

What Carers Want

Feedback from two major consultations about what carers want from Adult Social Care and health services in East Sussex, and how we have updated our plans as a result

“More frequent access for us both to a professional person to give us reassurance and some practical help”

“I would like to be able to have occasional Saturdays off but am not often able to find carers to come in to sit with my husband”

“Most important would be information and easy access to speak to someone if there were any questions within the information that people would like to ask”

“To have contact and know support is available and in the background – this helps keep stress levels down”

Quotes from consultation participants

Hastings and Rother 
Primary Care Trust

East Sussex Downs and Weald 
Primary Care Trust

If you took part in this consultation, thank you very much for your ideas.

About this booklet

This information should be of interest to anyone who cares about support for carers. You may be a carer yourself, providing unpaid support to a friend, relative, or partner who needs regular care. Perhaps you work for a local authority or the NHS and come into contact with carers regularly. Maybe you work for or support an organisation that works for or with carers. Or you could just be someone who's interested: after all, three in five of us will provide this type of care for someone at some point in our lives. The support available to carers should matter to us all.

How to get copies of this booklet

You can get copies of this booklet in another language, in large print, in Braille, as an audio file or CD/cassette, or in Easy Read. Please contact Debbie Charman on debbie.charman@eastsussex.gov.uk or 01273 482159 to request booklets in different formats or more copies of this booklet.

You can also download a copy of this booklet and copies of other documents related to carers and this consultation from:

www.eastsussex.gov.uk/yourcouncil/consultation/2009/supportforcarers

What to do if you are a carer and need support

Around one in ten of the people responding to the first part of our consultation told us they currently get no support. If you are a carer and would like advice or to get an assessment of your needs, please contact Social Care Direct on 0345 60 80 190, socialcaredirect@eastsussex.gov.uk or visit eastsussex.gov.uk/socialcare/applyingforservices.

There are also organisations that can give you advice and put you in touch with other carers, among other things. You can contact Care for the Carers on 01323 738390 or ReThink (if you're caring for someone with mental health problems) on 01424 716712. Adult Social Care also produce a booklet you can ask for which gives details of services available to you as a carer.

Thanks to:

Care for the Carers, Rethink, Action in Rural Sussex and other local voluntary sector organisations for their collaboration and assistance with this consultation.

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Introduction

“A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.”

[Carers at the Heart of 21st Century Families and Communities, 2008]

There are 6 million carers in the UK and every day over 6,000 people take on a caring role. 23% of people in East Sussex are over 65 (compared with 17% in the South East, and 16% in England overall). The proportion of over 65s in our society is likely to continue to increase in coming years.

In the 2001 Census, 50,600 people in East Sussex said they were carers (which is about 10% of the population). In fact, there may be many more people providing unpaid care to family or friends because we know not everyone who cares for someone thinks of themselves as ‘a carer’.

The majority of carers are between 50 and 64 years old. Research has shown that carers are more likely than the rest of the population to be financially disadvantaged, suffer depression and develop other health problems¹.

Carers should be recognised and valued for the enormous contribution they make and for the hard job that they do every day, though many carers would say they are simply doing what needs to be done for people they love. It's thought that carers save the UK economy £87 billion a year – which is the same amount of money that it takes to fund the whole of the NHS².

Background: why we consulted

To decide how we support carers in East Sussex, the County Council's Adult Social Care department works closely with NHS Hastings and Rother Primary Care Trust (PCT) and NHS East Sussex Downs and Weald PCT. We also work closely with the two major organisations supporting carers in the county, Care for the Carers and Rethink.

In 2007, we worked with the PCTs to develop and implement a plan for how we would support carers. This plan takes us up to 2010, so we need to make new plans that start from next year. We have been working together to develop a new plan (called a Joint Commissioning Strategy) for how we will work together to support carers from 2010 to 2015.

This plan covers adult carers only. Separate strategies are being developed by the Council's Children's Services department and both the Primary Care Trusts to support young carers and the parents who care for children with disabilities.

Our aims

When making our new plans, it was important to:

- Listen and respond to what carers say are key issues for them, now and in the future.
- Make sure that what we plan complies with laws that mean carers have a right to having their own needs assessed and we help carers get opportunities for education, skills and learning³.
- Ensure carers are not discriminated against because of their role⁴.
- Try to prevent carers becoming unwell because of the physical and/or mental stress of the role⁵.
- Respond to the government's 'Putting People First' plans, which say that services should be aimed at the most vulnerable in society, personalised so they respond to the needs of the individual carer, and help carers in their community⁶.
- Respect carers' knowledge and understanding as 'expert care partners' alongside professional carers⁷.

Phase One – carers: what we did and who responded

Since the last carers strategy was produced in 2007, we have regularly sought carers' views in a number of ways. For example, we held 'Closer to Home' stakeholder events with the PCTs in 2007 and we looked at the results of the Care for the Carers focus groups that were held in 2008.

During 2009, because we needed to make new plans for the next five years, we have held two large consultations. The first phase of consultation was with carers and the second phase invited anyone to respond.

What we did

In February 2009, we sent 3,200 surveys to people on mailing lists from Care for the Carers and ReThink (organisations that support carers in East Sussex).

We asked carers how we could improve the support we provide in the five areas the Government believes are most important for carers' well-being, namely that carers should:

1. Be respected by paid staff as expert partners in care;
2. Have easy access to information and training to help them as carers;
3. Have more planned breaks;
4. Have support to help stay mentally and physically well; and,
5. Have support to help them if they choose to remain in, or return to, employment.

We also held two focus groups where older carers from rural parts of the county and carers from minority communities gave us their views.

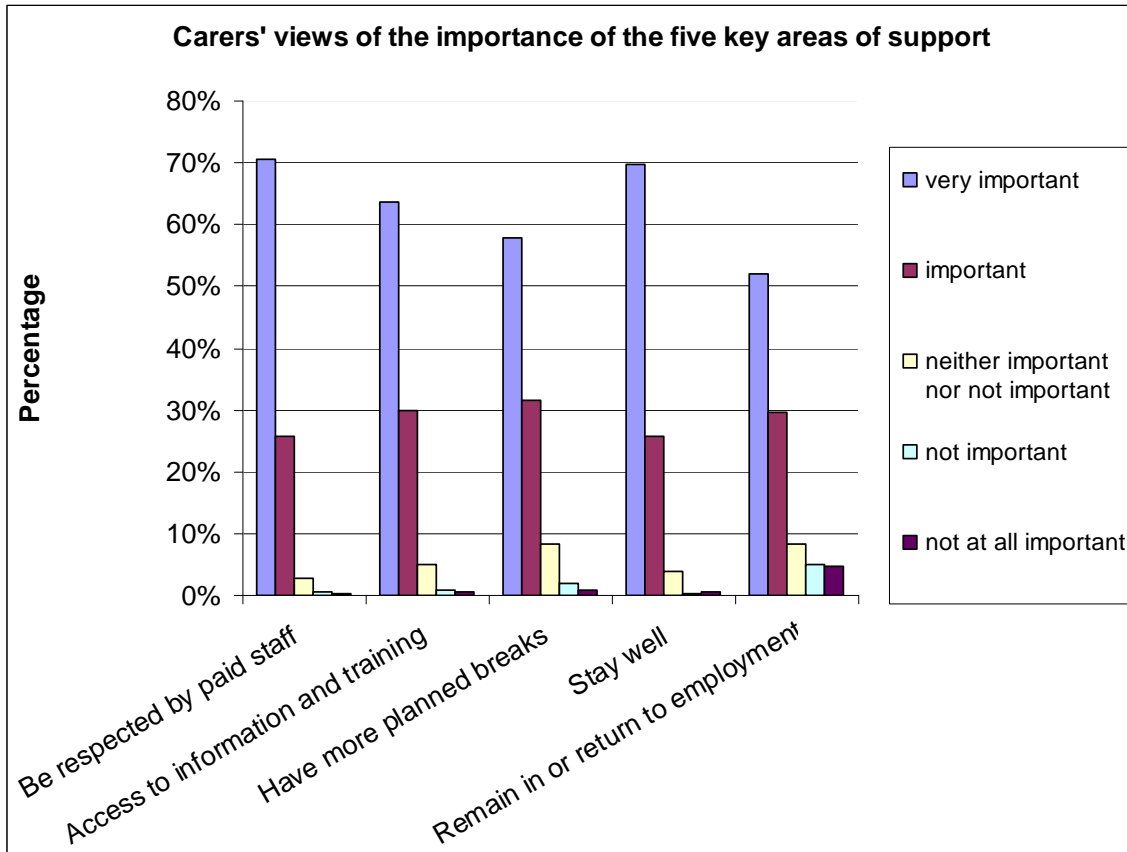
Who responded

920 completed surveys were returned (29%). Of the people who responded:

- three-quarters (74%) were women;
- half were over 65, and only 3% were under 35;
- around 95% identified themselves as white British; and
- 21% described themselves as disabled.

We had replies from all areas of East Sussex, with the most coming from around Eastbourne, Bexhill, Seaford, and Hastings. Replies were received from right across the county, including Groombridge, Wivelsfield and Camber.

Phase One: what we learned



Carers want to be respected and listened to...

“Carers’ knowledge, expertise and opinions should be acknowledged and listened to and taken into consideration when services ... are being considered, not ignored as happens at the moment”

Carers want to be listened to and have their views taken into account, to have their own support needs recognised, and for there to be better sharing of information between carers and ‘professionals’. In particular, carers said sometimes they don’t feel listened to and taken seriously by their GPs.

“Not to be patronised by someone on a first visit who has never met the person I care for. In this instance I am the most experienced on care”

Carers want to stay mentally and physically well...

“Someone to share the load, someone to talk to who understands your problems”

Carers said the best way of achieving this was by having more breaks (see below). They also wanted more access to healthy, relaxing or stimulating activities, and would like a regular visit from someone to see how they’re doing.

Access to emotional support from other carers was highly valued. Both focus groups mentioned the importance of peer support, and many carers also felt voluntary organisations gave much-needed support: often people said it was important just to know someone would be there to listen and advise in times of need.

“Clubs or groups where carers can meet other carers in the same situations, timed to fit in with the taking and collecting of the [cared for] person. Social meetings for carers – possibly with organised transport”

Carers want more breaks...

“I would like to be able to have occasional Saturdays off but am not often able to find carers to come in to sit with my husband”

Having planned breaks was ranked the fourth most important thing out of the five areas we asked carers about, but carers also gave breaks and respite great importance in relation to keeping mentally and physically well. Considering these questions together, having more breaks was actually one of the most important things mentioned. Sadly, more than one in ten carers said they very rarely, if ever, get a break.

Carers told us the best ways to provide more breaks are to:
ensure breaks are regular and reliable (not cancelled or changed at the last minute);
provide more financial assistance to have breaks;
make sure carers know their loved one will be well looked after while they have a break; and
have someone able to come to the home to look after the cared for person, particularly for older carers.

“Just knowing that my loved one was safe whilst I took some much needed time-out”

Carers want easy access to information and training...

“More frequent access for us both to a professional person to give us reassurance and some practical help”

Support could most be improved by providing information in different ways: a quarter of people preferred printed materials, while there was a fairly even split – about 10% each – between people wanting information from other carers, more time with professionals or information on the web or email.

Care for the Carers was mentioned numerous times as an excellent source of information and support. The most common barriers to getting more information and training were not knowing what was available and finding it difficult to get hold of because it is too expensive or complicated to leave the person being cared for. Practical training to support particular caring needs, for example safe lifting techniques, would be valued. The focus group of

carers from minority communities stressed that the information provided should be simpler and pay more attention to people's needs.

Carers want to be able to work if we choose...

“Flexible working hours and feeling secure that time off to care doesn't jeopardise career achievement opportunities”

Despite it being bottom of the priorities identified in the first stage of our consultation (probably because the majority of people who responded were no longer of working age), eight out of ten carers still felt support to get back to paid work was important.

We were told that having access to care for loved ones was the most useful thing that would help carers get out to work. Many people felt that losing the Carers' Allowance if they worked meant that they were in a difficult situation where it would not financially make sense for them to work.

Carers also told us employers need to recognise their needs by being more flexible and understanding, while one in ten carers said they couldn't possibly go out to work – for many, caring is a full-time job in itself.

Carers want financial support and recognition...

Finally, we asked if anything was missing from our list of five areas of support. Carers were clear that more financial support was needed. While we heard carers' concerns about not being fairly financially rewarded or recognised for the work caring involves, financial benefits are not part of the remit of health and social-care services. The Government has promised to review the Carers' Allowance in 2011...and the Council will focus on supporting carers in other practical ways.

What we did next

Feedback for participants was sent to the Care for the Carers and Rethink mailing lists in April/May 2009, and we put an article in CareLine, Your County and Brief Encounter (for East Sussex County Council staff). The Council website was updated with feedback documents including the raw data from people's questionnaire responses and a leaflet outlining key findings. We also provided feedback directly to people who participated in the events we ran.

You can find these documents here:

<http://www.eastsussex.gov.uk/yourcouncil/consultation/2009/supportforcarers>

A draft plan for support for carers from 2010-2015 (the Joint Commissioning Strategy for Carers) was drawn up based on what carers told us in Phase One of the consultation, as

well as the Government's priorities for support. To check we had understood carers' needs correctly, we tested the draft plan in Phase Two of the consultation.

Phase Two – the public: what we did and who responded

We designed another simple questionnaire to check our draft plans were correct. We also asked again for comments about anything we were missing out. Instead of mailing this to the same carers we had already consulted with, we made the questionnaire available on the Council's website, publicised it in local newspapers, and sent it to community and voluntary organisations, GP's surgeries, pharmacies, Community Matrons, and Citizens' Advice Bureaux . We also put articles in a range of community and interest-based newsletters and on local organisations' websites.

During a three month period (June-September 2009) we also took the questionnaire to a number of events across the county in order to reach out to as many people as possible, with a particular attempt to focus on younger people, and people from black and minority ethnic communities (given the low response rate from these groups to our first questionnaire).

These included: visits to three rural villages with a Carers' Consultation Bus, attendance at the St Leonards Festival, East Sussex Seniors Forum's Older People's Engagement Day, all the local Partnership Board meetings and sub-group meetings where appropriate and a variety of voluntary sector coffee mornings and rural network meetings. We also asked local voluntary organisations, directly and via the local CVS, to participate in the consultation themselves.

We asked Care for the Carers to host a conference for carers, which was themed around the consultation, as well as providing information. The conference, which was held in Eastbourne, was publicised very widely through the press with a view to attracting carers who were not necessarily already in touch with Care for the Carers, and it was attended by approximately 50 carers as well as managers from local statutory services. Carers and managers discussed the key themes of the strategy as it affected them in terms of the care group of the person cared for.

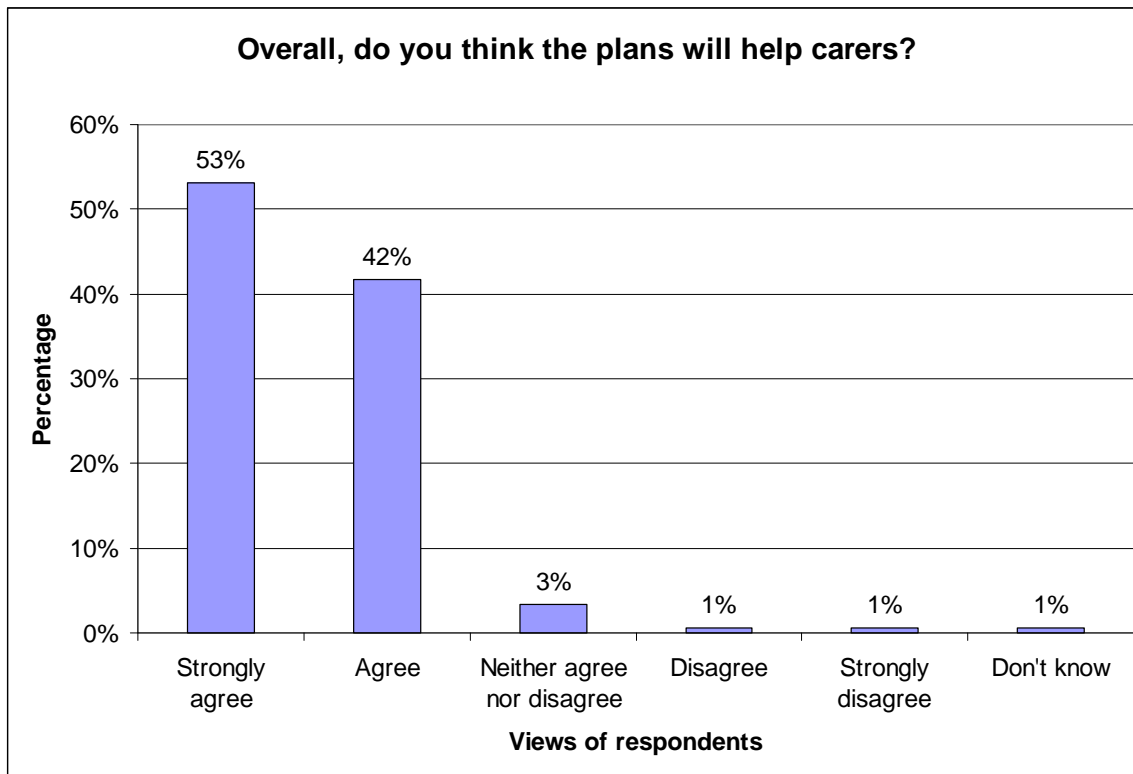
Who responded

185 completed surveys were returned. Of the people who responded:

- three-quarters (61%) were women;
- 48% were over 65, and 3.5% were under 35;
- 92% identified themselves as white British; and
- 21% described themselves as disabled.

The majority of responses came from around Bexhill and Hastings.

Phase Two: what we learned

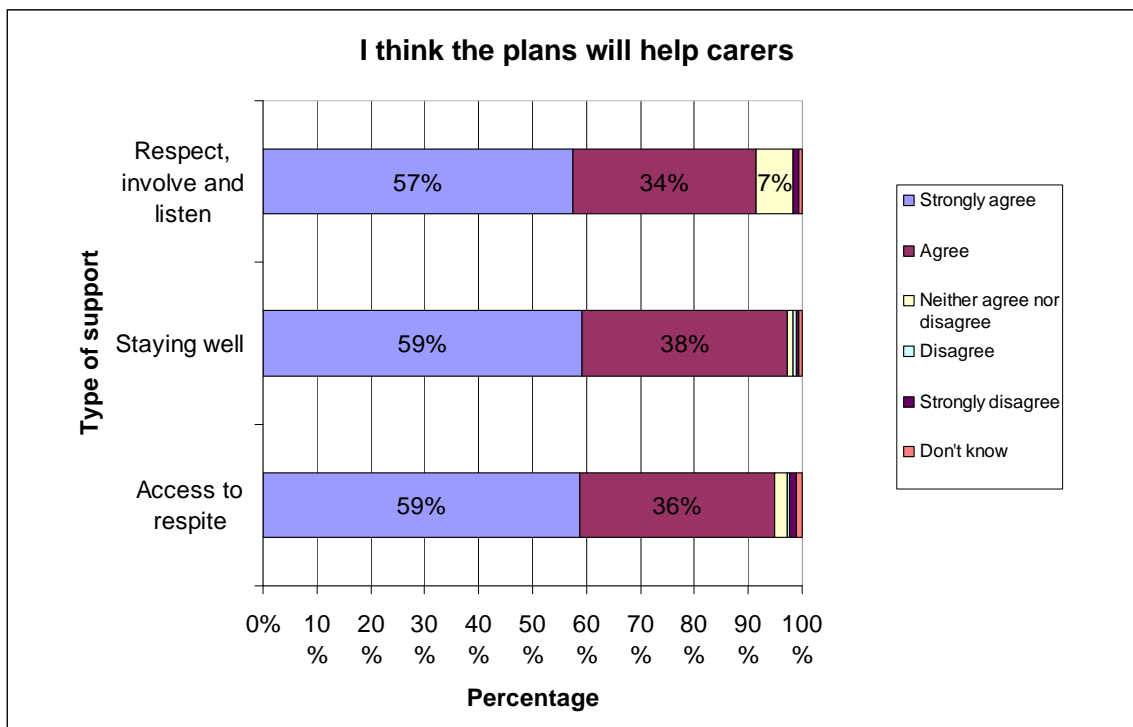


People who responded seemed to think our plans would help carers. This gives us a good sense that we are moving forward with a strategy that will provide the support that carers need.

The questionnaire set out our plans in the three most important areas identified during Phase One, namely:

- Staying mentally and physically well.
- Better access to breaks and respite.
- Being respected, involved and listened to.

This next graph shows the proportions of people who felt the different parts of our plan would help carers:



Many people added useful comments about what was important to them under each of these three key areas. These are the most commonly mentioned themes that we noted:

Access to respite/breaks

The top themes that emerged from survey respondents’ comments about our plans to improve respite are as follows:

Organising and implementation of plans (23 responses)

How will these plans be implemented? There was some scepticism about the plans, because respondents were unsure of how they would be made a reality:

“Plans need putting in force not stored as pipe dreams for the future. It is now today we need help or where 1 is ill there will be 2 soon”

Funding costs (16 responses)

Affordability and fair pricing are crucial to service users if plans are to be implemented:

“is not clear as to whether you are only going to make an annual charge if you need to use the service. Wouldn't it be more suitable to make a charge each time needed”

Cared for person’s needs (15 responses)

Considering the specific needs of the person who the carer cares for; when devising respite schemes for carers. Also looking at the impact of respite on the cared for individual:

“Will substitute carers be able to deal properly with client who perhaps has MS or a stoma,

Aspergers syndrome etc. It is of little use putting in a substitute carer who is out of their depth and can only deal with household chores etc”

Staying well

The top six themes are included below (we cannot separate a top five due to similar numbers of comments):

Scepticism over the implementation of the plans (20 responses)

Concern over how the plans will be implemented and how likely they are to be carried out. People seem concerned that they have seen little change over the preceding years and are doubtful they’ll see it now:

“These plans will only help if they are carried through”

Role of the third sector and not-for-profit (organizations like Crossroads, Care for the Carers) (11 responses)

Respondents valued the role of community and voluntary organisations and felt that some of the support in the plans could be provided by them:

“I would like to see the organisations like Care for the Carers and Crossroads doing these things. They already do them, are reliable, and carers, like me are already using them”

Training-both of carers and supplied care staff (11 responses)

Carers would value training on how best to support their loved-ones as well as making sure care staff are well-trained to deal with specific, often complex, conditions:

“I asked for training on my first assessment form. Carer's need to know how best to handle difficult situations”

Proactive support and action (11 responses)

Approaching carers before issues arise, providing information about support services:

“Is it possible to have a proactive health professional (much like a health advisor to a new mum) who contacts the carer regularly in the first months, then regularly throughout their time as a carer”

In the **Carers Workshops**, each group said that general support for carers and recognition of carers’ needs was vital. People commented that carers need to be involved in planning, to be assessed, and get good support from their GP and hospitals.

Respect, involve and listen to carers

The top five themes emerging from respondents comments are listed below:

Scepticism about plans and concerns over implementation of plans (20 responses)

Respondents felt that they had heard parts of the plan before. They felt a sense of scepticism over the plans or that the plans would be difficult to implement:

“I will believe when I see it. I have done everything on my own nearly”

Communication needs (information sharing, signposting for carers, direct pathways to talk to care management) (15 responses)

Carers often feel isolated because of a lack of communication. It is not easy for them to find the information they need to make decisions. Carers also want direct contact with those responsible for providing care:

“We need to know how we can speak directly to health and social care managers”

Participants in the **Carers’ Workshops** also identified the issue of access to advice and communication as extremely important to them. Communication between services (for example on discharge from hospital) was raised as an area for improvement as well.

Inclusivity of carers’ and cared-for’s needs (11 responses)

Considering the needs of carers in tandem with those who they care for:

“It is very important to listen to carers as well as the one who is being cared for”

Carers as experts (11 responses)

Carers should be treated as knowledgeable about their own needs and/or the person who they care for:

“Getting medical staff to accept that the 'carer' is an expert in the person cared for would be a big step”

Views of organisations

Care for the Carers welcomed “the general tone and direction” of our plans. They asked that we work with them to decide how best to put them into practice, and to be clear about the role of the Carers’ Strategy Group in producing the plan. They also made a useful point about making sure this strategy works alongside other plans (such as for people with learning disabilities or mental health problems). We will continue to work closely with them.

ReThink put forward a number of arguments about support for people with mental health conditions. In particular, they raise the issue of scant home-based respite provision for carers of people with mental health conditions. They say:

“...there seems a reluctance to provide it, presumably because of the increased risk... This may take the form of aggression, of self-harm or suicide, or other risky behaviours...However clearly there is a link between the stress on the carer and the diminishing chances of a break for precisely these points”

They highlight a number of ways that ASC should respond to this unmet need, which will be taken into account.

What we've done as a result

Our new strategy will soon be available on the Council website. Visit <http://www.eastsussex.gov.uk/yourcouncil/consultation/2009/supportforcarers>

We hope you will clearly see how it responds to the concerns of carers that have been set out in this report. We will write an annual Action Plan that will address each of the points in the strategy and we will closely monitor progress against this.

We have taken the views expressed throughout this consultation and used them to ensure our plans are correct for carers. The many hundreds of comments we have received will also be useful when we plan how to put this strategy into action. We feel we have a wealth of understanding of what can help or hinder carers, and evidence about what carers want that will be useful to secure continued funding for carers' services.

There are a number of very specific ways we have responded to what carers told us:

You said...	We will...
We need more flexible access to respite care to allow us to have breaks. We need emergency respite if we need to get out suddenly.	Commission (buy) a range of individual flexible services. Strengthen the emergency respite care system. Set up an Action Group to take this work forward.
Health service staff, especially GPs, do not always value carers' expertise or recognise carers' needs.	Set up staff training to encourage better ways of working between health a social care professionals and carers. Strengthen links between GPs and hospitals so carers get a better deal. Set up an Action Group to take this forward.
Social care services do not provide enough support for carers.	Make sure social care teams are aware of carers' support needs and what they are entitled to. Make sure all services provided by Adult Social Care make reference to carers and recognise their support needs. Make sure new government initiatives (such as Putting People First) pay particular attention to carers' needs.
We really value the support available from the voluntary sector (charities and community organisations).	Continue to provide services through respected voluntary sector organisations wherever possible.

We also really value the Carers' Support Grant from the Council	Continue with and improve this system.
We want to be respected by social care staff	Improve and extend staff training to be sure it includes a better understanding of carers and the issues that affect them, as well as being clear that carers are to be treated with dignity and respect, as partners in care, at all times.
We want carers to have a louder voice and more say in what goes on that affects us and our loved ones.	Set up new ways to reach out to more carers so that they can have opportunities to give us their views and hear about our plans – we will also strengthen the ways we work with our partners to ensure everyone understands their roles and responsibilities.
We want more information, more easily available, about the support we can get.	Make information more readily available, in a number of formats to suit carers, and distributed more widely and effectively. Set up an Action Group to take this forward.

Next steps

If you are an individual or from an organisation that has taken part in this consultation, thank you.

If you would like any more information about what we found out in this consultation and how we plan to move forward, please contact us at the address below.

We will be making action plans based on the issues carers' have identified. We will continue to work closely with organisations that represent carers' views, and will ask carers themselves to help us monitor our progress. If you would like to be kept informed and have more opportunities to share your views with us, or if you have any comments on this booklet, please email or write to us:

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References

¹ In Poor Health (Carers UK) 2004; University of Brighton study, 2006

² Valuing Carers (Carers UK) 2007

³ Carers (Equal Opportunities) Act, 2004; Work and Families Act, 2006

⁴ Equality Bill, 2009

⁵ Our Health, Our Care, Our Say, 2006; Putting People First, 2007; Putting People First without putting carers second (Princess Royal Trust for Carers), 2009

⁶ Putting People First, 2007

⁷ Carers at the heart of 21st century families and communities, 2008