

What you told us about....

Improving support for Carers

In February 2009, we asked you how we could improve the support we provide in the five areas the Government believes are most important for carers' well-being. We used a questionnaire to gather a wide range of views from carers across East Sussex, and we held two focus groups where older carers from rural parts of the county and carers from minority communities gave us their views.

If you took part, thank you very much. We've listened to your responses and this leaflet will tell you briefly what we heard and what we'll do with the information. You'll also find full detailed results on our website: www.eastsussex.gov.uk/haveyoursay

We are now moving into the second stage of this consultation, which is open to all members of the public. Your views have been used to develop a new draft strategy for supporting carers over the next five years, and we want to check that our plans fit in with the priorities identified.

Have your say on these vital issues for carers online here:
www.eastsussex.gov.uk/haveyoursay

Or contact us to request a copy of the questionnaire:
Write to: Debbie Charman (Strategic Commissioning Manager for Carers), Adult Social Care, A Floor, North Block, PO Box 5, County Hall, FREEPOST LW134, Lewes BN7 1BR
Email: debbie.charman@eastsussex.gov.uk

Who responded?

Of the 3,200 surveys that were sent out to mailing lists from Care for the Carers and ReThink (organisations that support carers in East Sussex):

- 920 completed surveys were returned (29%);
- three-quarters (74%) of people who responded were women;
- 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. Your replies were received from as far afield as Groombridge, Wivelsfield and Camber.

Half of our respondents were over 65, and only 3% were under 35. This doesn't accurately reflect the ages of carers across the county. Similarly, carers from minority communities were under-represented. To address this, we'll seek out the views of younger people and people from minority communities in stage two of the consultation.

You told us...

We 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"

Your answers showed you felt the most important thing was to be respected by paid staff as expert partners in care.

To improve this, you want to be listened to and have your views taken into account, to have your own support needs recognised, and

for there to be better sharing of information between carers and 'professionals'. In particular, you said sometimes you feel you're not listened to and taken seriously by your GP.

"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"

We will tell you about our ideas to improve your experience of feeling respected, involved and listened to by both health and social care staff in the second stage of this consultation.

We want to stay mentally and physically well...

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

You told us the second most important thing to you was to have support to help stay mentally and physically well. You said the best way of achieving this was by having more breaks. You also wanted more access to healthy, relaxing or stimulating activities, and would like a regular visit from someone to see how you're doing.

Access to emotional support from other carers was highly valued. Both focus groups mentioned the importance of peer support, and many of you also felt voluntary organisations gave much-needed support: often you 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...person. Social meetings for carers – possibly with organised transport"

In stage two, we will be setting out our plans to help you feel emotionally supported, as well as helping you find time for yourself to do activities that keep you well.

We 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"

You told us that having planned breaks was only the fourth most important thing out of the five areas we asked you about. But, you also gave breaks and respite great importance in relation to keeping you mentally and physically well. Considering these questions together, breaks were actually one of the most important things to you. Sadly, more than one in ten of you told us you very rarely, if ever, get a break.

You felt 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"

Our second questionnaire will ask you for your thoughts about our plans to help you have more breaks (respite).

We 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”

Having easy access to information and training was the third most important thing identified. You said support could most be improved by providing information in different ways: a quarter of you prefer 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 you care for. Practical training to support your particular caring needs, for example safe lifting techniques, would be valued by many of you. The focus group of carers from minority communities stressed that the information provided should be simpler and pay more attention to people's needs.

Our new plans outline our commitment to make access to useful information easier. We will also investigate how we can provide more practical training for you.

We 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 of you still felt support to get back to work was important.

You said that having access to care for your loved one was the most useful thing that would help you get out to work, and 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.

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

For carers who want to work, more flexible respite care, as mentioned above, may be helpful. You will be able to comment on our plans to provide this in stage two of this consultation.

We want financial support and recognition...

Finally, we asked if anything was missing from our list of five areas of support. You told us clearly that more financial support was needed.

We hear your concerns that you are not fairly rewarded financially for the work that you do as a carer. The issue of financial benefits is outside the remit of health and social-care services, but the Government has promised to review the Carers' Allowance as part of a review of all benefits in 2011. In the meantime, we will focus on supporting carers in other practical ways.

Get support now if you need it

Around one in ten of you told us you received no support at all. We hope that you have since been in touch with us to find out about the support that's available. If you haven't already, please call Social Care Direct on 0345 60 80 190 for advice or to have an assessment of your needs done. Alternatively, 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.

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

What happens next?

Thanks again if you took part in the first stage of this consultation. Based on your responses to stage one, we have a clearer idea of your priorities.

To finalise our new ideas for supporting carers, in stage two we will be asking for your comments on our plans, which focus on:

- improving your access to breaks and respite care;
- helping you stay mentally and physically well; and
- ensuring you are respected, involved and listened to by health and social care professionals.

It is unlikely that we will have extra money to provide these improved services. So we are aiming to use available money in the most effective ways possible to ensure fair access to services for all carers. We hope you will find the time to give us more information about the areas that are important to you, by completing our second questionnaire by **8 September 2009**, when the consultation closes.

Improved support for carers

We will use your responses from stage one and two of our consultation to develop our final plan, and we will do our best to make sure it works for all carers equally, regardless of personal factors like age, race, disability or **your** location in the county.

We will let you know about our new plan in November, via Care for the Carers, ReThink and the East Sussex County Council website.

Your views are important to us and help us provide health and social care services that give you the support you need when you need it.

Thank you.

Please take part in the second stage of this consultation.

Online: www.eastsussex.gov.uk/haveyoursay

To request a copy of the questionnaire, write to: Debbie Charman (Strategic Commissioning Manager for Carers), Floor A, North Block, County Hall, St Anne's Crescent, Lewes BN7 1UE

Or email: debbie.charman@eastsussex.gov.uk