

# POPULATION ASSESSMENT BRIEFING DOCUMENT: CARERS

## 1. Introduction

Through the Understanding Our Communities project, public services are gaining a better understanding of the good things about communities, what matters to people and how their experiences and what they have to offer can help us to plan and provide services.

The Social Services and Well-being (Wales) Act has been put in place to make sure that public services are doing all that they can to support people using care and support services to have their say and get involved in managing their own well-being. The Act means that public services will need to make sure that the right support is available for the people who need it at the right time and in the right way.

Under this Act, public services must carry out and publish a Population Assessment, which looks at:

- the needs for care and support, and the support needs of carers;
- the extent to which those needs are not being met;
- the range and level of services needed to meet those needs; and
- how services are delivered through the medium of Welsh.

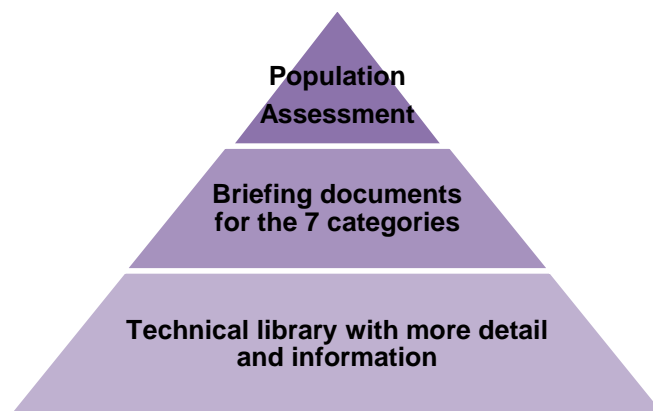
In Cwm Taf, we have been collecting lots of information for the Assessment, from the people making policy and commissioning decisions about services, the people delivering services and the people receiving services. In order to look at all of this information in an organised way, we used the seven 'themes' of the Act;

- Carers;
- Children and young people;
- Learning disability;
- Mental Health;
- Older people;
- Physical disability and sensory impairment; and
- Violence against women, domestic abuse and sexual violence.

We then spent some time, talking with these people about the headlines that emerged under this theme and really thinking about how they affect people and what we as public services can do to meet the needs of people using our services, in the best possible way, now and in the future.

A summary of the headlines relating to Carers are contained in this document. The document shows how the Carers headlines fit into the 'bigger picture' and the key messages which relate to *all* themes and what we currently do and/or could do to deal with these headlines.

The overall Population Assessment report contains the headline information across all themes.



The triangle shows the different parts of our work which taken together make up Cwm Taf's Assessment Report. Each level of this Assessment is supported by a more detailed level of data and information. The Assessment Report has been put together like this so that each reader can explore the information we have collected and analysed in as much or as little detail as they would like and can follow up any particular areas of interest. All of the information gathered throughout the project to inform the headlines in this briefing document is also available in an online library.

## 2. Carers

The SSWB Act provides the legal framework for improving the well-being of people who need care and support. This includes carers who need support and it is significant that now carers have equivalent rights to those that they care for. As defined in the Act, a carer is a person of any age who provides or intends to provide care for an adult or disabled child but who is unpaid except for carers related allowances. The Act has removed the previous requirement that carers must be providing "a substantial amount of care on a regular basis". Carers are legally

entitled to a carer's needs assessment regardless of the amount or type of care they provide, their financial means or the level of support they may need.

Alongside this legal definition and the use of the term "informal care" which is often used, we recognise that there is no typical carer. Carers of all ages, whether young carers, young adult carers, parent carers of children with a disability, working age or older carers, those who look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide can be physical, emotional or social. Carers are individuals who may not see themselves as carers, but consider themselves above all a parent, wife, husband, partner, son, daughter, friend or neighbour. Caring will often have an impact on the whole family, not just one person.

Carers' circumstances vary enormously, as can the type and amount of support they give. Caring can be a gradual process as over time someone becomes more frail and needs more support or it can happen suddenly, for example if someone has an accident or a health problem like a stroke. Young carers often have adult caring responsibilities while having the legal status of children. Whilst it is also rewarding, caring can be both physically tiring and emotionally stressful. Carers often feel isolated, unsupported and alone, with poorer health, less financial security and fewer opportunities to participate in day to day life outside caring.

This document will consider the needs of carers in Cwm Taf but given the nature of caring, in terms of the ages and life circumstances of both the carers and the cared for, it must be read in conjunction with other documents produced as part of the Population Assessment, for example in relation to Children and Young people, Older People, People with a Mental Health problem and Learning Disability/Autism.

### 3. The current position in Cwm Taf

Current services for carers in Cwm Taf are provided by a range of organisations in the statutory and Third Sector. As well as accessing general services like GPs in primary care available to everyone, there are also specific services to support carers, including young carers and young adult carers. These include:

- In RCT, a Carers Support Project run by the Local Authority.
- In Merthyr Tydfil, a Carers Network of service providers coordinated by Voluntary Action Merthyr Tydfil (the County Voluntary Council).
- Services commissioned from the Third Sector including Crossroads Care, Barnardos, Age Connects Morgannwg.

- A network of over 420 Carers Champions in settings across health, social care, education, housing, leisure, Job Centres and in the voluntary sector.

Information to help carers is provided in a variety of ways, including a Carers A-Z Guide, regular newsletters and the use of carers notice boards, for example, in GP surgeries. During 2016, the new Cwm Taf Information, Advice and Assistance Service has been established together with the use of an online resource DEWIS.<sup>1</sup>

Training existing staff across all sectors has been increased with the development of an e-learning tool. Training sessions for nursing and social work students in our local universities and colleges have also been provided. Training is important as we want to ensure our current and future workforce is carer aware.

### Cwm Taf Carers Strategy 2016-2019

Building on the work locally over the last three years to implement the Welsh Government's Carers Measure (which promoted the early identification and support of carers), partners agreed that one of the priorities in addressing the requirements of the SSWB Act was to develop a new Carers Strategy for Cwm Taf.

The new Cwm Taf Carers Strategy<sup>2</sup> was developed through engagement with a wide range of stakeholders, including carers themselves. It is about what we need to do to support carers, understanding and meeting any needs they have in their own lives, as well as working together with them to address the needs of the person they are caring for. Based on what carers told us, we developed a Vision Statement:

*Carers of all ages in Cwm Taf will be recognised and valued as being fundamental to supportive and resilient families and communities. They will not have to care alone and will be able to access information, advice and support to help meet their needs, empowering them to lead healthy and fulfilled lives, balancing their caring role and their life outside caring.*

The Cwm Taf Carers Strategy includes 5 key areas for action:

- Identifying carers of all ages and recognising their contributions.

If we are to meet their needs, we first have to identify carers of all ages, raising awareness amongst the public and with our staff about who carers are and what they do. For example, young carers told us that even though they carried a great responsibility, they also felt very proud of what they were doing and their closeness

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<sup>1</sup> [DEWIS website](#)

<sup>2</sup> [Cwm Taf Carers Strategy](#)

to their family members. However, they wanted more people in their schools and in their communities to understand what it was like for them on a day to day basis.

Carers of all ages need us to understand and value their caring role, recognising that they are key partners in the care they provide, involving them in decisions that affect them and the person they care for.

- Providing up to date, relevant and timely information, advice and assistance to carers of all ages.

It was clear from our engagement that getting the right information and advice at the right time can make a huge difference. When people are first faced with a caring situation, or if their caring situation changes over time if someone's health deteriorates, they need information as quickly as possible so that they can make better decisions for themselves and their families. Helping people to realise they are carers as early as possible helps ensure they don't miss out on valuable information, advice and help.

Whatever the information needed, for example about managing money or allowances available, advice about the impact of caring on health and well-being, or how to access support services, it must be provided in a variety of understandable formats, accessible locally and promptly to help carers make informed choices.

- Providing support, services and training to meet the needs of carers of all ages.

By this we mean different types of support which can help carers carry out their caring role effectively and meet a range of needs, including maintaining their own physical and emotional health and well-being, being able to take up education, training and employment opportunities as well as participation in activities outside their caring role.

Whilst all carers face different circumstances, a consistent message from our engagement was that time consuming or demanding caring responsibilities do restrict freedom and opportunities. Carers want better and more affordable respite (breaks from caring) available in a variety of ways and at different times of the day and weekends if they are to have valuable time for their own needs, whether this be in terms of working or leisure activities. Carers need to recharge their batteries but can only do so having confidence in the alternative care being provided to the person they care for.

- Giving carers of all ages a voice, with more choice and control over their lives.

By this we mean ensuring carers are involved in and consulted on issues and decisions that affect their daily lives and the lives of the person they care for. In addition, we must enable their voice to influence the planning, design and delivery of future services that affect them.

By coming together as a supportive community of carers, people can share what is on their mind and talk about issues that affect them with people who understand and can help. The value of peer support groups for both younger and older carers was stressed in our engagement, as was the value of professionals taking time to “check up by a quick phone call or text just to see if they were doing ok.”

- Working together to make the most of our resources for the benefit of carers of all ages.

Individuals, their families and carers may require care and/or support from more than one organisation. Where this is the case, the care and support they receive should be effectively coordinated and delivered - the right services at the right time in the right place.

We will need to deliver local services in a joined up manner to meet the needs of individuals but also make the best use of resources available to ensure carers and their families achieve a greater degree of independence and improved quality of life. We can do this by supporting and building on the range of skills, talents and resources already available in our local communities.

Alongside implementing our Cwm Taf strategy, we will also review any further actions needed as a result of Welsh Government refreshing the All Wales Carers Strategy. A national Statement of Intent is due out in the New Year.

## 4. Headlines

This section summarises the headlines from our assessment. More detail, including the data sources and engagement reports that support them, can be found in the Carers section of the online assessment library.

Undertaking this assessment has given us an opportunity to revisit and build on what we know about carers, both in terms of data and the things that carers say are important to them, as summarised in the box below. It has reaffirmed and refined the key areas we need to focus on if we are to meet carers’ needs for care and support.

One of the most important messages we have consistently been given is that “what good looks like for carers is when we get it right for the person they are caring for.”

The most common issues raised by carers during engagement:

- Easy access to a central point of up-to-date, easy to understand information and advice.
- Access to respite and short breaks to recharge batteries and more free time for young carers to spend with friends/socialise.
- Professionals should respect, communicate with and listen to carers.
- Awareness raising is needed to increase knowledge and understanding of the caring role, both in society and with professionals.
- More practical support would ease the pressure on carers.
- More emotional support would prolong the health and well-being of carers.
- More funding and resources is needed for carers.
- Support Groups for both younger and older carers are highly valued.
- Carers would like accessible and discounted transport.
- Better understanding is needed from employers and schools.
- Carers need more understanding of Carers Champions and their role.
- Better communication is needed between different agencies with automatic referral processes.
- Access to appropriate training and workshops to support carers in their caring role.

*The higher levels in Cwm Taf of poor physical and mental health, chronic illnesses and disabilities, together with an ageing population, have an impact on the need for informal care and the number of carers locally.*

People living in Cwm Taf have lower life expectancy and live with a higher burden of ill health for longer than elsewhere in Wales. There are areas of significant deprivation which also impacts on health and well-being. By 2039, the population in Cwm Taf is expected to rise from 295,865 to 304,543 but within this figure the numbers aged over 65 years and over will grow significantly, with the biggest

increase being seen in those aged 85 years and over.<sup>3</sup> We are likely to see a rise in the number of people living with a range of chronic conditions such as heart and respiratory disease as well as cancer and dementia. Over 40% of people aged 75 and over in Cwm Taf live alone. All of these things will have an impact on the need people have for care of some kind, much of which will be provided by informal carers who may be family, friends or neighbours.

The 2011 Census<sup>4</sup> provides us with information about carers but must be treated with some caution as it is based on people “self reporting” that they are carers and answering the census questions accordingly. From our engagement, people do not always recognise themselves as carers and the true level of informal caring is probably higher. Census data for Cwm Taf tells us that:

- Nearly 13% of the population in Cwm Taf (29,640 carers in RCT and 7,427 in Merthyr Tydfil) were providing care to a family member, friend or neighbour. This is slightly higher than the all Wales figure of 12% and higher than the England and Wales figure of 10%.
- 57% of carers in Cwm Taf are female and 43% are male.
- The majority of carers locally are over the age of 50, with the largest group of people (34%) aged 50-64.
- The number of carers over the age of 65 is increasing more rapidly than the general carer population. There has been a 32% increase since 2001. With an ageing population, this is likely to increase further over the coming years.
- There were 3263 young and young adult carers under the age of 25, an increase of 19% since 2001.
- 11,752 carers in Cwm Taf (32%) provide over 50 hours of care per week. This has increased from the 2001 Census. This highlights that Cwm Taf carers are providing substantial levels of care, which is frequently not recognised or valued and which can often impact on the health of the Carer themselves.

This headline alerts us to the significant numbers of carers in Cwm Taf and, given the time they are spending in their caring roles, the enormous contribution they are making as part of the health and social care community through the informal care they are giving to their family, friends or neighbours. Many carers will not be “known” to statutory organisations or their role properly understood and

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<sup>3</sup> [Stats Wales](#)

<sup>4</sup> [Census - Office for National Statistics](#)



appreciated by others in the wider community. We need to do more to raise awareness and understanding of the impact of a caring role.

*Carers need to be recognised and valued for their caring role. Carers want to be listened to and have more control over their lives but “one size does not fit all.”*

Whilst we have some data about carers from the census and from carers known to services locally, we also know from engagement with carers and other groups in the community, such as children and young people, older people and people with a mental health problem, that often family members or friends who are providing help and support do not see themselves primarily as a carer or find the use of this term causes confusion with paid care workers.

The issues associated with caring will vary considerably depending on the individual circumstances of the carer and the needs of the person they are looking after. This headline reminds us that whilst carers have many common concerns, for example, wanting to be listened to or how to find information or support, the nature of their particular circumstances and those of the person they caring for means that “one size does not fit all.” How we respond to the needs of a young carer who is supporting a parent and siblings at the same time as trying to keep up with their education or just have time to go out and have some fun will be very different from the support needed by an older person caring for their spouse or partner who is also elderly or a parent carer of a child with disabilities.

We will only be able to respond appropriately if we respect, listen to and actively engage with carers as individuals who have a great deal of knowledge and experience about themselves and the needs of the person they are caring for. If we listen to what they want to achieve in their own lives and what works best for the person they look after, we will be better able to support them in their caring role.

*Carers must be able to find the information and support they need easily and quickly to help them sustain their caring role.*

We know that carers in Cwm Taf are providing substantial levels of care a week (as explained in headline (a) above). From our own engagement and a number of surveys undertaken by national organisations including Carers UK<sup>5</sup> and Macmillan<sup>6</sup> we also know that caring impacts in many ways both on individual carers and their families, including on the physical and mental health of the carers themselves. In addition to impacts on health, many people suffer financial hardship as a result of

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<sup>5</sup>[Carers UK](#)

<sup>6</sup>[Macmillan](#)

caring. They may be juggling work commitments or unable to sustain employment, worrying about possible changes to welfare or housing benefits.

Census data in 2011 for Cwm Taf carers showed that 35% of carers rated their health as fair, bad or very bad.

Carers UK 2015 State of Caring report found that 82% of carers felt caring had a negative impact on their health and 55% reported they had suffered from depression as a result of their caring role.

In Carers UK 2016 State of Caring report, 54% of carers reported that they expected their quality of life to get worse in the next year and 49% of carers had given up work to care whilst 23% had reduced their working hours.

This headline highlights that if we want carers to enjoy good physical and mental well-being, we need to support them appropriately as well as making sure the person they are looking after has their needs met effectively too. If any stresses and strains on the carer are reduced and they receive the information, advice and assistance they need easily and quickly, they are more likely to be able to cope with and continue their caring role. This is positive both for them and for the person they care for. It may avoid someone having to move into residential or nursing care or reduce the length of time they spend in hospital.

The right support for the carer will vary considerably from person to person. It might be providing information about managing money and financial entitlements, training on how to improve their own health and emotional well-being such as mindfulness and stress relieving courses, training in relation to the specific care they are providing to their loved one, more practical support in juggling all the demands placed upon them or equipment that can help them with caring tasks. Too often services only become available when there is a crisis whereas the focus should be on prevention and earlier intervention.

*Carers want to participate in and stay connected to a life alongside caring.*

Caring can lead to social isolation and fewer opportunities to participate in activities outside caring. A Carers Trust (Wales) report in 2016<sup>7</sup> found that 35% of carers without good social support experienced ill health compared with only 15% of those who had good support. Young carers face particular challenges coping with school life and maintaining relationships with their friends in their life outside caring. This can ultimately impact on their aspirations and life chances.

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<sup>7</sup> ["Investing in Carers, Investing to Save"](#) Carers Trust Wales 2016

There may be opportunities for carers and the cared for to socialise and undertake activities together, for example in dementia cafes or choirs run by the Alzheimer's Society. Sometimes, however, it is about carers wanting a break from caring to follow a particular interest or just have "time out" but in order to make this happen, they need to be confident that they can safely leave the cared for person for a period of time and/or they might need to be looked after by someone else. Respite care is a big issue for carers as we found during our engagement, both planned and in an emergency situation.

Staying connected to friends and the wider community helps people remain resilient and confident during their time caring. It also means people are better placed to carry on with a fulfilling life after caring which many carers often find challenging.

In addressing this headline, we will need to think about how best opportunities are provided and nurtured in local neighbourhood networks for people to build relationships, socialise and support each other through a range of activities and experiences.

*Carers and service providers must work together with more effective communication and coordination between services, seeing the person and not the problem.*

Caring can bring many benefits to both the carer and the cared for person and should not just be seen as a burden or problem. However, the challenges carers face often mean that there are more negatives than positives. For example, a recent report by the Older People's Commissioner for Wales "Dementia: more than just memory loss"<sup>8</sup> found that a lack of cooperation between services creates unnecessary difficulties and barriers for people living with dementia and their carers who often find themselves taking on a "care coordinator" role. This problem is borne out by our engagement with carers and not just those caring for someone with dementia. Carers asked for better communication between agencies, professionals to have empathy with what it is like to be a carer, improved sharing of information and continuity of care so they do not have to keep telling their story and liaising with lots of different people and organisations.

Addressing all the components of well-being encompassed in the SSWB Act means that not only will health and social services need to work together more effectively

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<sup>8</sup> [Older People's Commissioner for Wales](#)

but a wider range of other partners including housing providers, Third Sector organisations, employers and businesses will have a role to play to meet the needs of carers for care and support. This approach will also help to maximise the use of our resources, skills and expertise to provide sustainable services.

## 5. Links to other headlines and common themes

The things which affect carers do not stand in isolation. As individuals, they may also be service users in their own right (for example, as an older person, someone with a sensory impairment or a mental health issue) and their needs will have been the focus of other sections in this Population Assessment. Similarly, the care and support issues facing the person they are caring for will be addressed in the other sections of the Assessment under the specific themes. However, as our headlines have illustrated, it is really important we recognise the overlaps and see people “in the round”, taking a holistic approach to what both carers and the cared for person need, avoiding working in silos and ensuring our responses and plans are joined up.

Some of the key issues faced by those covered by the other themes of the Population Assessment as well as carers are:

- Information and advice.

Time and again in our engagement, people (both service users and staff) commented that they were not aware of services and activities being discussed or highlighted as examples of good practice or how they would be able to access them. There may be lots of information in a variety of places and formats (paper copies, online etc) but it would appear that people still can't easily find what they are looking for or it doesn't give them the answers they need to make informed choices and decisions.

It is early days to assess the impact of the new information, advice and assistance services provided locally as a result of the SSWB Act but we will need to ensure we are meeting this need. For example, information should be readily available where people go in their local communities and could be shared more effectively with a collaborative approach to communication rather than every organisation producing its own leaflets.

- Being listened to and understood.

Whilst our engagement activities recognised and valued the importance of a citizen focus and a person centred approach, it was also clear from service users that too often they feel they are not being listened to sufficiently and that services are planned and delivered around what best suits organisations rather than individuals.

The SSWB Act's emphasis on personal well-being outcomes will help refocus our approach but we will need to find ways of balancing individual views with service user voices that can be aggregated to inform the planning and commissioning of services at a population level.

- Preventative services.

The SSWB Act emphasises the benefits of prevention and early intervention as the most effective way of supporting people rather than reactively responding to crises by which time their needs will have become more serious. Services which help carers maintain their own good health and well-being can be seen as preventative both for themselves and by enabling them to continue caring, which may well prevent the cared for person requiring more specialist services provided by statutory agencies like the Local Authority or Health Board. We need to give people more opportunities to seek help earlier, with more options and innovative ways of providing the assistance they need.

- Community connectedness and resilience.

National policy promotes the development of community based activities and neighbourhood networks both as a means of improving health and well-being but also enabling individuals to take more control over their own care and supporting communities to help themselves.

Our assessments have also recognised that this local community capacity and resilience will be vital to improving and sustaining services. People and communities in Cwm Taf have untapped potential and something to give (assets in terms of skills and resources) that can be identified and harnessed to connect people and places more effectively. This brings people together with a sense of purpose and value to address individual and community issues which can improve quality of life, for example by tackling increasing problems of social isolation and loneliness.

- Coordination and working together.

A common message from carers and other population groups is that services must work together more effectively, both within individual organisations and across agencies, particularly where people have multiple or complex needs. This is important not just for health and social care but also other areas like housing, leisure and transport if needs are going to be met fully.