

Improving Lives for Carers

Our West Wales
Carers Strategy
2020-2025

Foreword

Welcome to the 2020–2025 West Wales Carers Strategy 'Improving lives for Carers'.

Caring is such an important part of life and during the COVID-19 pandemic the role of unpaid Carers has become more prominent. Carers are holding families together, enabling loved ones to get the most out of life, and Carers themselves are making an enormous contribution to society.

Census data suggests that within 'West Wales' there are more than 47,000 unpaid Carers representing 12.5% of residents (ONS, 2011) and we know there is a considerable number of 'hidden' Carers who do not define themselves as such. When we use the term 'West Wales' we are referring to the counties of Carmarthenshire, Ceredigion and Pembrokeshire.

Most Carers accept their responsibilities as they wish to assist and support their family and friends. Caring can be lonely; it can exclude people from employment, lead to social isolation, financial hardship and difficulties maintaining a life of their own. While caring can have a positive and hugely rewarding experience, it can also have a negative impact on the physical and emotional well-being of Carers.

The West Wales Care Partnership (WWCP) recognises the essential role that Carers, including those under the age of 18 and parent Carers play in supporting people who could not otherwise manage on a day to day basis without their help and support. Without Carers, our communities would be economically and socially poorer.

Our vision is to ensure that Carers are universally recognised and valued as expert partners in care. We are committed, through this Strategy, to engaging with Carers and working together to drive actions over the course of the 5 years. Priorities towards achieving our aims will be monitored and reported on annually helping us achieve the good outcomes that Carers want and deserve.

We look forward to improving lives for Carers.



Cllr Jane Tremlett Chair, West Wales Regional Partnership Board

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Bringing the strategy to life through the eyes of the Carer

Throughout our strategy we have used the lens of the 'Teulu Jones' family to bring the strategy to life, viewing the priorities through the eyes of 'the Carer'. The 'Teulu Jones' family was developed by Hywel Dda University Health Board (the Health Board) and its partners, to support its work on transforming health and care services in West Wales.



Teulu Jones' aren't a real family but they have been designed to be typical of some of the people living in the Hywel Dda area and the types of caring roles within families. Throughout our Carers strategy, we have used the family members to help us think about how our priorities could make a difference to Carers in our communities. Here is an introduction to some of the family members.

Mari's story

Mari Jones has lived in Newcastle Emlyn all her life. She lives with her husband Alun in an old two-storey house. Mari is a retired teacher and is President of the local Merched y Wawr. She has recently developed mild dementia and has become increasingly frail and relies on family members for support.



Alun's story

Alun Jones is 80 years old and lives with his wife Mari. He loves to watch the rugby and supports Carmarthen Quins. Alun enjoys his daily walk to the local shop to get the newspaper and always does the crossword. He has a history of heart disease and had a heart attack when he was 70 years old. Alun still drives a car, and he and Mari visit their daughter Sioned in Tumble regularly. Sometimes they stay overnight so they can spend time with their granddaughter and great-grandson.



Sioned's story

Sioned is 47 years old and lives in Tumble, near Llanelli with her daughter and grandson. She is juggling her part-time job as a health care support worker in Prince Philip Hospital, Llanelli and having to help care for parents and is increasingly worried about her mother Mari. She also helps her daughter Lianne by providing childcare for her grandson, Ben.





Gareth's story

Gareth is the 38 years old younger brother of Sioned. He is the Finance Director of an engineering company in Talybont, where he lives but spends a lot of time in Birmingham for work reasons. He is married to Aysha and they have two boys. Gareth tries to visit his parents as much as he can and stays in contact with Sioned.

Lianne's story

Lianne Thomas is 19 years old and lives in Tumble with her mum and dad, and her three-year-old son Ben who has respiratory problems and mild developmental delay. Lianne is pregnant with her second child and is doing a full-time childcare course at the local college. Because her mum works shifts, Lianne is often relied upon to care for her elderly grandparents.





Ben's story

Ben Thomas is three years old. He lives in Tumble with his mum, Lianne, and mamgu and tadcu. Ben is a happy little chap and always puts a smile on everyone's face. Ben was born prematurely and has respiratory problems and a developmental delay.

Who are carers?



A Carer can be anyone, of any age who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse. Unpaid Carers are the single largest provider of care to people with support needs in our communities, and they save the NHS and Social Services millions of pounds a year.

Source: Welsh Government, 2013



The Social Services and Well Being (Wales) Act 2014 defines a Carer as a person who provides or intends to provide care for an adult or child. This definition includes Carers of all ages.

The term Carer includes people who may or may not be a relative and who may or may not be living with the person they care for. It does not include volunteers who provide care as part of their work for a voluntary organisation, or anyone who is paid to provide care.

Carers are individuals who may not see themselves as Carers, but as a parent, child, wife or husband, partner, friend or neighbour. Carers' circumstances vary enormously and Carers must be considered as individuals in their own right with their choices and lifestyles respected.

Across the UK today 6.5 million people are Carers, supporting a loved one who is older, disabled or seriously ill.

Every day 6,000 people become Carers.

Source: Carers UK, July, 2020

In Wales more than 370,000 unpaid Carers of all ages provide care, worth around £8.1 billion to the Welsh economy each year.

Source: Carers Wales, 2015

3 in 5 people in Wales will become a Carer at some point in their lives.

Source: Carers Trust Wales, July 2020

It is important to note that there are many children and young people under the age of 25 who provide care, support or assistance to a family member with care needs. The majority of these young Carers care for a parent but the person with care needs may be a sibling, grandparent or any other family member. Within this Strategy the term "Young Carer" is used to identify Young Carers aged under 18 and Young Adult Carers aged between 18 – 25.

In West Wales 2011 Census data suggests that there are more than 47,000 unpaid Carers of these 3,436 are Young Carers (defined as 5-17 -year olds) in West Wales.

Source: Office of National Statistics, 2011

A recent Track the Act Report by (Carers Wales, October 2019) highlighted that the unpaid Carer population across Wales is expected to increase significantly in the coming years. By 2037 it is estimated that the Carer population will rise from 370,000 to over half a million. A report by the Social Care Institute for Excellence (2018) reported that Wales also has the highest proportion of older Carers and Carers providing more than 50 hours' care a week.

People are living longer with limiting health conditions and will need support from their families and friends. We also know that the experience of lockdown during the COVID-19 pandemic and the need to safeguard people who are more at risk of the disease, has further highlighted the important role that Carers play within our communities.



Working together – our shared vision

Over recent years there has been progress towards recognising and supporting Carers through legislative changes. These include the Social Services and Wellbeing (Wales) Act 2014, the Well-being of Future Generations (Wales) Act 2015 and the long-term plan for health and social care "A Healthier Wales".

Support for Carers in West Wales has been driven through a partnership approach taken by the West Wales Carers Development Group (WWCDG). The WWCDG is a formal sub-group of the West Wales Regional Partnership Board (RPB). It includes representatives of Hywel Dda University Health Board, the three Local Authorities of Carmarthenshire, Ceredigion and Pembrokeshire, as well as Third and Voluntary sector organisations, and representatives of service users and Carers in West Wales. This group is long established and has been working on the Carers agenda for many years.

The WWCDG have been working collaboratively to address the needs of Carers identified in the West Wales Area Plan 2018-2023, as well the priority areas set by the Welsh Government and the Welsh Government Ministerial Advisory Group for Carers.

Recognising that there is more that can be done to improve outcomes for Carers in West Wales, in January, 2020 the WWCDG engaged with Carers about 'what mattered to them' to inform the development of a longer term strategy for Carers with input from Carers and Carer organisations.

This overarching strategy therefore identifies a set of key priorities over the next 5 years which will be supported by a series of dynamic annual action plans which will be owned, monitored and reviewed by all partners including Carer representatives.

Our Carers Strategy draws on a number of important principles, including:

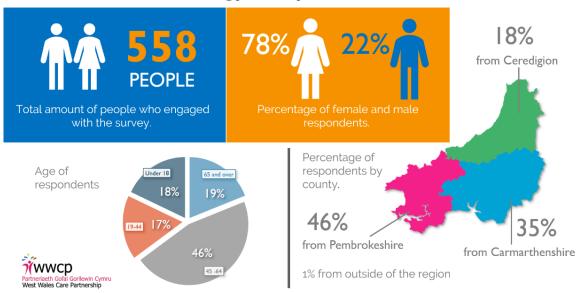
- Seeing the individual and valuing the person first
- Recognising the importance of relationships and supporting them
- Providing non stigmatising information
- Providing reliable and accessible short breaks (respite)
- Providing support that is flexible, responsive and joined up
- Being creative in how we involve Carers responding to the needs of our local communities
- Being reflective and open to learning

The voices of Carers

Caring for someone can be a rewarding experience but it can also be very challenging. Whilst there is a lot of national research highlighting the impact that caring responsibilities can have, we sought to invite feedback from Carers in West Wales recognising that circumstances can be different for each individual.

In developing this Carers Strategy, we made sure we listened to the views of a wide range of Carers. We have found out the things that matter most to Carers in West Wales including how best to support Carers during the COVID-19 Pandemic. We show some of the results from these engagement activities in the next sections under the headings: 'What is the picture in West Wales?'

West Wales Carers Strategy Survey 2020



Our approach to engagement has included:

- A regional engagement exercise with Young Carers and Young Adult Carers undertaken in 2019 which involved 251 Young Carers.
- A 'Refreshing Respite Review' undertaken in July, 2019 which included a series of engagement events facilitated by Swansea University.
- A regional Stakeholder engagement session held in January 2020.
- A Carers engagement session held in Carmarthenshire in March 2020. Unfortunately the response to the Covid-19 pandemic prevented us from holding the planned sessions for Ceredigion and Pembrokeshire.
- Feedback from our third sector partners highlighting needs including those from parent groups.
- A regional on-line survey for unpaid Carers (11th May to 14th June 2020). With this, we engaged with a wide variety of Carers and 558 responses were received across a range of age groups, including Young Carers and Young Adult Carers; people in different caring relationships (for example, partners, siblings or parents); Carers in employment and

education; and Carers supporting people with a variety of care and support needs.

Through our engagement activities we have also discovered that some things matter more to younger people - or have a greater impact on them. This means we need to plan action that takes account of the different needs of Carers across the different age groups.





What are we going to do?

Our Carers Strategy sets out 4 priority areas in order to set a clear vision for how we will work together to plan, develop and deliver services that will improve outcomes for Carers and their families. Defining the priority areas was informed by feedback we have received from recent engagement activities, as well as the national priorities set by Welsh Government, and the 2017 population needs assessment for West Wales.

The West Wales Carers Strategy will support services for Carers that are based on the principal of equality and fair access for all. We have assessed the impact of the strategy using an equality impact assessment and will ensure further work is undertaken to promote inclusion and eliminate discrimination. We will also ensure the help we provide and commission promotes the use of the Welsh language and is as accessible as possible to Carers who live in the most rural areas of West Wales.



In the next section we set out:

- Why each priority is important.
- The current picture in West Wales drawn from our engagement work.
- What we will do over the lifetime of the Strategy supported by Annual Action Plans.
- What success will look like from the experience of Carers.

Priority 1: Improve the early identification and self-identification of Carers including Young Carers and Young Adult Carers

Why is this important?

Identification and self-identification of Carers is vital to ensure that they are able to access the right help and support at the right time, as well as maintain their own health, well-being and independence.



Carers Wales 'Missing Out' report noted that in Wales, 55% of Carers took more than a year to recognise their caring role, while 24% took more than five years to identify as a Carer (Carers Wales, 2016).

In November 2019, a report from the National Assembly for Wales, Health, Social Care and Sport Committee found that there was a need to continue to raise awareness of Carers' rights in order to raise the profile of caring, and promote the benefits of needs assessments under the Social Services and Well-being (Wales) Act 2014.

Estyn in 2019 reported that many secondary schools, colleges and pupil referral units do not know which learners have a caring role at home and identified the importance of improving provision and outcomes for Young Carers.

What is the picture in West Wales?

Only 38% of respondents to our Carers' survey indicated that they recognised their role immediately, or within 6 months of becoming a Carer, and 49% agreed that they had missed out on support as a result. Survey respondents in the 35-44 age group felt that being a Carer had impacted negatively on finances, work, physical and mental health as well as on relationships.

Only one-fifth of respondents to our Carers survey indicated that they had spoken to a health, social care or third sector organisation about what to do if the condition of the person they care for deteriorates, or they are no longer willing to provide care.

Our Local Engagement Event in Carmarthenshire during March 2020 identified that it can be difficult to identify older Carers and parent Carers compared with other groups.



Early identification of Carers is critical as this unlocks support.

Schools need to do more for Young Carers, including greater understanding

Comments Regional Carers Survey Responses July 2020



What will we do?

- Improve consistency of Information, Advice and Assistance to unpaid Carers across the Region
- Ensure that staff in health, social care, education (schools and colleges), other public, private and third sector organisations are "Carer aware" and have robust systems in place to proactively identify Carers, including Young Carers and Young Adult Carers.
- Continue to develop the Investors in Carers Scheme and increase the number of settings achieving an Investors in Carers Award.
- Deliver a programme of Carer awareness campaigns linked to national days and events e.g. Carers Week, Young Carers Day, Carers Rights Day to promote the identification and self-identification of Carers.
- Develop a Carers ID Card scheme across the region that supports Carers to self-identify and access Carer-based support / benefits.
- Promote and identify opportunities for Carers of all ages to be involved in the co-production of services to ensure Carers are given the opportunity to shape and influence.
- Raise awareness of Carers with employers, including small and medium enterprises through the Employers for Carers Scheme.

What will success look like?

By the end of the strategy:

- Information about Carer information services will be consistent and visible within the community and online.
- More organisations and their staff across all sectors will be Carer Aware.
- There will be an increase of 10% each year of settings across the Hywel Dda area who achieve an Investors in Carers Award.
- There will be an increase of 10% in enquiries / new registrations through our Carers Information Services from Carers who have not accessed support previously.
- There will be an increase of 10% in Young Carers and Young Adult Carers identified and receiving support.
- Carers of all ages across the region can access a greater range of benefits as a result of the introduction of the Carers ID Card.

Carers will say

"To be honest I've never thought of myself as a Carer. After all, they are my parents and looking after them as they get older is just what you do. A friend of mine said they had seen a poster in the council offices titled 'do you look after someone' and they immediately thought of me. I rang the number right away and was given lots of information on help and support available which I shared with my sister Sioned." Gareth Jones, Carer for his elderly parents.



Priority 2: Ensure a range of services is available to support the well-being of Carers of all ages, in their life alongside caring

Why is this important?

Caring is such an important part of life. Carers are holding families together, enabling loved ones to get the most out of life, and Carers themselves are making an enormous contribution to society. However, Carers tend to neglect their own needs and sometimes their own health and well-being can suffer. Carers should be able to enjoy good health, emotional and physical well-being.

Ensuring that the needs of Carers are considered holistically acknowledges the wider determinants of health and well-being. Carer needs may also change over time so access to a Carers needs assessment is an important part of ensuring that the most appropriate "information, advice and assistance" is made available at the right place at the right time.

What is the picture in West Wales?

Our Carers survey revealed that 75% of former Carers who took part in the survey felt that they had experienced a negative impact on their physical health and mental well-being as a result of their caring role. The themes which people commented on were linked to mental well-being and exhaustion. This feedback was echoed in our Regional Forward Planning Event in January, 2020 where emotional support for Carers and Young Carers was further highlighted.

Feedback from our Carers survey also indicates that 81% of people had not had a Carer's assessment or review of their assessment within the last 12-months. 62% of those who had an assessment or review during the transition from children's to adult services, felt that the assessment process and subsequent consideration of the care and support needs did not properly consider their needs. These findings resonate with the findings of the 'Refreshing Respite Review' undertaken on behalf of the WWCDG in July, 2019 by Swansea University.

Whilst it is recognised that not all Carers need or want a statutory Carers assessment, it is important that Carers know how to access the support they require as their needs or circumstances change.

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Support with 'navigating the system'; financial benefit advice, emergency funds, Carers allowance increase.

Bereavement – emotional support, practical support e.g. housing, benefits.

Comments Regional Forward Planning Event, January, 2020

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What will we do?

- Local Authorities and the Health Board will work together to develop services to meet recognised local and regional need (this may include new approaches such as peer support and Carer networks).
- Identify funding opportunities to commission increased support for Young Carers and Young Adult Carers that is person-centred, age-appropriate and flexible to meet their specific needs.
- Ensure Carers have an offer of a timely holistic assessment of their circumstances in a language of their choice, that gives the Carer choice and control to identify what they need in order to maintain their caring role, and support to develop emergency action plans for situations when they are unable to care.
- Develop provision of alternatives to traditional respite (short breaks) including new models of delivery.
- Continue the work with GPs, Community Pharmacies, Hospitals and Public Health to promote the health and well-being of Carers via the Investors in Carers Scheme.
- Explore opportunities to connect with other partnership forums to address associated needs including housing and transport.

What will success look like?

- All Carers who contact the Carers Information Services will be informed of their right to and given information on how to access a Carer's assessment.
- Carers will be offered information on how to plan for an emergency and support to develop a contingency plan.
- A short breaks model will be in place across the Region which strengthens and or sustains the informal caring relationship.
- There will be an increase in Carers accessing courses that support their own well-being e.g. through the Education Programme for Patients and similar programmes.
- There will be an increase in the number of peer support groups and Carer Networks across the region.
- There will be an increase in support for young Carers and Young Adult Carers including support through to transition.
- There will be improved delivery of services through the medium of Welsh.
- Collaborative working to address associated needs including housing and transport.

Carers will say

"I never considered myself to be a Young Adult Carer or parent Carer. I care for my grandparents and my son Ben who has a developmental delay. The holistic assessment enabled me to access a short break for my son so that I could have some time to myself. I feel so much better and Ben really enjoyed the time away too." Lianne Jones – Carer for her son Ben



Priority 3: support Carers to access and maintain education, training and employment opportunities

Why is this important?

Changing demographics and an ageing population mean that 3 in 5 people will end up caring for someone at some point in their lives (Carers UK, 2020). The statutory organisations who are partners within the West Wales Care Partnership are the biggest employers in West Wales. Carers Wales estimate that 1 in 7 of the workforce are juggling paid work with caring for someone who is older, disabled or seriously ill. By recognising the needs of Carers, employers are more likely to retain experienced staff and reap the rewards of creating a supportive working environment for Carers.

Problems with school attendance or attainment can impact on the future of Young Carers and often results in unemployment, reduced earnings, poor health and depression. Research from Carers Trust Wales (2015) suggests that Young Carers have significantly lower educational attainment at GCSE level and are significantly more likely to become NEET (not in education, employment or training) between the ages of 16 and 19, than those without caring responsibilities.

A report published by Estyn in 2019 that there is a lack of reliable data to identify how many Young Carers there are in schools and colleges across Wales. Consequently, the provision and support for Young Carers at secondary schools and colleges varies widely.

What is the picture in West Wales?

26% of those who responded to our Carers survey indicated that they were in employment, and 91% of were aged 35-64. 64% of people also commented that caring has had a negative impact on their own physical health and mental wellbeing.

62% of Young Carers and Young Adult Carers in West Wales said that their caring role affected how well they do in school and education (West Wales Young Carers and Young Adult Carers Report, 2019).

"I had to leave university because I became depressed with my caring role."

"My dad was really ill and died so I missed school."

West Wales Young Carers and Young Adult Carers Report, 2019

On a positive note during the Young Carer and Young Adult Carer Consultation in Hywel Dda in 2019, 69 % of Young Carers thought that being a Young Carer would not affect future education/work choices.

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I can still try and achieve my dreams, caring for someone only affects me when I have homework.

It's made me want to do a job in the caring sector.

West Wales Young Carers and Young Adult Carers Report, 2019

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What will we do?

- Strengthen links with local education departments, colleges, head teachers in primary and secondary schools and establish Carer leads in all schools through the Investors in Carers Scheme.
- Work in partnership to ensure that Carers can access support to gain skills to seek employment, or retain existing employment e.g. promoting Workways+ programmes or similar schemes.
- Support the regional rollout of the Employers for Carers (EfC) support and resources across the region, in particular with statutory organisations as well as with small and medium enterprises.
- Explore how community benefits could be strengthened within public sector procurement processes to include recognition and support for Carers.

What does success look like?

- Increase in Carers of all ages, including Young Carers and Young Adult Carers, receiving help to continue or access education, employment and training.
- Increase the number of schools and colleges in West Wales who have nominated Carer leads.
- Statutory organisations have Carer Policies that strengthen their commitments to support working Carers to balance work and their caring responsibilities.
- Evidence that public sector procurement processes and contracts include recognition of unpaid Carers e.g.in social responsibility clauses.

Carers will say

"I love my job, but juggling work and caring for my elderly parents, including my mum who recently developed mild dementia, as well as supporting my daughter to care for her son, is a real challenge. My employer has recently developed a Carers Policy, which has raised awareness of the role of Carers. This has given me the confidence to ask for support from my line manager and I've been able to reduce my working hours to 30 hours a week which has been a huge help."



Sioned Jones - Health Care Support Worker and Carer

Priority 4: Support Carers to become digitally included

Why is this important?

Whilst we are lucky to benefit from living in West Wales, for some individuals and communities living in rural areas with limited public transport can create challenges when trying to access services. Recent feedback suggests that the Covid-19 lockdown has encouraged people of all ages to develop new digital skills in order to stay connected with family and friends.

What is the picture in West Wales?

We're aware that digital connectivity has been an important theme throughout the Covid-19 pandemic but are also aware that we'll need to continue to collect and collate local information to increase our understanding about how best to support all Carers to access support on-line.

Feedback from our survey indicates that some Carers have accessed increased support during the Covid-19 pandemic due to the increased availability of services on-line. Only 24% of people responding to the Carers survey said that they don't use any form of technology to support their caring needs. 64% said they use the internet as a source of information and those aged 75 years or older were most likely to use technology for vital signs monitoring.

"Grasp the opportunities presented by online shift during Covid-19" "Further exploration of online options: interactive groups, webinars, toolkits and training"

"Growing importance of websites and social media in highlighting available services"

Comments Regional Carers Survey Responses July 2020

"Not everybody has access to information online - excluding a large population by using online information tools; share a range of online and physical information resources"

Comments Regional Forward Planning Event January 2020

What will we do?

- Develop a bilingual regional web based platform to support the provision and accessibility of consistent information and advice for Carers.
- Increase the delivery of Carer support services using digital mechanisms alongside traditional approaches.
- Work in partnership to enable Carers to maximise the support they can access via Technology Enabled Care to meet their needs.
- Support Carers to be digitally included through training and access to technology.

What will success look like?

- Proactive use of bilingual web based platforms and digital technology by Carers to access information and support.
- An increase in Carers reporting that they are digitally included and connected.
- Increase in usage of online support by Carers.
- Carers will be able to identify what support is available to them to get online.
- Carers will be able to identify different platforms and technologies available to support them in their caring role.
- Carers facing barriers associated with limited transport options having alternative ways of connecting with services.

Carers will say

"Even though I'm 80 years old, I still like to keep up to date with things happening in the community and the rugby of course. Being a Carer for my wife, it's sometimes hard to go out as I don't like to leave her alone. Being able to access the dementia Carer support group via skype is great. A volunteer came to the house and showed me how to use a "tablet" and since then I've accessed lots of support that I never knew was there!"



Alun Jones - Carer for his wife who has mild dementia

Measuring and reporting our progress

The West Wales Regional Carers Strategy sets out our direction of travel towards improving the experience and outcomes of Carers across the Hywel Dda region. This will be supported by annual action plans that will be responsive to emerging issues raised by Carers and changes in needs resulting from changing national priorities.

As this is a new Carers Strategy the West Wales Carers Development Group will be keen to receive feedback about how our actions are leading to improved outcomes for Carers. To do this we will:

- Establish mechanisms to obtain regular feedback from Carers on their views of the progress with the strategy and its impact.
- Hold 'check and challenge' sessions with Carer representatives to ensure actions are delivered in response to feedback from Carers of all ages.
- Undertake Carers experience surveys; and
- Collect feedback in the format of Carer Stories seeking to capture and understand the most significant changes.

The West Wales Regional Partnership Board will oversee the implementation of this strategy by:

- Receiving and scrutinising regular update reports from the West Wales Carers Development Group (as a sub group of the Regional Partnership Board).
- Publishing a report annually on the impact of the Carers Strategy for West Wales.
- Seeking assurance, through the WWCDG, that contract and performance management of commissioning arrangements for Carer services includes regular service user consultation, data collection and outcomes monitoring.
- Ensuring that the Strategy is supported and resourced effectively to deliver on the priorities identified; and
- Ensuring that the Strategy has sufficient priority within the Regional Partnership Board in order to raise the profile of caring and Carers' needs across the region in areas such as health, education, housing and transport.

Progress in respect of the implementation of this strategy will also be monitored, and scrutinised by the statutory partners: Hywel Dda University Health Board and Carmarthenshire, Ceredigion and Pembrokeshire County Councils through their own corporate reporting processes.

Through this strategy we will plan for the anticipated rise in the number of unpaid Carers. We will take a long-term view of what the needs of Carers will be in the future and how by working in partnership through the West Wales Carers Development Group we can meet those needs.

References and data sources used to develop the strategy

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