

Carers Day: Summary Report

On Carers Day 2011, carers were asked to consider the 'true face of carers' through discussions around the following questions:

- How do carers think society sees them?
- What is the reality of caring in the UK in 2011?
- What qualities do carers need?
- What are the biggest surprises that you encounter when you become a carer?
- What can really make a difference to carer's lives?
- What help do carers receive from statutory agencies, voluntary organisations, local and national government?

This report pulls together some of the themes that emerged over the course of the day, helping to provide a focus for progressing services for carers and may be of interest to carers, strategic partners and other organisations working with carers.

How being a carer makes me feel and the qualities carers need

Some carers commented that only those in the same situation can truly understand how they feel. Some feel isolated by their caring role, or frustrated by the difficulties they face accessing support.

There was also a feeling that carers have to reach rock bottom before they get help, which results in feelings of stress, pressure and powerlessness.

Some carers had been surprised by how little time was left for a personal life once they became a carer. This can result in changes to relationships, with carers taking on new or changed roles and responsibilities

Carers describe a myriad of qualities that are needed to sustain their caring roles. Patience was the most commonly cited, closely followed by acceptance, understanding and commitment. Other traits that were seen as positive include a sense of humour, energy, love, enterprise and optimism. It was also noted that good time-management, resilience and an awareness of your strengths and limits as a carer are important.

Several traits relate to how carers feel they have to battle to be heard: being outspoken, having a thick skin, being forceful, persistent and tenacious.

On a positive note, some carers described the satisfaction they get from being a carer- *"For me, It's fun"*, another noted being surprised by their own strength.

How society sees me as a carer

Several carers felt that others in society do not recognise them at all: *"We're invisible... not on the radar"*. Others used the phrases *"hidden army"* or *"unsung heroes"* to describe the place of carers in society. Although the needs of the person cared for may be evident to others, the personal needs of the carer can be overlooked.

Others have experienced a lack of understanding and tolerance rather than a lack of awareness, with a feeling that many people not in this situation themselves don't appreciate the difference between paid and unpaid carers. Carers not living with the person they care for have also found they are not recognised by others as carers, as have parents caring for children with disabilities.

Many carers described having close friends and family that understood and supported their situations- however, some felt that in today's society many carers don't have the support of an extended family network. Furthermore, others outside of the carer's close circle sometimes don't know how to help, or prefer not to know- *"caring is seen as something that happens to others"*.

Carers also felt that the national government has not meeting its promises to carers, although others acknowledged that the government are beginning to show more recognition.

The financial impact of caring

Some carers reported a drop in income as a result of being a carer, with several commenting on the importance of accessible information about the benefits and allowances that they or their cared for person may be eligible for. Another had found that people outside of the situation believe that carers *"claim for everything"*.

Carers Allowance sparked a range of responses with some seeing this as a sign of recognition and a source of support, while others felt the amount paid is inadequate and that it should not be a means tested benefit. Another carer felt that means testing for adaptations to the home was also unfair.

Where carers receive direct payments they were seen as a helpful and effective form of support.

More generally, there were comments that statutory agencies focus too much on budgets and not enough on carers as individuals, and that they have found accessing financial support more difficult in recent times.

How Health professionals treat me as a carer

There were a number of discussions about how GPs respond to carers, quite likely because they are the key health professional that most carers come into contact with either as a result of their own health needs or those of the person they care for. Some praised their doctors for asking how they are and for having awareness posters and information in their surgeries. They were generally found to be better at recognising carers which may be a positive reflection on the work that has been done through the Investors in Carers award scheme. However, some carers had different experiences with GPs not recognising them and called for more training for GPs.

Elsewhere within Health, carers appreciated when district nurses are able to signpost them to other services. Community Resource Teams were also identified for their good practice in sharing information holistically and linking services together. However this good practice was not a universal experience- one carer had found the physiotherapist supporting the cared for did not communicate well with them as an expert carer, and communication between teams around transfer of care from hospitals is not always effective.

What I think about the services I receive

Many of the carers in attendance access at least one service that supports them as a carer, or a service for the person they care for that allows them some respite. Supported transport such as the Green Dragon Bus and Cars for Carers are appreciated, as are replacement care or sitting services provided by a number of organisations including Crossroads. Other services carers specifically mentioned included Action for Children, Mind, PAVS and Hafal- and overall the voluntary sector received high praise from the carers. Being able to access day centres, family aides, holiday play schemes and almoners also helps carers.

Not all carers have found support easy to access. Key issues are the timeliness of support, weaknesses in support around times of transition, a lack of coordination between services and a feeling that carers must “fight” to receive support, or that they are “*passed from pillar to post*”.

Other frustrations include delays or lack of a diagnosis for the cared for person, a lack of rehab facilities after strokes, and poor continuity of replacement carers. Whilst some carers had found carers assessments beneficial, others commented on the length of time it had taken to receive one.

The information and knowledge I need as a carer

Lots of carers talked about the importance of having access to the right information. An ability to research was cited as important for carers. Having to seek out this information can be difficult however- “*information should be provided by your GP or social worker, you shouldn't have to go looking for it*”. Carers appreciate being signposted to other services and being supported through training.

Suggestions were given for ways to improve the provision of information to carers: Carers need more training and hands on advice and guidance; information could be more detailed- for example, providing more details of the activities of local branches of a service rather than contact details of national societies. Carers would also appreciate a “one stop shop” to gain access to information and services.

Finally it was felt that the national media could do much more to raise public awareness of carers. Although this even took place during Carers Week, only one carer had seen anything about this in the national media.