Evidence of Need

“To be a carer is not so easy from time to time, it is so nice to know there is someone out there who can help.”

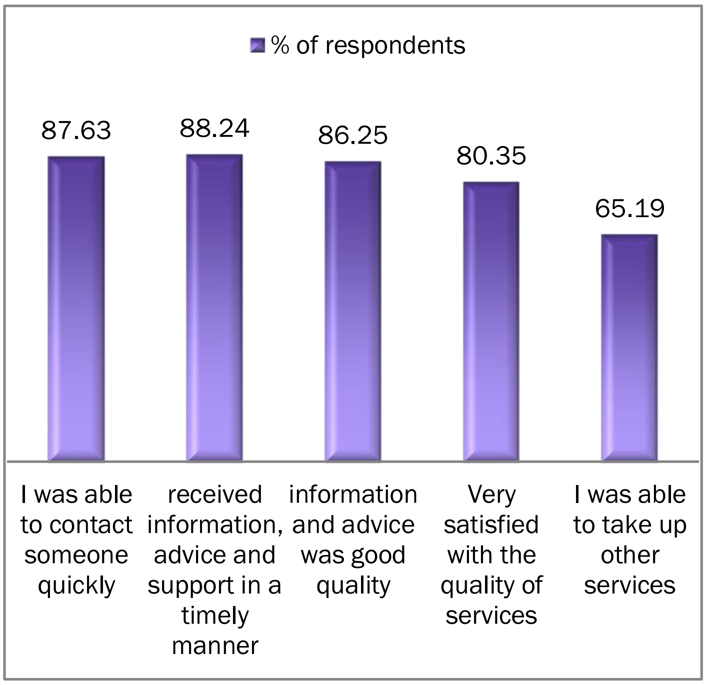
The key themes of carers needs evidenced by the consultation has informed our Strategy together with the wider contextual evidence of other research, policy and legislation summarized here.

Carers Support West Sussex provides a gateway service to support and other services across West Sussex. For Carers the provision of good quality accurate information and advice is critical to them in finding ways to cope.

General Information and Advice

The majority of enquiries (68%) we receive are for general information and advice about support available to the Carer themselves as well as that for the person(s) who they care for.

42% of carers felt that because of the information and advice provided they were more recognised as expert partners in care.



Carers Rights and Expert Partners

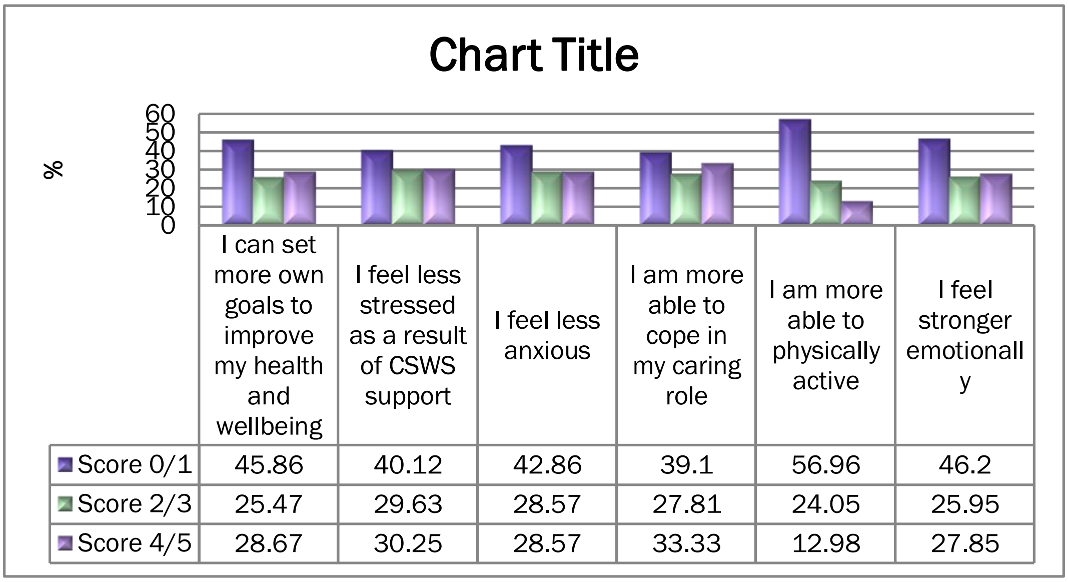
Many carers appear to be unaware of their rights and what is available to them. Many are frustrated by the multiplicity of professionals they have to deal with and having to continuously explain their situation.

Although 34% of carers felt more informed about their rights many quoted lack of time and frustration in trying to deal with professionals as a barrier to accessing services they need.

Through the Carer Support Newsletter and our involvement in statutory Carer Assessments this situation should change significantly over time.

Raising the profile of the needs and rights of carers in West Sussex is a key focus for CSWS. Carers Voice and Carer groups will also be media through which to continuously keep Carers informed and for us to gather evidence and feedback for development and promotion to professionals.

“I just don't feel that carers are listened to by the powers that be who make the big decisions. It's as if lip service is paid but, in truth, we are not heard. The awful truth is that if we carers were not prepared to take our role seriously the NHS would have a catastrophe on their hands. What we are paid, for what we do, is a pittance and a disgrace. Spend time in our shoes, hour by hour, day by day, week by week, month by month, year by year and THEN they would have some idea of what things are like. Professionals themselves are full of advice and may work with patients on shifts, but I have yet to meet ONE who has actually lived alongside a loved one who is struggling with a mental illness. A parent/carer cannot afford emotional detachment which makes the task even more heartbreaking.”



	I can set more own goals to improve my health and wellbeing	I feel less stressed as a result of CSWS support	I feel less anxious	I am more able to cope in my caring role	I am more able to physically active	I feel stronger emotionally
Score 0/1	45.86	40.12	42.86	39.1	56.96	46.2
Score 2/3	25.47	29.63	28.57	27.81	24.05	25.95
Score 4/5	28.67	30.25	28.57	33.33	12.98	27.85

Carer Health and Wellbeing

It is well evidenced that carers suffer high levels of stress, anxiety and have poor emotional, physical and psychological health. They can suffer physical injury as well as the stress relating to their caring role. There is evidence of a clear link between carers suffering poor health as a result of their caring roles. From one study we know that 86% of carers reported suffering from stress, anxiety and depression and 54% felt isolated. The Princess Royal Trust for Carers found that 96% reported a negative impact on their health and wellbeing.

The above chart shows that this is still the experience of many carers in West Sussex. However, we need to look at the context in which the responses were given to fully understand the results. The most common reasons cited for not being able to address issues of stress, anxiety, to reduce their isolation, become socially or physically active is simply that they do not get any breaks from their caring role making it impossible to address their own health and wellbeing needs.

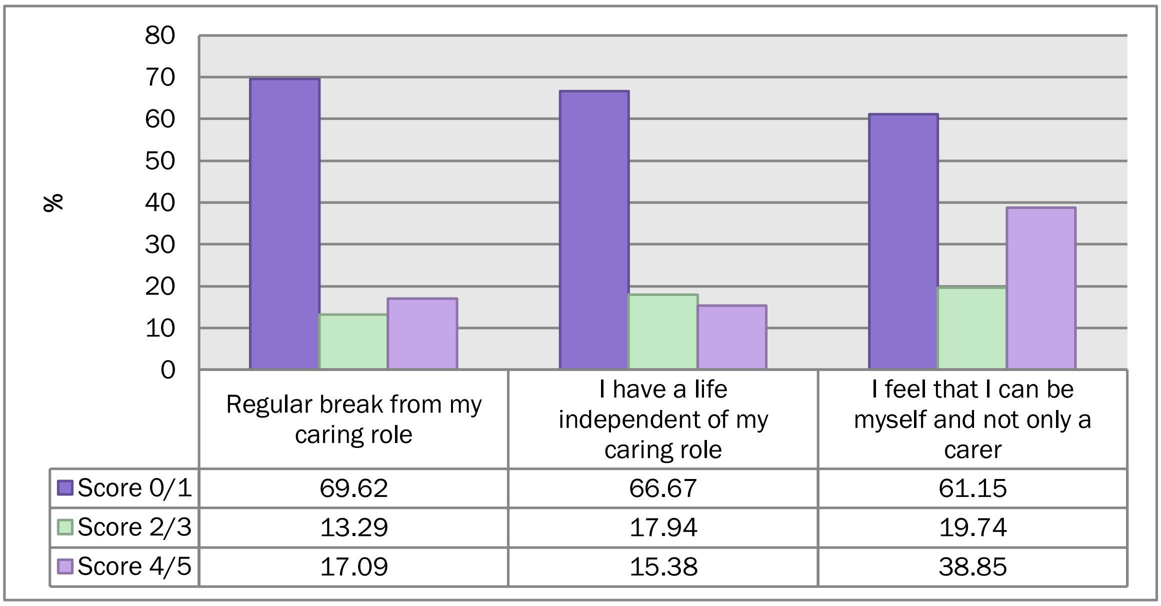
Continuing and expanding services such as counselling, groups and support to reduce stress, anxiety and isolation is essential. The Carer Wellbeing Fund is also cited as an essential lifeline for many carers.

> *"I have been forced into a change of my previous life due to my role as a carer. I am less able to pursue my hobbies outside the home such as playing golf and membership of societies which need time away from home where I am needed."*

> *"Feel less isolated and know where to turn for help or just for a chat, knowing my needs will be understood."*

> *"The emotional support from other carers and staff from Carers Support has been invaluable and both have been good sources of information."*

> *"I now meet people, go for a healthy walk once a week. I very much look forward to that I don't feel so invisible that way."*



	Regular break from my caring role	I have a life independent of my caring role	I feel that I can be myself and not only a carer
🟪 Score 0/1	69.62	66.67	61.15
🟩 Score 2/3	13.29	17.94	19.74
🟪 Score 4/5	17.09	15.38	38.85

The above chart shows that many carers in West Sussex do not receive any respite or have a life of their own outside of their caring role.

Many carers are self-funders on limited incomes, or diminishing savings and with limited opportunities for respite available to them and which can support the needs of the person cared.

The issue affects carers regardless of their age, whether parent carer, young adult carer or older carer.

Many carers also spoke of their anxiety about what would happen to the person(s) they care for if something happens to them. Many expressed financial worries, living on low incomes, and especially those in receipt of state pension who have no other source of income and can no longer access Carers' Allowance. The cost of caring can be high with many hospital visits and increased utility costs such as heating.

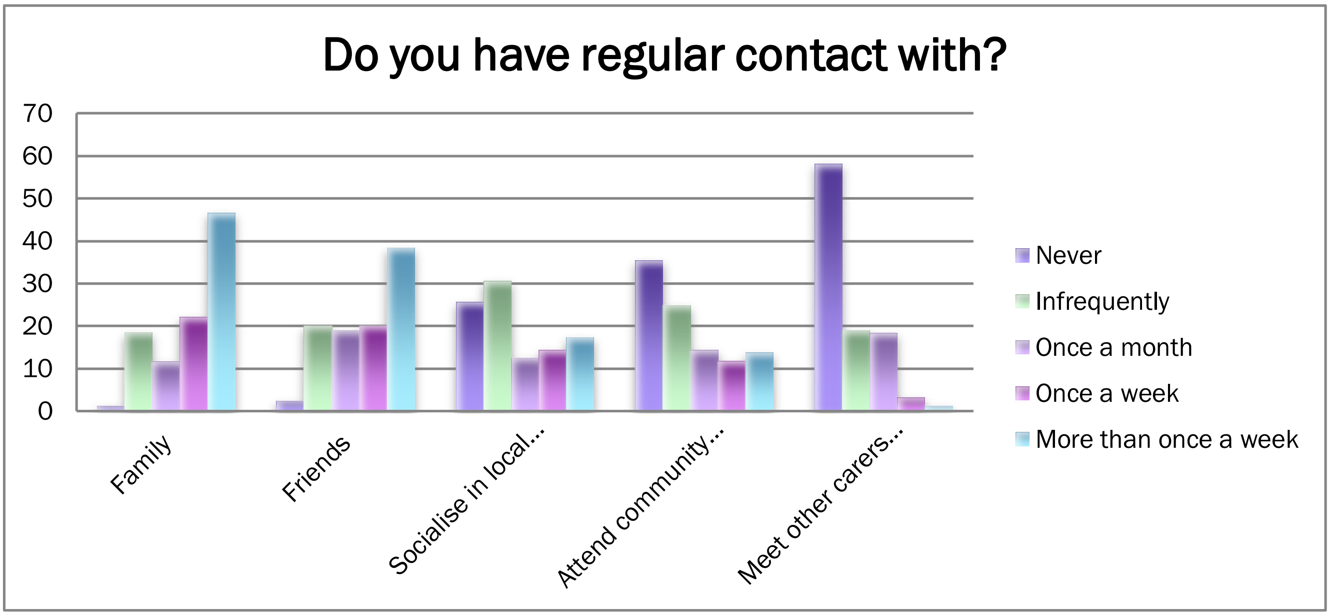
The most commonly requested support is:

- Affordable day respite
- Emergency support
- More access to the Wellbeing Fund
- More counselling face-to-face
- Male carers groups
- Carer groups with support for the person/people the carer cares for.

> *"I care for my wife 24/7 except for the time my wife spends in the day care centre because of her condition I have to be close all the time / caring for my wife is reducing my savings rapidly and unable to entertain the idea of respite."*

> *"No difference at all. My entire life is determined by what my son can and cannot manage on a day to day basis. He cannot be left so i have no option but to be with him all the time."*

> *"Although I have accessed the short break funding a couple of times this is not a regular break, hence the 3 rating. however, it should be stressed that these breaks were invaluable to myself and my family at the time - I wish these were a regular treat to look forward to as I am unable to access any of the support groups given that I work full time (40 hours per week)."*



Losing social contact with friends and family, losing social life and life outside caring is a significant gap identified by many carers responding to the survey.

The quotes opposite show the challenges carers face but for those who are able to attend the support groups, as well as other activities like being able to attend their local church, groups can be invaluable to helping maintain social contact, health and wellbeing.

One carer stated:

"I think if I had gone on the way I was before I joined the Carers Support Group I would have had a physical and mental breakdown. I had a strong sense of the danger of this and this made me join the Carers Group. I didn't, I admit, have much hope of it at the time but I am amazed at how huge a difference it has made and I am VERY VERY grateful."

The results of feedback and consultation on needs has informed our aims and objectives and focus on the following priorities identified:

- Increasing choice and control through information, advice and guidance to enable Carers to have a good quality of life and a life outside of their caring role.
- Increase knowledge of Carers' rights and give Carers a voice and raise the profile of their needs with public sector and others in the County to ensure there is a menu of support including respite and social, recreational, work and volunteering opportunities.

"I have lost all my confidence, I am isolated now use to be sociable, no circle of friends."

"We are prisoners in our own home."

"So much depends upon the duties placed upon the carer. This is different in each individual case. For me it was necessary to give up all the external interests I had as my wife became more incapacitated. Also finding the time and making arrangements for care of my wife in my absence restricted the amount of time I could give to any outside interests."

"It's hard for me to attend carers group meetings as I care for my mum I can't leave her on her own for a long time. I would like to go along to these meetings but at the moment it's not possible."

External Context

All public sector funded services are facing opportunities and challenges arising from legislation. The Care Act 2014 and other legislation emphases need for person-centred services and recognition of service users and carers as expert partners. This increases choice and control. Alongside increasing demands and expectations, public sector and not-for-profit sectors are feeling the consequences of austerity and competition for funding.

Commissioners are looking for solutions to achieve more for less whilst delivering sustainable outcomes; there is a focus on early intervention to prevent people accessing more costly or acute services and reduce pressure on very stretched community services. This is against a backdrop of local population changes with far higher demands for care and support (hospitals, dementia, mental health and other medical and social support specialties.

Demographic Data

West Sussex enjoys higher life expectancy than the England average - 80.5 years for men and 83.8 years for women (WSCC JSNA). The 2011 census data shows that across the region the greatest population increase is in the 50 plus age group.

The Joint Strategic Needs Assessment (JSNA) also states that more people are living with long-term conditions including increases in physical and sensory impairments often for decades, and there is a fast-growing number of people with dementia. People living in deprived areas of the county are also found to be more likely to have more poor health conditions.

Health and Social care policy is aimed at increasing and promoting 'self-care' and 'self-management' enabling people to stay independent and in their own homes for longer, and supporting people to maintain and improve their own physical and mental health.

1 in 10 people in West Sussex are estimated to have a mental health problem and demand for talking therapies has grown in recent years with over 4,700 referrals per quarter.

The 2014 JSNA has a number of overarching themes and states:

"Prevention and resilience in relation to individuals, families and communities - good health and wellbeing is reliant on a wide range of factors, factors which act to promote physical and mental health and good quality of life. These include employment, housing, education and less tangible issues such as the quality of social networks, friendships and support. These act as protective factors to individuals, families and communities."

Equality and Diversity

Research undertaken in 2009 'Focus Quality Issues in Social Care' found that Black and Minority Ethnic people want: accessible information about services leading to options about which services they use; control over decisions about their future; services that recognise differences in cultures without making assumptions; support from staff with positive and respectful attitudes towards them and services that enable them to have contact with people important to them and to be connected to their communities.

The JSNA also identifies specific communities with additional health needs including gypsies and travelers, students, young adult carers. Our own consultation highlights that Gay, Lesbian, Bisexual and Transgender carers are another specific group with the same and sometimes different needs.

2008 research (YAC in the UK Fiona Becker, Saul Becker) found that 25% of young adult Carers are caring for more than 20 hours per week and 12% for more than 50 hours per week. They found that as the caring role increased this often resulted in strained relationships with the cared for. Support from schools was mixed and they had poor career prospects and job search advice. Many reported finding it difficult to socialise, make friends and had insufficient time for themselves, suffering lack of confidence and low self-esteem.

Together with these practical social and demographic issues affecting Carers is the need for organisations to work creatively and find different solutions to address the current drivers to change the way support is provided.

Organisations can no longer work in isolation, building strong collaborative working and Asset-Based Community Development (ABCD) is going to be a key component of success going forward, to seek shared and better solutions to support Carers in West Sussex.

Carers Support West Sussex is already a partner in the West Sussex Consortium – 'Supporting Community Based Solutions' – lobbying for ABCD locally and has signed up to become a member of the new national 'Coalition for Collaborative Care'.

Funding Environment

Cuts and budget constraints are well known. The pressure on charities and service providers to do more for less whilst at the same time prove that they are achieving better outcomes and reducing the burden on the taxpayer are at the forefront of local authority commissioning as well as other funding programmes.

The Public Services (Social Value) Act requires commissioners to take account of social, economic and environmental impact of services that come under EU commissioning legislation. However, many local authorities are applying these principles to all funding programmes, including WSCC.

Monitoring and Evaluation Framework for CSWS

CSWS Monitoring and Evaluation framework is to be based on Social Value – Made Real methodology that includes calculations of unit cost, social capital and preventative value of services. Gathering statistical and qualitative evidence to demonstrate outcomes and the difference services make, how collaboration has worked will enable calculations to be made to demonstrate how well services are meeting the 'invest to save' and early intervention and prevention policies. This is going to be vital to CSWS sustainability going forward.

Our strategy also identifies the need to diversify our income streams. This will not only lever valuable funding to support future commissioning and demonstrate increased value for money, it will enable us to develop services to meet carer needs that may not be covered by local authority commissioning.

Alongside this we will be ensuring we accurately calculating our volunteer and in-kind contributions.

The WSCC Dementia Framework shows that the cost of care for people with dementia is £23m. With the changing demographic it is estimated that this alone will increase demand for spend between 2013 and 2021 by a further 25%.

CSWS needs to effectively monitor and evaluate its services to demonstrate how well we are enabling Carers to continue in their caring role for longer, maintain health and wellbeing – their own and for the person they care for.

Our monitoring and evaluation framework will enable us to calculate the potential cost-savings to the public purse and how we are supporting the public sector to save costs for pressured, crisis, acute and more costly services. We will be able to show the social capital and added value benefits of our work.

Personalisation and Direct Payments will also have impact.

We need to be able to accurately cost our own support services to be able to quote these clearly.

We need to ensure that where we can fund-raise to provide subsidies for new services over and above the commissioned universal offer services, we ensure any contribution from carers is affordable.

This is critical for carers who do not meet public sector funding eligibility but are nevertheless financially insecure and unable to pay the full cost of any support – for example, relaxation therapies and short respite breaks - as evidenced by the many quotes and carer feedback we receive.

Challenges of the Local Area

West Sussex is made up of 768 square miles with a population of 806,900. It is classified as being ‘significantly rural, according to the department for the Environment, Food and Rural Affairs (DEFRA). The majority of people live in the main towns of Worthing, Crawley, Horsham and Chichester. Three out of the 7 districts are classified as rural with Chichester and Mid-Sussex having more than 80% of their populations living in rural settlements or large market towns. Horsham is between 50% and 80% rural. The remaining districts are classified as urban - Crawley, Adur, Worthing and Arun.

To develop our county-wide, equitable service offer to all Carers is a challenge given the make-up of the county and the dispersed populations. Access to accessible and affordable transport has been identified by Carers as presenting a particular issue either – due to limited availability, access or cost issues. Although many buses are wheelchair-friendly these can only take one at a time and if the space is full wheelchair users may not be able to physically get on a bus.

Transport to access services, Carer groups, events and activities, as well as hospital and primary care appointments has been highlighted as a particular problem for carers.

There is also a range of other legislation that impacts on our work:

- The Care Act 2014
- Children and Families Act 2014
- Children Act 2004
- Human Rights Act
- Disabled Person’s Act
- Equality Act 2010
- 2005 Mental capacity Act.

Local health and social care policy are also key drivers in how we work. For example WSCC Dementia Framework 2014-2019 in partnership with the Clinical Commissioning Group – Carers Support West Sussex was represented on the county-wide Joint Implementation Group for Dementia and remains an active provider partner.

The Framework looks beyond the medical needs of people living with dementia and cites the need to provide integrated support to reduce barriers between physical, mental, social care and community-based provision.

Research by SCIE (Social Care Institute for Excellence) demonstrates that older people with dementia and their carers, and people with mental health problems, benefit most from consistent contact with organisations they can trust and know well.

Loneliness and isolation is also known to increase the likelihood of dementia. Recent research by the Kings Fund showed that 64% of people experiencing isolation were at a higher risk of developing dementia compared to those who are not lonely. Being a carer is also a risk factor.

This report also highlights other risk factors associated with loneliness and isolation including psychological stress, higher blood pressure, sleep problems, depression and cognitive decline.

Parent Carers

Parent-carers face additional challenges.

Many parent-carers have more than one disabled child, or have other children that they need to care for. They consider themselves as parents first but have a child or children with additional needs. Many refer to the demands of the caring role and the many professionals that are involved in their life. Recent evaluation of Short Breaks for Disabled Children demonstrated that 70% of disabled children supported had Autistic Spectrum Disorder, learning disability, behavior and complex health needs create a complex picture. It is estimated that there are in the region of 4500 – 6000 disabled children in West Sussex in receipt of medium and high rate care component of Disability Living Allowance.

Transition to adult services, ability to work, and have a life outside their caring role are all important issues highlighted by parent-carers.

Other Available CSWS Information

Internal Context

- ✓ Staff Structure – organogram and staffing lists
- ✓ Volunteers – recruitment, training and support, activity
- ✓ Governance information – Trustee skills, Governance Action Plan

Communications Strategy

Including promotional activity and materials

Quality Assurance

- ✓ Throughout the organisation including: safeguarding, risk assessments for activities, customer service standards, applying values and behaviours. Access and communications could also be included here.

Budgets and Cash Flow forecasts.

Business Continuity Plan and **Risk Register**.