are recognised as experts by experience. 20. Awareness of Carers is commonplace. 21. Standard approaches across department's e.g. schools, IAA services, hospital discharge. 22. There are consistent approaches across and within organisations.
Support services	<ul style="list-style-type: none"> 24. New developments and changes are co-produced with carers. 25. Carers services are funded sustainably 26. Carers are actively offered direct payments. 27. Carers' positive and negative experiences are used to inform service improvements. 28. Carers have responsive and flexible access to mental health and well-being services.

November 2021

Date: 1st November 2021 10am to 11.30pm

Zoom Call

Meeting Summary

Welcome and introductions

A Carer from the core planning group was not available to Chair this meeting so the Carers Development Officer, Johanna Davies Chaired the meeting. It was noted that Carers are under a lot of pressure and that the time available to engage with the Forum was limited. The planning group welcomes new members to help support how the Forum progresses and would like to hear from people interested in helping.

Presentation – Carers Strategy, themes and explanation

Johanna's presentation gave an overview of the Carers strategy and a short recap on the work that had been done in the July Forum meeting. A question was raised about the Population Needs Assessment and how carers could get involved in reviewing it. Carers can express their interest via carers@nptcvs.org.uk.

Prioritising themes

The group used the mentimeter link to choose the next 2 themes from the strategy to discuss. The first breakout session looked at Balancing Priorities and the second will look at Supporting each other. There was a tie for the second theme so the carers in the room voted for their preferred one.

Breakout session 1

Questions for the session.

Consider the outcomes for the “theme”:

- What actions need to be taken to enable these outcomes?
- What are the roadblocks?

Balancing priorities – people told us

- This heading can mean so many things for different people.
- Juggling work, family and caring – different carers will want support with different things.
- If carers get information advice and support at the right time then it would make things easier.
- Good quality sleep is so important the lack of sleep can contribute to things slipping.
- Holistic approach to assessing needs and independent of the person being cared for.
- More work is needed to unpack more about Balancing priorities.
- Priorities are difference depending on the carer's situation and own life situation.
- Carers need to be prioritised along side the cared for.

- There are so many things on the “carers job description” where to start with which things to offer help with.
- More in depth work is needed to explore this theme and further understanding is needed on e.g. respite, assessments and direct payments.

Breakout session 2

Questions for the session.

Consider the outcomes for the “theme”:

- What actions need to be taken to enable these outcomes?
- What are the roadblocks?

Supporting each other – people told us

- Peer support is one of the best kinds of support
- Variety of support is needed – it doesn’t always need to involve talking or sharing experience of caring.
- Time is critical – having a range of activities at different times is needed.
- Funding is challenge plenty of short term funding more long term is needed.
- One stop shop for disabled people and carers – what does that look like regionally?
- Knowing what’s available regionally as well as locally how do make sure carers have the same opportunities across the region.
- Lots of jargon doesn’t help carers support each other.
- Right information at the right time means people get to peer support early.
- Staff need to be supported to engage with the Carers Forum and work.
- Connecting across Local Authority areas – how can carers support each other without consistent information.
- Carers rely on the lived experience learning they get from each other.
- Training for staff on carers rights is needed because carers do get the wrong information sometimes.
- Diagnostic pathways could provide early information but more work is needed to understand what information would be needed.

General discussion

A quick poll was conducted to ask if people were interested in a face to face social event.

- 57% Yes - but only if outside and socially distanced
- 86% Yes - in doors with plenty of space
- 0% No - I'm still not comfortable with face to face
- 14% No - My caring roles means I haven't the time or support to be able to come

The core planning group are looking for more carers to get involved in helping deliver this forum. Contact carers@nptcvs.org.uk for more information.

Updates from attendees:

SAN have a weekly coffee morning for parent carers on a Wednesday 10am to 12pm Brynhyfryd House, Britton Ferry.

<https://www.facebook.com/groups/664637053711730>

Direct Payment Forum with Swansea Council 10.30am 26th November – link with Swansea Co-production Group facebook group.

<https://www.facebook.com/groups/1624236177637031>

Swansea Parent Carer Forum - Giving you time back, members of Swansea Parent Carers Forum can get help with a food box, cleaning, household and handy person tasks. <https://swanseapcf.org/>

A question was raised about how we engage with Young Carers. The West Glamorgan Region funded YMCA Swansea to develop a Young Carers Forum and it would be good to see a similar forum set up in NPT. Johanna is in regular contact with the YMCA Swansea and NPT Youth Service and is progressing this work.

Date of next meeting: 8th November 10.30am to 11.30am

Date: 8th November 2021 10am to 11.30pm

Zoom Call

Meeting Summary

Welcome and introductions

A Carer from the core planning group was not available to Chair this meeting so the Carers Development Officer, Johanna Davies Chaired the meeting. It was noted that Carers are under a lot of pressure and that the time available to engage with the Forum was limited. The planning group welcomes new members to help support how the Forum progresses and would like to hear from people interested in helping.

Presentation – Carers Strategy, themes and explanation

Johanna's presentation gave an overview of the Carers strategy and a short recap on the work that had been done in the July Forum meeting.

Prioritising themes

The last two themes to discuss were “Identified and recognised” and Dignity and respect” We asked the carers in the meeting to show hands in support of the one they wanted to discuss first. Dignity and respect was chose as the first theme.

Breakout session 1

Questions for the session.

Consider the outcomes for the “theme”:

- What actions need to be taken to enable these outcomes?
- What are the roadblocks?

Dignity and respect – people told us

- Self recognition is critical people are husbands, wives or parents first getting people to recognise themselves as well.
- People are concerned about letting social service in feel that they may interfere.

- Expectation that family will provide care, carers have the right to refuse to do this but rarely do.
- There is a stigma to caring that needs to be addressed.
- Husbands and wives need different advice, information, and support.
- What does assessments mean, some carers feel it's an assessment of them and the care they provide.
- Recognising the experience that carers bring to their role.
- Need to focus more on person centred care, assessments shouldn't be tick box.
- Feeling that you can speak free from judgement.
- Taking a partnership approach can help foster dignity and respect – need to work with third sector.
- Family are suspicious of giving lots of information. Need to build trust.
- Outcome focused approach is important for both the carers and the cared for. They also overlap and are all part of a bigger jigsaw.
- Communication is key to carers feeling dignity and respect.
- Carers are not always spoken to or listened – need to be seen as a unit.
- Where support isn't available this also needs to be acknowledged as well as finding solutions.
- Individual caring roles and experiences are different but there are clear ways in which we speak to people to maintain dignity and respect.
- Making it clear to carers that their contribution is seen as the most important from the outset.
- Listening to families because they know the situation best.
- Recognition is not always given in big organisations smaller organisation can be more responsive.
- Need to champion the role of carers in organisations.
- Education for people about what dignity and respect means
- Communication and services need to improve. Services are not going to end so why not invest in communication with carers.
- Continuity of care is important to carers.
- Improve carer recognition in recruitment processes.
- Time is a roadblock – rushed care is not dignified care.
- Hearing the voices of carers is important and Forums like this are important and need to carry on.
- Language is a big roadblock – Welsh and other foreign languages.
- Carers need to be praised for what they do – we all need praise at times.
- Strengths based approach is needed and needs to underpin what we do.
- Professionals need to realise that carers can refuse to provide care. This would be catastrophic for statutory services.
- Human rights-based approach, Carers need to know their rights.
- Terms like “co-production” and “partnerships” are being used more technically rather than being used in practice. We need to make sure people understand what they mean and really deliver them.

Breakout session 2

Questions for the session.

Consider the outcomes for the “theme”:

- What actions need to be taken to enable these outcomes?
- What are the roadblocks?

Identified and recognised – people told us

- Caring can be a negative concept and experience: communication needs to be clearer, languages need to be considered, how things are defined is important.
- “Carer” isn’t a common term in some languages.
- Culture - there is a stigma around some disabilities as well can be a negative experience and be a barrier for people to identify as a carer.
- Too many questions can be asked when looking for support, can feel intrusive.
- People’s experiences are really important and caring is sometimes seen as negative and always seen as asking for support to do it. If the term carer didn’t exist would we view it negatively?
- Lots of carers don’t identify themselves, we need to make sure that they come to understand they do extra.
- Information needs to be given at the right time but not to bombard people with information.
- Carers are exhausted, caring is 24/7 we need to better understand that.
- Is it right to ask carers to identify themselves, shouldn’t we shift our focus to asking questions about “who looks after you” or “do you look after anyone”?
- If we provide good care for the person who needs it then the role of the carers becomes far easier.
- Fairness – want to spread high-quality services for all.
- Diagnosis information is variable, ranges between no information to too much information. Need to target what information people need and when at key point.
- If you have a diagnosis then that sometimes help to discuss plans and support. Not everyone gets this and people become a carers overnight with no information.
- Good old days and getting to talk to others for advice and information. We need to get information out creatively following the pandemic.
- Financial assessments and a benefits advice can be an opportunity to signpost for other support.
- Caring often evolves and increases gradually and before you know it you’re doing lots and don’t know where your caring role ends and your life begins.
- What happens when your caring role ends, grief and support is needed to deal with this transition.
- If carers said no tonight, what would happen, services would collapse.
- Many carers end up on benefits, because they have to give up work to care. If you claim Carers Allowance it is deducted from your income support. Carers actually don’t get extra for the role they take. We need to recognise this even though it’s not something we can change.
- Women often don’t have the options to develop careers and develop relationships outside your caring role. We need to recognise these obstacles to carers wellbeing.

General discussion

Johanna explained that there wouldn't be another Carers Liaison Forum until the New Year. However, the Core planning group of Carers would be meeting to put together a plan for the next few meetings.

The core planning group are looking for more carers to get involved in helping deliver this forum. Contact carers@nptcvs.org.uk for more information.

Updates from attendees:

Swansea Parent Carer Forum - Giving you time back, members of Swansea Parent Carers Forum can get help with a food box, cleaning, household and handy person tasks. <https://swanseapcf.org/>

Care and Repair Western Bay have extended the support to NPT as well.

Hafal have been overwhelmed by applications for respite support.