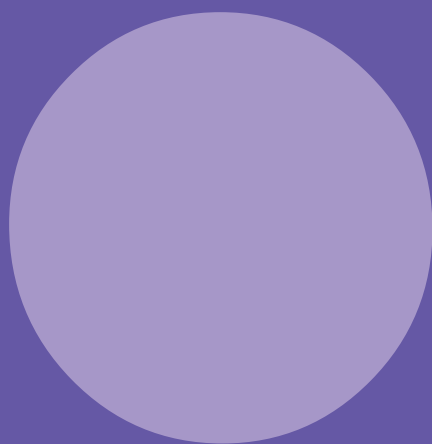


connecting with carers

**Carers of people with epilepsy share
their needs and experiences**



January 2012



connecting with carers

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introduction

During January to March 2011 Epilepsy Society delivered a project focusing on the needs - and experiences - of carers of people with epilepsy in the UK.

Whilst many individuals with epilepsy do not have, or need, someone to be their 'carer', for some individuals their epilepsy affects them in such a way that a carer provides vital help and support, without which life would be very difficult. For some this help might be in the short-term; for others it may be life-long.

The project, funded by the Department of Health's Reaching out to Carers Innovation Fund, gave us the unique opportunity to dedicate time and resources to seeking the views and experiences of carers of people with epilepsy. It allowed us to focus on identifying the information and support needs of carers, and why caring for someone with epilepsy is different to caring for someone with another condition.

We believe that being awarded the project grant recognised two important points.

- Carers are an important group of individuals who provide valuable support to some individuals with epilepsy, and should be recognised for their importance and contribution.
- This group deserves specific focus to identify their needs both as individuals and as care-providers to people with epilepsy, and to identify ways in which they can be best supported both in this role and as individuals.

This report brings together the findings of this project. Presented here are the results of surveys and focus groups, alongside the real experiences of carers, in their own voices.

Rona Eade
Elaine Falkner
Bridget Gardiner

"There are around 6 million carers in the UK."

NHS Choices

"A carer is someone who looks after a family member, partner or friend who needs help because of a health condition, disability or frailty, and who would not be able to manage without this help. All the care they give is unpaid."

Epilepsy Society

foreword

The first step towards being able to provide first-class services and support to carers is to determine their needs, which is why I applaud Epilepsy Society for commissioning this report.

At Crossroads Care we pride ourselves on being the people that carers turn to, and we are committed to developing our understanding of, and support for, carers.

But we are only one charity, and we're increasingly keen to work with other condition specific charities to expand our collective knowledge of carers and their needs. So when we were approached by Epilepsy Society to help recruit carers for their research, there was no hesitation about getting involved.

From our work we know that carers are a huge source of support for the people they care for, helping them with a wide range of tasks, from providing day in, day out practical and emotional support, to negotiating with health care professionals around care and treatment packages when necessary.

All this comes at no little cost to the carer themselves, who often selflessly sacrifice their own health, wellbeing and social life to support the one they love.

Despite the huge contribution that carers make to the economy, a contribution which is estimated at £119 billion a year, they can still feel incredibly undervalued. As this research shows, this is no less the case for those who care for people with epilepsy.

The report makes a strong argument for epilepsy to be seen as a special case. Yes, all carers have to deal with changing situations on a daily basis, adapting their own lives to make sure they can provide the support that is needed. But for carers of those with epilepsy this is even more pronounced, due to the highly unpredictable nature of the illness.

There's no easy fix for carers, and what works for one may not be appropriate for another. However, that doesn't mean that appropriate support can not be provided to carers of those with epilepsy.

The Department of Health has made a number of promises to carers within its Carers Strategy that would greatly improve services and support for this key group. But even if all recommendations were met, there would still be a need for support from charities such as Crossroads Care and Epilepsy Society.

The beauty of this report is that it has truly connected with carers. I was moved by the case studies within it, and its findings should galvanise us all to pledge ongoing support to this group.

Epilepsy Society has already made strong, strident steps in that direction, developing new sections of its website and providing specific resources for carers of people with epilepsy.

Its work should be applauded, and I am confident that this report will continue to influence service development for carers of those with epilepsy in the months and years to come.

Anne Roberts

Anne Roberts
Chief Executive
Crossroads Care



thanks

We would like to thank the following organisations and people for their help, without whom the project would not have been as valuable or productive as it was.

Epilepsy Society's regional service volunteers who handed out surveys and encouraged people to complete them. *You are our 'feet on the ground'.*

Everyone on the project steering group, especially Ali, Anne and Margaret. *You helped us steer the direction of the project, and gave guiding perspectives on the needs of carers to help keep our focus on this group.*

All the individual carers, people with epilepsy and healthcare professionals who completed an online survey. *The honest contributions you kindly shared gave us so much insight into caring for someone with epilepsy.*

Everyone who attended the focus groups. *Your contributions helped make the focus group a successful, inspiring and productive day.*

And the following organisations who helped to promote the project and the surveys. *Thank you for helping us to get so many responses!*

Carers Direct
Crossroads Care
The Encephalitis Society
Epilepsy Specialist Nurses Association
Epilepsy Wales
HFT - creatively supporting adults with learning disabilities
International League against Epilepsy UK chapter and GP Society
Jan-net
Joint Epilepsy Council
The Princess Royal Trust for Carers

summary – what did we learn?

This project was about exploring the impact of caring for a person with epilepsy upon the carer. We focused on their experiences and needs, as well as their wishes and aspirations for the future. We found many interesting, and some unexpected, outcomes.

- Carers often find caring both rewarding and challenging.
- Many carers help the cared-for person in both practical and emotional ways, from help with physical and day-to-day tasks to meeting the often complex emotional and support needs of the person they care for.
- Carers can feel unsupported by the services designed to support and help individuals with epilepsy, and they feel that there are not enough services for carers.
- While many carers agree with the key messages in the Department of Health's Carers' Strategy*, they feel that recognition, help and support for carers is not provided. There is much agreement that carers, and their needs, are not well recognised but equally, carers are reluctant to seek help and support for themselves.
- Many carers feel that there is a lack of knowledge about epilepsy within the services. This leads to a perceived or actual lack of competency in services, and also in confidence in asking for, or accepting help from, such services.
- In many respects, epilepsy is a 'special case' as many challenges facing carers are epilepsy-specific. For example, the need for care can vary greatly from one individual to another due to the variable nature of the condition. Needs can also vary *within* an individual at different times.
- The need for care can be unpredictable and so cannot be planned for. For many carers this has an impact on their employment, as employers may not understand that care cannot always be planned, and carers may need time off without notice. Some employers are understanding, while others are not, which can cause an additional burden on carers.
- As epilepsy is often poorly understood by service-providers, it can be a challenge for carers to demonstrate the need for care in a condition which is often 'invisible' for much of the time.
- Carers feel that they would benefit from proactive offers of help and support, information and signposting, and opportunities to explore their own needs. All of which is fundamental to carers having a good quality of life for themselves alongside their caring role.

why epilepsy is a special case

Through the course of the project an important point became obvious. Not only was the project an opportunity to identify and acknowledge the role of carers and the impact of caring upon an individual, it also became clear that, in many ways, epilepsy is a condition that poses unique challenges to carers.

Through the project, we found that carers were identifying with many key issues raised in the Department of Health Carers Strategy*. But other issues seemed to be directly linked with the cared-for person having epilepsy as a condition.

Many of the experiences shared at the focus group resonated with others in the group. Some experiences were due to a lack of knowledge about epilepsy in the general population, the stigma surrounding epilepsy, and how people often do not understand that some people with epilepsy need carers. Some issues were around the lack of expertise amongst professional care staff, meaning that carers are often reluctant to leave the individual with epilepsy in the care of another. Others centred around the difficulties faced because of the unpredictable nature of epilepsy.

Why is epilepsy a special case?

During the project we identified several reasons why epilepsy is a 'special case' and why the help that carers of people with epilepsy need can be fundamentally different to other health conditions.

Epilepsy is a group of conditions that sit on a spectrum in terms of their cause, symptoms and impact, so it does not follow a predictable course. For some, seizures will become controlled and their epilepsy will have little or no impact on them. Others may need support when seizures happen, which may include the need for emergency medication to be given in the context of prolonged seizures. For others, their epilepsy may come alongside other conditions, and may mean that they need a full time carer or residential care service. The added complication of not always being able to predict the course of epilepsy for an individual, means that the care they need can *change* over time.

Seizures can happen spontaneously, out of the blue and without warning. This means that the *need* for care cannot be predicted. For some, care will be needed instantly a seizure happens, and the individual may need someone to keep them safe, and look after them whilst they recover. For some, their seizures may be prolonged or repeated, and there is a need for emergency medication to stop them. Such a situation can be life-threatening and so the need for a carer is urgent and crucial.

The experiences of many of the carers suggested that carers are not supported with information at the point at which the individual is diagnosed, so they do not realise or recognise that the term 'carer' might apply to them. The term 'carer' may be more easily recognised for those who support people with more visually 'obvious' conditions (such as for someone whose condition means that they use a wheelchair) rather than a condition like epilepsy where it is not obvious that someone has it (unless they have a seizure). The term 'carer' may also be linked closely to 'people with disabilities'. The term 'disabled' does not always easily fit with epilepsy. This is partly because epilepsy varies so greatly: for some their epilepsy will have little or no impact on them (and is not disabling) yet for others, their epilepsy has a long-term impact on them (and so they are disabled by it). An unwillingness to accept the term of 'carer' could be linked to the implications of the term 'disability'.

There is felt to be a lack of knowledge and understanding about epilepsy amongst the services set up to help and support carers, such as social care and respite services. Training within these services needs to be improved to increase the level of care provided to people with epilepsy. In addition, carers need to feel confident that the services are providing appropriate and personalised expert care. Only then will carers feel safer leaving their loved ones in someone else's care.

The needs of carers can change over time and at short notice, and therefore they need greater flexibility in the support they receive.

For all these reasons, epilepsy may be a 'special case' in terms of the needs of carers.

what is a carer?

Early in the project we set out to establish what we mean by the term 'carer'. We looked at definitions from some of the leading carers' organisations and reviewed them and developed a definition that we felt encompassed the complex nature of providing care for someone with epilepsy.

"A carer is someone who looks after a family member, partner or friend who needs help because of a health condition, disability or frailty, and who would not be able to manage without this help. All the care they give is unpaid."

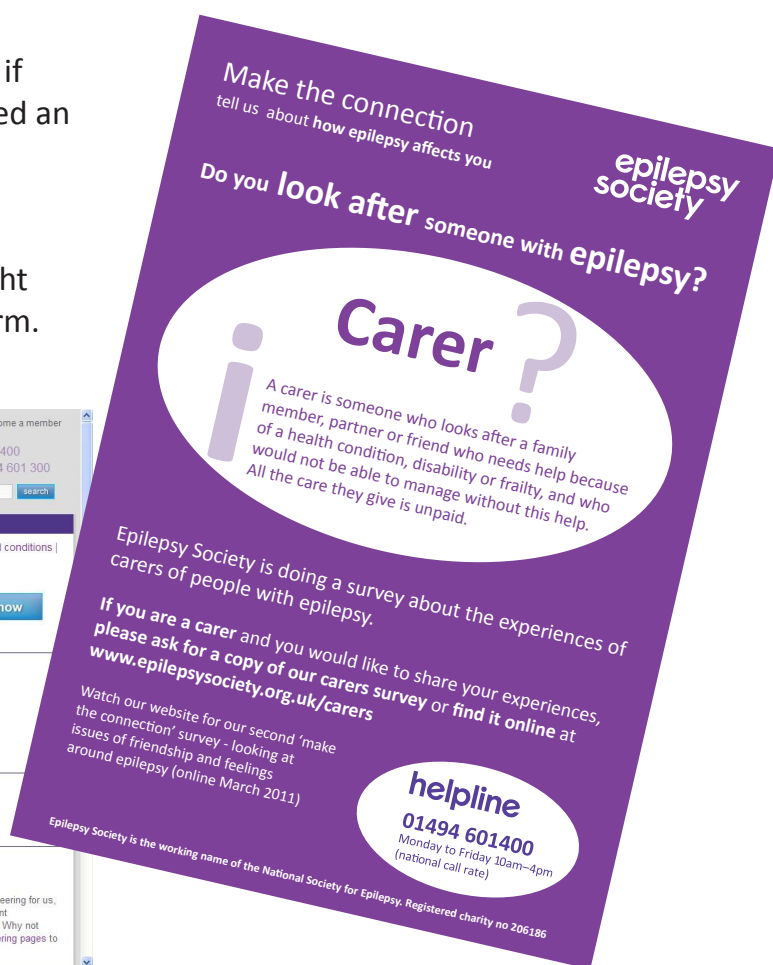
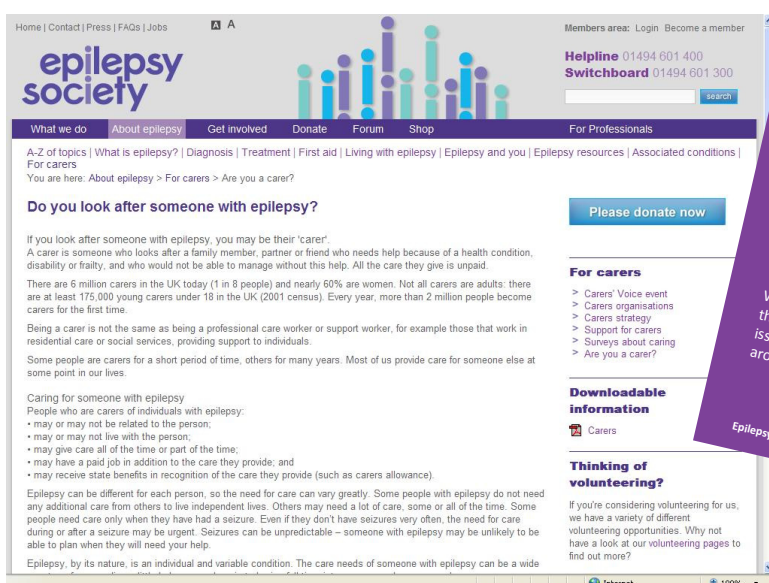
We used this definition when promoting the activities around the carers' project, including the surveys, focus group and new section of the website. For those who might not consider themselves to be a carer, we also included the question 'do you look after someone with epilepsy?'

As not everyone readily identifies with the term 'carer', and to avoid 'labelling' people as a carer if they are not comfortable with it, we also included an explanation of what we mean by the term.

On our website, we included details about what being a carer for an individual with epilepsy might entail, so that people might identify with the term.

"I am a mother first and foremost but with my carer's hat I do need to be proactive for my daughter".

Frederica, carer of an individual with epilepsy



Carers and professional care staff

During the project it became clear that some people use the term 'carer' to refer exclusively to people who care for someone in a paid capacity, such as when working in a residential care home.

It is important to differentiate between individuals who care for someone as part of their job (often referred to as 'professional care staff'), and those who care for a friend or relative voluntarily and are not paid (and who meet our definition of a 'carer'). Only individuals who are carers would be entitled to statutory support and help, such as a carers' assessment or carers' allowance.

Through the information on the carer's section of the website, which was developed during the course of the project, we tried to make these differences clear.

"Being a carer is not the same as being a professional care worker or support worker, for example those that work in residential care or social services, providing support to individuals."

Are you a carer? www.epilepsysociety.org.uk/carers

We also included information about sources of help and support for carers, with links to carers' organisations and the Department of Health's Carers Strategy.

"I think it's important to identify yourself as a carer. You tend to be the intermediary with different hats. It is important to see the carer role as separate".

Caroline, carer of an individual with epilepsy

There is a difference between a 'carer who is a relative' (who has emotional involvement) and a 'professional carer' (who has a non-emotional involvement). Parents become carers when the amount of physical and emotional effects of epilepsy increase.

Feedback from the focus group

background to the project

Epilepsy affects not only the individual with the condition, but also their family, friends and those close to them. When an individual develops epilepsy, this may place family members or friends in the position of being a carer. Often this is without warning; without question; without choice. Many take this position without really noticing that they have taken on the role of a 'carer', and that their relationship has changed from that of parent, child, partner or friend, to that of a 'carer'. Many do not accept the name of 'carer' that goes with this position: do not identify themselves as a carer, and may not identify or consider important, the impact that caring for someone has on their life and relationship to that person.

At Epilepsy Society we see the impact that caring has on people who look after someone with epilepsy. Our vision reflects this; placing carers within our vision of a full life for people affected by epilepsy.

An individual with epilepsy's need for care varies from one person to another, can be unpredictable and can change over time. Needs that arise due to having epilepsy are on a spectrum: from having a shoulder to lean on or a gentle reminder to take medication, to taking an essential role in drawing up a care plan or giving emergency medication in potential life-threatening situations.

This project gave us an opportunity to focus on carers specifically: demonstrating what an important role they have, and to focus on their needs too. But to really know what the issues for carers are, and how they feel their caring role affects them, we needed to ask carers themselves.

Equipping carers with information and support for themselves is an important tool in both supporting the individual and in maintaining the wellbeing of the carer themselves.

Epilepsy Society's vision is a full life for everyone affected by epilepsy.

Epilepsy Society, 2011

"The Government wants carers to be able to maintain a life of their own alongside their caring responsibilities. It is keen to improve early identification of carers so that they can be supported in considering their various options and make informed choices."

Department of Health

Reaching out to Carers Innovation Fund

During 2010, the Department of Health identified funding to run projects that would help ‘reach out to carers’ and provide support, information and signposting for people with caring responsibilities.

The funding was targeted at helping to identify people who are carers early on in the diagnosis of the individual they care for, to help carers see themselves in this role, and to support them in their role as a carer.

In November 2010 we submitted a project proposal, which was successful. Our project was to run from January to March 2011.

The Carers’ Strategy

The ‘Reaching out to carers innovation fund’ was set against the backdrop of the government’s carers’ strategy.

The strategy, ‘Recognised, valued and supported: Next steps for the Carers Strategy’ was published by the Government in November 2010. This strategy sets out “how the Government will prioritise actions over the next four years to ensure the best possible outcomes for carers and those they support”. The scope of the strategy covered plans to better support carers in many areas across health, social care, education and services such as employment.

In developing the strategy, the Government considered the views from over 4,000 carers. From this they developed some key messages and actions for the future. These key messages include the following:

- carers need better and timely access to information;
- carers can often feel excluded by clinicians;
- carers often feel forced to give up work to care;
- carers often neglect their own health; and
- carers need breaks from caring.

The strategy leads on to identify four priority areas, which are discussed in more detail in section 3 (see page 26).

“Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.”

Carers at the heart of 21st Century families and communities, Department of Health, 2008.

The project aims and outcomes

The Carers Innovation Fund project allowed us to focus on carers of people with epilepsy: a group of people who often go unnoticed, unrecognised and unappreciated (often by carers themselves).

Through the project we wanted to focus on the experiences, needs and aspirations of carers. As we work closely with carers throughout their journey with epilepsy (through our membership, helpline, online forum, regional volunteers and supporters) we are well placed to engage with them, and the people they care for. We were also very fortunate to have support in promoting it from various epilepsy organisations, carers' organisations and other healthcare professionals.

Our project had three main objectives:

- to identify the experiences, needs and aspirations of people who care for someone with epilepsy, through engaging with carers directly;
- to identify ways in which Epilepsy Society can continue to best support people with epilepsy and their carers; and
- to report back to the Department of Health the views of carers of people with epilepsy.

Through the project we wanted to deliver several outcomes:

- to help carers of people with epilepsy to recognise themselves in a caring role, and to help them understand what help and support is available to them;
- to develop a section of our website specifically for carers of people with epilepsy, focusing strongly on providing information and signposting, to support them as individuals;
- to develop and distribute a new information card to signpost carers to sources of help;
- to develop and deliver an in-depth survey amongst carers, to understand what they do for the person they care for, to find out what information, help and support they want and get, and to understand the issues unique to supporting someone with epilepsy; and
- to engage with carers through focus groups to get in-depth feedback on the Government's Carers' Strategy, to see where this supports carers of people with epilepsy and where carers of people with epilepsy are unique in the issues they face.

Carrying out the project

The project was run over the course of three months, and spanned many areas within Epilepsy Society. Involving carers of people with epilepsy in the development and delivery of the project was important to ensure a genuine focus on the needs of carers.

To carry out the project we set up a steering group to oversee and direct the work to make sure it was feasible, achievable and would result in actions that Epilepsy Society can take forward into the future.

The teams involved in carrying out the project at Epilepsy Society included:

- the information team (who ran the online surveys, developed the project information resources and website content, and collated the results of the surveys);
- the regional services team (who helped promote and give out the surveys, and attended the focus groups);
- the helpline team (who have daily contact with people living with epilepsy and their carers, and were able to give insight into how epilepsy affects the carer); and
- the communications and website teams (who helped promote the surveys, develop and promote the carers' section of the website, and who generated press interest in the project).

"People say "Poor you – what a lot you have to cope with" as they go off to play golf! But how can people put themselves in your shoes? They can't understand your life. You feel normal when you are in a support group. Other people understand your problems."

Carer of an individual with epilepsy

Ali's story

I have eight year old twin boys, Adam and Archie, and a 12 year old son Harry. We live in a pretty village in Norfolk. Archie was diagnosed with hydrocephalus when he was just two years old. This means that he has a shunt fitted, just under the skin, on the right side of his head. This drains the excess fluid around his brain into his tummy.

Completely out of the blue Archie had a seizure in February 2008 when he was five.

The convulsing lasted for over an hour and he had to stay in hospital for four days. We were told it was probably a febrile convulsion (as he had a high temperature) but we later discovered that one in three people with hydrocephalus have seizures. Over the next six months Archie had two more long seizures and my husband and I had to give him buccal midazolam (an emergency medication given to stop prolonged seizures) to reduce the length of the seizures. After this it was decided that Archie should start taking medication for the seizures.

I don't think of myself as Archie's carer, I'm first and foremost his mum!

I don't think of myself as Archie's carer, I'm first and foremost his mum! Having twins, I have a direct comparison between the two boys. I realise that Archie needs more 'looking after' than his brother although I try not to be over-protective! However, there are certain things which we are conscious of. We always have Archie's emergency medication with us (in fact Archie usually carries it himself in his little red backpack). We always have our mobile with us so that should Archie need an ambulance we can make that call (and if the school needs to get hold of us, we're contactable). If we're going abroad, we make sure we know where the nearest neurological hospital is.

It is the unpredictability which makes epilepsy different from other conditions.

As Archie's seizures have been mainly during the night, we have subconsciously turned into lighter sleepers! We don't have an alarm but we do have finely tuned ears to the squeaking of Archie's bed! It has not been oiled for this very reason and when the squeaking is more than just a 'turning-over' or minor fidget, we seem to be up and by his bedside within seconds!

We also encourage Archie to be independent and remember to take his tablets by using a pill dispenser, although we check this and make sure he takes them at the same time each day.

It is the unpredictability which makes epilepsy different from other conditions. You can never totally relax because you just don't know when a seizure is going to happen and the possibility is always at the back of your mind. We try to avoid 'triggers' such as being over-tired by making sure Archie has enough sleep, even if it means that his twin sneaks down-stairs after Archie falls asleep, to stay up a bit later, without Archie knowing!

Archie's brothers are brilliant back-up alarms and always look out for him. They know what to do if Archie has a seizure and are keen to share their knowledge! I think that education and awareness of epilepsy needs to start early so that everyone has a basic understanding of what to do. Let's face it, it could happen to anyone, anywhere, anytime!

surveys

To understand the needs of carers and the effect of caring, we ran three online surveys to connect with carers, people with epilepsy and healthcare professionals, about the experiences of carers.

Using surveys allowed us to gather the views of many people while also giving them an opportunity to express their feelings and share their experiences. It also helped to demonstrate the value and importance of carers, to carers, people with epilepsy and healthcare professionals.

Through the surveys we were able to identify several different aspects of caring for people with epilepsy. This included the following:

- what caring means to carers (and the people they care for);
- what carers do for people with epilepsy (what is involved practically and emotionally in caring for someone with epilepsy);
- what needs carers have themselves and how these needs are met; and
- what, if any, unique challenges caring for someone with epilepsy presents.

Promoting the surveys

We were able to promote the surveys through several routes.

- Surveys were promoted on a carer-specific section of Epilepsy Society's website (developed for this project) and from the home page.
- Posters promoting the surveys were sent to our regional services volunteers to put up in clinics where we have information services. Some volunteers also promoted the surveys to local support groups.
- The surveys were featured in an Epilepsy Society e-newsletter sent out in February 2011 to our subscribers' mailing list, which includes individuals with epilepsy, their carers and healthcare professionals.

We were very fortunate in enlisting help from several organisations in promoting the surveys (see over).

"Caring for a loved one takes time and patience. It has ups and downs – is heart-breaking and heart-warming. There have been times when we see no light at the end of the tunnel – but somehow a spark comes through and we count our blessings again and keep going."

A carer of an individual with epilepsy.

- Carers Direct (part of NHS Choices) tweeted about us online and created two links from their website to ours;
- Crossroads Care added links from their website to ours;
- The Encephalitis Society added a link from their website to ours;
- Epilepsy Wales promoted our surveys through their website;
- the Epilepsy Specialist Nurses Association promoted the surveys to members;
- the secretariat of the International League Against Epilepsy UK Chapter emailed their members to promote the surveys;
- Jan-net (an email network of professionals with an interest in epilepsy) emailed their members to promote the surveys;
- the Joint Epilepsy Council promoted the survey to their members; and
- the Princess Royal Trust for Carers tweeted about us online and added a link to the surveys from their Young Carers website.

Limitations to the surveys

We recognise that the results from these surveys represent only the views and experience of the people who responded, and cannot be assumed to represent the views of all carers, individuals with epilepsy or healthcare professionals.

People who completed the surveys were obviously motivated to respond. Individuals and groups that are 'harder to reach' (such as people with learning disabilities or who do not have English as their first language) are under-represented. Healthcare professionals who are motivated to complete a survey may be more proactive in their care of people with epilepsy than those not motivated to respond, so those less motivated are under-represented.

The majority of carers who completed the survey were caring for an individual with epilepsy and other conditions (or 'co-morbidities') alongside their epilepsy, for which they have care needs. Individuals with co-morbidities may have more complex epilepsy, be more affected by their epilepsy, and have greater care needs than those with less complex epilepsy. However, people with well-controlled epilepsy, or who only have care needs in the short-term, are less likely to need ongoing care and so this survey may be less likely to apply to them.

Over 140 carers responded to the survey, and 53 healthcare professionals. As only 15 individuals with epilepsy completed a survey the results from that group are not covered in depth within this report.

summary of survey 1 - carers

The results from this survey paint a picture of how unsupported and uninformed the carers feel they are. Although some respondents find that being a carer is rewarding, most find caring a stressful, difficult and tiring task.

"I don't really think of myself as a 'carer', rather a parent with extended responsibilities."

The vast majority of the carers help and support the person with epilepsy with 'tasks' related to having seizures (such as helping during and after seizures); related to managing the individual's epilepsy (such as taking medication); and with daily living tasks (such as transport and finances).

Carer of an individual with epilepsy

Very little information and support was given to the respondents at the time they became a carer, demonstrating a potential gap in provision of support to carers. Most said that they would have found information and support helpful at the point at which they became a carer, demonstrating both a need and a desire for such information. Information would be helpful on a range of topics including epilepsy and medication, practical issues around help from social services and about benefits, and support from charities and helplines. However, it is worth noting that most of the carers have been a carer for more than 10 years: the need for information and support for carers may be much better recognised now.

When it comes to asking for specific types of help and support either for themselves or the person they care for, the results were quite positive: most people had asked for help from social services and had applied for welfare benefits for the person with epilepsy and themselves, and most would consider contacting a carers' organisation, epilepsy helpline or a self-help or self-management groups. However, most would not consider finding out about respite care nor would ask social services for help for themselves (such as a carer's assessment). This is disappointing as the respondents were largely caring for people with epilepsy and other conditions or disabilities, and perhaps would be giving a level of care that puts them in great need of respite or help for themselves.

summary of survey 2 - people with epilepsy

This survey focused on the needs, experiences and views of people with epilepsy about their carers. As only 15 individuals completed the survey, and only 14 currently had a carer, the results are only included as a summary, and not in further detail.

"I feel happy my parents are there to care for me but sad and upset my condition negatively affects them."

The results from these surveys show areas of both similarity to, and difference from, that of carers. Some of the highlights from the survey are below.

An individual with epilepsy

- The individuals were aged from under 16 to 59.
- 50% of the individuals had had a carer for more than 10 years.
- 50% of the individuals were cared for by their parent, 29% by their spouse or partner and 14% by their child.
- The majority of individuals live with their carer.
- 57% of respondents had no other condition or disability for which they need care or support (compared to 28% in the carers' survey).

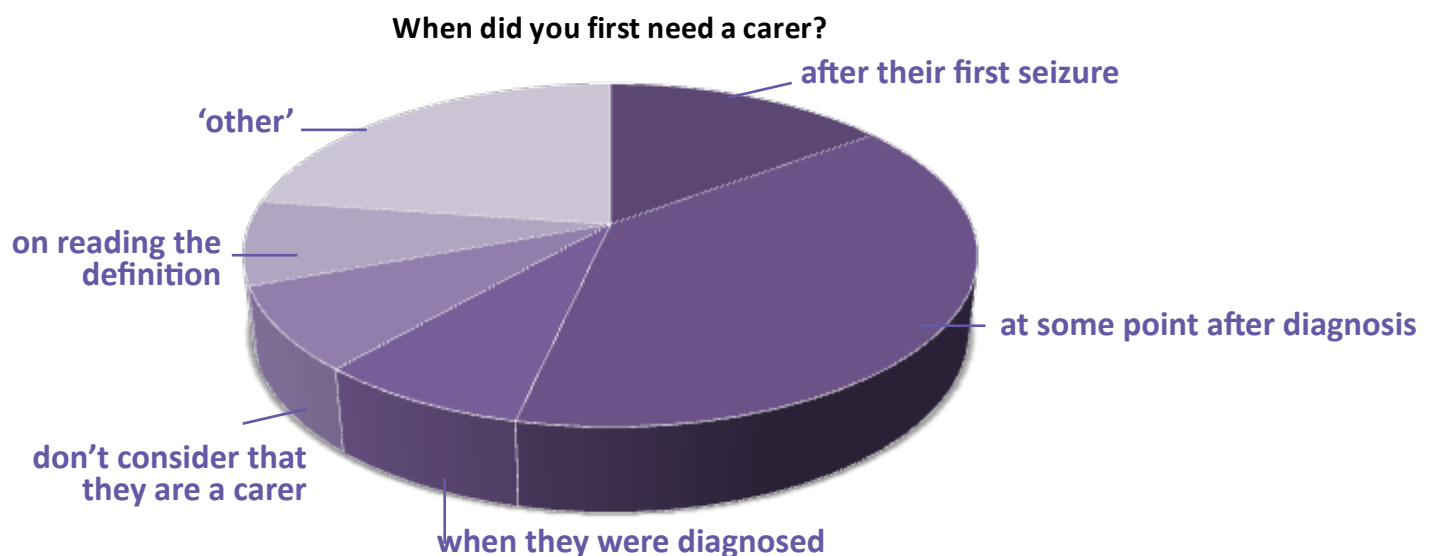
The results show that the individuals with epilepsy commonly need the same sort of help and support as each other, both during and following seizures, and at other times. This was also reflected in the carer's survey.

In terms of information given when the individual first developed epilepsy, the results matched that of the carers: individuals were not given information but they would have found it helpful. In addition, when individuals were given information, they often found it useful.

When asked about the impact of caring upon the carers, individuals often recognised the impact of caring upon the carer in some respects (such as their social life, time for themselves and their mental wellbeing) but did not in others (such as their education, employment and physical health). Interestingly, individuals were uncertain about whether their carers find caring rewarding or enjoyable, and they find having a carer equally a positive and a negative experience (compared to carers who more often find it a negative experience).

Respondents were asked at what point they considered that they needed a carer.

- 15% said after their first seizure;
- 8% said when they were first diagnosed;
- 39% said at some point after their diagnosis;
- 8% said when they read the definition;
- 8% said that they didn't think they needed a carer; and
- 23% gave other explanations, including when "my mum struggled to care for me".



Respondents were asked whether they had contacted different agencies for help, or whether they would consider doing so. Most respondents would not consider asking for or accessing help and support, either for themselves or their carers. The exception to this is that most individuals had applied for welfare benefits for themselves.

While we do not know for certain why individuals had not or would not access help and support, the reasons may be many and diverse. Some may not be aware that help and support exist or that they may be eligible, or it may just be that they do not need to access them. Some may be aware of the help and support, but feel uncomfortable asking for it, feel that they are not eligible for help or it makes them feel vulnerable. For others, acknowledging that they need help and support may be too difficult.

summary of survey 3 - healthcare professionals

The healthcare professionals who responded to this survey were, largely, very positive about ways in which they can and do support carers of people with epilepsy.

The results indicate a proactive and holistic approach from respondents, demonstrating an insight into the impact on, and needs of, carers. However, the results from this survey largely contradict the results from carers themselves who, largely, feel under-supported by the healthcare system and professionals.

Although this survey had relatively few responses, those of healthcare professionals represent their experience with a number of people with epilepsy and their carers, whereas the results from carers and individuals with epilepsy can only represent their own experience.

“Carers are strong and resourceful people who are very skilled at what they do. However, caring can dominate their life and leave little time for their own interests.”

Healthcare professional

focus groups

In order to get detailed information about the needs of carers and the effects of caring, we ran a focus group. This allowed us to talk to groups of carers and people with epilepsy, and explore their thoughts, ideas and experiences.

We ran the focus group in London, inviting both people with epilepsy and carers of people with epilepsy.

We sent open invitations to many carers, although recruiting people to attend was challenging. It is difficult for some carers to attend a meeting because, by the very nature of caring, they are not always able to leave the person they are caring for to attend. Some of our carers attended with the person they care for. This allowed us to have two groups of carers and a group of people with epilepsy: providing valuable insight into the needs of carers themselves, but also the views and experiences of caring from the point of view of the person with epilepsy themselves.

While we considered having mixed groups – of carers and people with epilepsy – we wanted to keep the focus on carers, and to ensure that carers had a ‘safe space’ to give their honest opinions without feeling the need to ‘be careful’ about what they said in front of people with epilepsy (or, indeed, the individual with epilepsy that they care for). It also allowed us to have a group of people with epilepsy giving their experiences of ‘being cared for’ without having to adjust what they said in front of carers. We felt that this encouraged an open and honest exchange of experiences and opinions.

We asked all three groups the same questions, all of which were based on the four priority areas identified in the carers strategy. We combined the responses from all three groups to get perspectives from both carers themselves and the people they care for.

Following are the discussions around each of the four priority areas, as identified in the Department of Health’s Carers Strategy, along with a summary of the responses from the focus group.

Priority area 1 – Identification and recognition

*“Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.”**

This priority area identifies several fundamental issues around how carers are recognised in their role, both by themselves and others, and the impact of this recognition on the carers themselves.

The strategy says that **“a significant number of people with caring responsibilities do not readily identify themselves as carers.”**

Many people take on a caring role when an individual is diagnosed with epilepsy. This role may be for the short-term only (particularly if the individual’s seizures become controlled and therefore their epilepsy has minimal impact on them). However, for others, the caring role may be longer-term, and often sits on a spectrum from the occasional need for support to intense periods. This varies from one individual to another, can be intermittent, and can also change over time. Many carers see the support that they give to the individual with epilepsy as either ‘just a normal part’ of or as an extension to their role as parent, partner, friend. For many, the term ‘carer’ does not ‘sit well’ with them, they may have expectations of what a ‘carer’ is and they do not recognise themselves in this role, or they object to the term ‘carer’ as it suggests that the individual with epilepsy is ‘in need of caring’. Perhaps this also has depends on what the term ‘carer’ means to each person.

For some, a caring role is assumed to be a role that someone would undertake, rather than something that they can ‘choose’ to do or not. There may be an expectation that someone will take on a caring role. Perhaps this ties in with perceptions about how it would be if someone chose not to care for their loved one, and a host of emotions that would go alongside such a decision.

“I don’t want to be called a carer – I’m just a mum. It is a family duty so I don’t identify with the word ‘carer’.”

Doreen, carer of an individual with epilepsy

“Mothers and fathers have always been carers of their children. Being a ‘carer’ is a new label. Now it’s like a job with payment.”

Carer of an individual with epilepsy.

The strategy says that **“many carers do not identify themselves as such until they have been caring for a number of years.”***

If an individual with epilepsy gets their seizures controlled quickly and their epilepsy has minimal impact on them, then the need to take on a caring role may be only short-term. Perhaps in this situation it is easy to understand why someone would not consider their role to be that of carer. But others may take on this role in the longer-term, yet still not accept that the term is one that applies to them. From our experience, many ‘carers’ are completely focused on the needs of the individual with epilepsy, often to the exclusion of their needs. Some even seem surprised or confused if they are asked about their needs, views and wishes. Perhaps this is because some feel that to focus on their own needs is ‘selfish’ or suggests that they are ‘unable to cope’ – both of which would be a disincentive to take on the term.

It may not be until a carer needs to seek additional help or support that they recognise themselves in the role of a carer. For some, help and support is only forthcoming if it is asked for, and if the person claims the help ‘as a carer’. For example, carers are able to apply for carers’ allowance, but would only be able to do so if they recognise themselves as a carer and that this benefit is available to them.

The strategy says that **“Many carers are not offered or do not seek early access to information and advice on the specific illness or condition of the person they are supporting to help them care effectively and safely. They may also find it hard to know how to access information and advice on how to balance a caring role with other responsibilities and opportunities in their lives.”***

Many carers access Epilepsy Society’s services for information. Our helpline receives around 5,000 calls per year, 1,000 of which are from people in caring roles (either people who recognise themselves as ‘carers’ or those that may be in a caring role such as parents, partners or children). 250,000 people access our website for information each year. However, where access to information and support may be lacking is in that offered to carers from health and social care professionals. The results from our surveys (see appendices, from page 46) tell us more about this.

“When other people’s children reached their teens I realised I was doing more than them, so I am more of a carer.”

Carer of an individual with epilepsy

Responses from the focus group

Each group was given the following statements, derived from the Carers' Strategy*, and asked whether they agreed or disagreed with them.

- Carers are helped and encouraged to see themselves as carers early on when the person they care for is diagnosed with epilepsy.
- The value of the carer's contribution to the person they care for and society is recognised.
- Carers of people with epilepsy are involved from the beginning in deciding on the most appropriate care for the person that they care for. This includes medical care (such as from the GP and hospital) social care (such as support from social services) and putting together a care package for the person they care for.

"Some people are forced into being a carer and some people can't be the 'perfect carer'. There is a lot of pressure on the person to suddenly become a carer."

An individual with epilepsy

Responses

- The term 'carer' needs more exploring: is there a better way to describe it? Can we avoid 'labels' and empower people?
- There is a difference between a 'carer who is a relative' (who has emotional involvement) and a 'professional carer' (who doesn't have an emotional involvement). Parents become carers when the physical and emotional effects of epilepsy increase. When a child is physically ill it means you are a carer as opposed to being a parent, when the child is not physically ill you are a parent.
- Being a carer needs to be 'normalised', and the stigma surrounding epilepsy needs to be reduced.
- Carers [as well as the individual with epilepsy] may also go through a period of denial. There can be a spectrum from 'denial' to 'over protective' to a 'positive carer' (balancing their needs with that of the individual they care for).
- Carers need to feel that they have permission to have their own feelings, which they can express and explore, and not just about the person with epilepsy. Seeing a counsellor could be helpful, or having a spokesperson or 'carer's buddy'. Support groups, community groups and online groups are important, so carers can discuss their problems openly with people who will understand 'where they are coming from'.
- One of the benefits of recognising you are a carer is acknowledging that you *want* to do rather than being *forced* into it. Identifying yourself as a carer also means you have access to ask for personal budgets and carer's allowance.

- There needs to be more help and better support for carers.
- Carers need to be told about respite care.
- Where to go for information (for example, on personal budgets and entitlements) needs to be clearer and easy to access. Knowledge is really important for carers: need more knowledge as their own lack of education about epilepsy can be a barrier.
- Having carers attend appointments with people with epilepsy is sometimes difficult because of the confidentiality boundaries in place: a person over the age of 16 can attend without an adult present. Is this always the best practice for the people with epilepsy and their carers?
- Should the carer have a chance to talk to the medics like people with epilepsy do? This might acknowledge that a carer has rights (versus the confidentiality of the patient-physician relationship).
- Sometimes the person with epilepsy cannot give information to the neurologist so a carer is an important way of feeding back information to them.
- Perhaps the severity of epilepsy should determine whether or not a carer is present at meetings with doctors and neurologists.
- Meetings with epilepsy nurses are generally more informal.
- Carers often get information when they are with the person with epilepsy but they also need to be able to access information without the person with epilepsy present (the carer might fear asking certain questions in front of them).
- Social workers need to be more clued up [about epilepsy] – they need to have sessions on how to care for people with epilepsy.
- Carers don't always know who to contact for information as there are too many changes in services and there can be a lack of continuity when dealing with different organisations.

Summary

The group felt that carers of people with epilepsy are not helped to see themselves as carers. They felt that the term 'carer' may be misunderstood or avoided because of the implication that the individual with epilepsy is 'needy' or labelled as 'disabled'. They also felt that carers are not listened to, or supported by, professionals involved in the care of the individual with epilepsy.

"The doctors made an assumption about my knowledge of epilepsy. I was not actually told that my daughter had epilepsy. They said because of the medication she was prescribed, that I should have worked it out."

Doreen, carer of an individual with epilepsy.

Priority area 2 – realising and releasing potential

*“Enabling those with caring responsibilities to fulfil their educational and employment potential.”**

This priority area identified issues around how carers are able to balance their caring role alongside their education and employment.

The strategy says that **“inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers’ lives, including their health and educational achievement.”***

Our focus group did not include young carers, and we have little contact with them through our helpline. However, our ‘new media’, such as the forum, facebook and twitter, allows us to reach out to, and engage with, more diverse audiences including children and young adults.

The strategy says that **“It is crucial that we place a much higher priority on supporting people of working age with caring responsibilities to remain in work... yet many carers currently feel forced to give up work because they feel they have no other options available to them.”***

The focus group highlighted that carers often feel that they have limited choices around education or employment. Key to being able to stay in education and employment is knowledge and understanding: from both the education provider or employer, and the carer themselves.

The strategy says that **“the fluctuating nature of some conditions... can mean that caring responsibilities can also fluctuate, often unpredictably.”***

This is particularly relevant to many carers of individuals with epilepsy. There seems to be a misconception in the general population that if an individual with epilepsy does not need ongoing support for *most* of the time, they would *never* need a carer. For some individuals this will be the case, for others, they will need a carer to be available as needed: often unpredictably. Perhaps this is because of a general lack of understanding of the nature of epilepsy: that epilepsy has a spectrum of impact from people being fully independent and seizure-free, to those needing emergency medication to control prolonged seizures, to those needing intensive 24-hour support.

Responses from the focus group

Each group was given the following statements, derived from the Carers' Strategy*, and asked whether they agreed or disagreed with them.

- Carers are helped and encouraged to fulfil their potential at school, college, university and further education.
- Carers are helped and encouraged to fulfil their potential at work.

"I was working when my daughter started having seizures. I had several months off and she couldn't have got through it if I hadn't done that. She needed me."

Carer of an individual with epilepsy

Responses

- Support for young carers (school age) is quite good, information and support is easy to access. As you get older things can get harder, as less help is offered and you are not always 'looked out for'. 'Pastoral' needs are recognised and met at school, but this is seen less in adults.
- Siblings sometimes care for young carers. And there is an impact on the child who doesn't have the condition. It is awful for an adult who has elected to care but for a child this is even harder. Support to young people should be given top priority.
- Carers need some kind of official recognition or acknowledgement, so they can show that they have certain rights, for example when they talk to their employers if they need to take time off.
- Carers need to be aware of their rights under the Equality Act in order to know what to expect of their education provider or employer.
- Employers need to be educated about the needs of carers.
- To go to a hospital appointment with the person with epilepsy it means that if the carer is working they will need to take the time off as annual leave. Small companies might find it hard to accommodate this.

Summary

The group felt that carers of people with epilepsy desperately need help, support and encouragement in order to fulfil their potential in education and employment, and that this is currently not available. The group also felt strongly that education and employment provider's understanding of epilepsy should be improved, and that understanding the responsibilities of a carer of an individual with epilepsy is vital. Recognising that some conditions are fluctuating in nature is a key part of understanding the needs of carers of people with epilepsy.

"I just had to give up a job and stay at home and write. I had an interview then my daughter had a seizure and I couldn't get to the interview. What I needed at that point was a few hours' respite."

Caroline, carer of an individual with epilepsy.

Priority area 3 – a life outside of caring

*“Personalised support both for carers and those they support, enabling them to have a family and community life.” **

This priority area identifies issues around how carers are able to balance their caring role alongside other areas of their life, including their family, leisure and community life.

The strategy says that **“all services and support available to carers should be tailored to their specific needs as far as possible. No assumptions should be made about a carer’s ability and willingness to care.”**

Alongside the need for treatment and management for an individual with a disability to be personalised, so too should be the help and support for carers. A ‘one size fits all’ approach is not appropriate for services: the individual nature of a carer’s needs, experiences and, importantly, wishes, determines what support is needed and when. Offering the same services to all carers would be a waste of time, effort and money as not all carers will need the same services all the time. Or worse, it could result in a general lack of support for all carers when services are under pressure for time and money. Personalising services is important, and fundamental to this is understanding, knowledge and appreciation.

The issue of making assumptions about a carer’s ‘ability and willingness to care’ depends upon both the carer themselves and those around them. Some carers will make an assumption that they should take on a care role themselves, or assume that they do not have a choice or that it is expected. Part of this may be due to often deep emotional issues around guilt, perceived selfishness and ‘what others might think’. There is also the important issue that many people will naturally want to care for their loved ones, or not want anyone else taking on that role. The ‘flip’ side to this is when health or social care professionals, or others, make an assumption that someone is going to take on the role of carer, regardless of that person’s wishes or current situation (such as education or employment). Again, this situation can bring an emotional burden on to carers, and one which they may feel reluctant or unable to voice.

“My social worker was doing an assessment and said “Everything you have talked about is about your daughter’s needs but you haven’t talked about your own needs”.

Doreen, carer of an individual with epilepsy.

“Employers must be flexible with staff. You may get a call from your child’s school but this is erratic. Months can go by with no problem.”

Ali, carer of an individual with epilepsy.

The strategy says that **“personalising support includes a number of ways in which carers can be more effectively supported as individuals to maintain their caring role and have a life of their own, maximising the opportunities for them to direct their own support.”**

In part, this depends upon an individual’s acceptance of the role of ‘carer’ in order to access services. If they do not apply the term ‘carer’ to themselves, they are unlikely to seek out carer-specific support, or to be told about it. Such support needs to be tailored to the individual needs of each carer, and to take into account their wishes for their ‘life outside of caring’. For some carers, recognising and valuing their own needs can become secondary to their role as a carer, and in this case they may need to be supported in identifying what their wishes and aspirations for themselves actually are.

“I am permanently holding my breath, anxious, what is happening, who can I phone to support me? Having to think about phoning somebody up and what I can ask for. There is no support.”

Frederica, a carer of an individual with epilepsy

Responses from the focus group

Each group was given the following statement, derived from the Carers’ Strategy*, and asked whether they agreed or disagreed with it.

- Carers are given individual help and support for them, and the person they care for, so that they can have a family and community life.

Responses

- Carers need recognition, involvement and support. They need to be enabled to get support from different avenues. If they are recognised and respected it might encourage them to get involved in social activities.
- Help and support should be proactive and not reactive. You need to know what’s available: “no-one tells you”. You need to be signposted to entitlements and assessments, and know what your needs are in order to get the money/funding required.
- There needs to be more input from social services, and social services need more education and knowledge about epilepsy. There could be a social services ‘link person’ to help support carers by having a bank of trained and reliable carers available. People who request this service would need an assessment of their requirements to avoid individuals ‘sucking up resources’. This could be part of personalised budgets.

“My friend has a son in a wheelchair in a care home but she is always on call. Every time he has a seizure they call her. There is a lack of training of staff in care homes to look after people with epilepsy.”

Carer of an individual with epilepsy.

- Carers need to be given permission to say 'I need time out'. They should be able to ask for a certain type of help for the individual that they are caring for. For example, someone who knows about epilepsy and is trained to help. It is pointless having professional care staff, who you will be paying, if you don't feel able to trust them.
- You can't plan when you are going to need care, because of the unpredictability of epilepsy. There are issues around professional care staff giving emergency medication for prolonged seizures.
- There is not enough respite available with staff trained in epilepsy, so family carers are still on call (and so cannot relax).
- Provision is not geographically consistent and varies depending on where you live.
- There needs to be more opportunities for carers and people with epilepsy to socialise together. It is difficult to get people to attend this sort of thing and not everyone will want to attend.
- It can become easy for an individual with epilepsy to become dependent on the carer: that individual needs to know that a carer might not always be around, and has a right to 'time off'.

"I have gone back to university as my son has moved out but sometimes he still needs help and I have no family members who can help. My leisure opportunities are very difficult."

A carer of an individual with epilepsy

Summary

The group felt that not enough is done to help support carers or tell them about what is available to them. This is fundamental: carers cannot take breaks, organise care, or have a 'life outside of caring' until the individual with epilepsy that they care for is provided for first. The group also felt that the services that are available are not consistent across the country or for all ages, and are not active in telling carers what is available. Also, the group felt that often staff supporting individuals with epilepsy do not know enough or have experience in specific needs related to epilepsy, so carers do not feel confident in using the services. Therefore, what services there are may not be used because of the concern that the individual with epilepsy would not be appropriately cared for.

"I have no leisure time. I have carers coming in but I need to trust them. They don't always know enough about epilepsy as my daughter has lots of different types of seizures. Carers are not always professional and they don't always 'care'. Their attitudes vary. Sometimes they try to do too much. I get no respite."

Doreen, carer of an individual with epilepsy.

Priority area 4 – supporting carers to stay healthy

*“Supporting carers to remain mentally and physically well.”**

This priority area identified issues around how caring can affect mental and physical health, and how carers can be best supported to stay well.

The strategy says that **“caring can be very rewarding and fulfilling but it can also be emotionally and physically draining without recognition and practical and emotional support.”***

From our surveys (section 2), it is clear that whilst many people find caring rewarding and fulfilling, many also find it tiring and stressful. And many feel both ways. Within the focus group many individuals felt the negative impact of caring, and explained that it can be very hard to feel rewarded by the experience when caring for a loved one. Recognising the positive and negative impact of caring helps to give a rounded view of caring, to understand why many people take on a caring role, and also why it is important that carers are supported. Fundamentally, support to keep a carer well is important if they are to continue to be a carer.

The strategy says that **“there is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. Carers can neglect their own health because they are so busy supporting someone else.”***

The focus group recognises the impact of caring on their health and wellbeing, and also on those around them. Often carers put the needs of the person they are caring for before themselves, so their own health becomes of lesser importance or, in some cases, neglected altogether.

The strategy says that **“access to relevant information – at the right time – is crucially important for all carers. Information and focused support at key stages along the care pathway... can improve health outcomes and experience for carers and be cost-effective.”***

Key to helping to support carers is information, both for them and for those around them. Feeling unable to ask for help and support from others, because of their lack of understanding about epilepsy, means that many carers take the burden of caring exclusively on their own shoulders. This can be very isolating.

“There is nothing ‘rewarding’ about seeing your child or your wife having a seizure.”

A carer of an individual with epilepsy

“I am supporting my daughter; I haven’t any money, which is a strain. I haven’t got the time to go to the doctors myself. This leads to depression and social isolation.”

Caroline, carer of an individual with epilepsy.

Responses from the focus group

Each group was given the following statement, derived from the Carers' Strategy*, and asked whether they agreed or disagreed with it.

- Carers are helped and supported to keep mentally and physically well.

"Caring is only rewarding if you choose to do it."

A carer of an individual with epilepsy

Responses

- Carers should be respected for what they do. A 'carer's protocol' would identify what they do and acknowledge their contribution.
- Carers need support. A carer's support group would be an opportunity for carers to 'off load' openly and honestly without being judged. A closed forum specifically for carers would give people time allocated to themselves, and an opportunity to off load honestly and confidentially.
- Carers should be recognised and rewarded and empowered.
- Carers have a constant strain of worrying about what will happen if they can't care, focusing on the person and forgetting about their own health.
- Carers need to be assured that someone will be able to care for the person with epilepsy if they are no longer able to care for them.
- A lack of understanding can mean people make negative judgements on how a carer feels – the situation needs to be made more 'normal'.
- Carers need to know how to look after themselves, such as information on eating, exercise, medication adherence and so on.
- Could carers have appointments with the neurologist to discuss their needs?
- Information on respite care and finances would be helpful.
- Being a carer means no time for oneself, tiredness, and stress.
- Becoming a carer makes you worse off.

Summary

The group felt being a carer is not always rewarding, and that it is very difficult to see someone you care for having a seizure. It also depends on whether the carer has actively *chosen* to be a carer or not. The group felt strongly that there is not enough emotional and practical help and support available to carers. Group members acknowledge the mental and physical impact of caring upon their *own* health.

"You can learn a lot [at a support group] and get problems off your chest. Friends don't always understand."

A carer of an individual with epilepsy.

anne's story

Our daughter Katherine is 23 years old, and lives in a specialist home for people with epilepsy. When she was a little girl, we would never have imagined that she would be disabled in such a complex way, and that she would not be able to live independently.

Katherine is our second child and was an easy baby. When she was around 20 months old, and her younger sister was born, she developed very severe eczema and hardly ever slept. It wasn't until nearly her third birthday that she had an obvious seizure and that epilepsy was diagnosed. At that point I thought that epilepsy was easily controllable with drugs and that all would be well, I was completely unaware of the impact this condition would have on all our lives.

Being supported with knowledge would have made our lives as parents and carers easier.

Katherine was diagnosed with Lennox Gastaut syndrome when she was 13. Her behaviour was very challenging – not least because she has a fear of sleeping (she has nocturnal seizures and would try anything to stay awake) – and this impacted on her learning. We did not realise that epilepsy and the drugs that we tried to control it with could affect her language, her memory, her appetite, even her personality. As parents we were very concerned that we were failing in getting her to sleep, or to behave in public, or to be less aggressive to her siblings, and we couldn't make her less anxious about school. It wasn't until much later that I found out that one of the descriptions of Katherine's condition is childhood dementia, and knowing that and being supported with that knowledge would have made our lives as parents and carers easier.

Part of being the parent and carer is knowing when to let go, and when to ask for and accept external help.

The unpredictability of epilepsy increased the general stress level of the whole household. Not just the seizures, which could either be completely unheralded or else preceded by several hours of manic behaviour, but also the exhaustion of the whole family if Katherine had kept us awake. Trips to A & E at all hours, for head stitching, or broken arms, being asked to leave three schools before she was seven because her behaviour had been so disruptive.

There was also the constant fear of Sudden Death. The rare nights that she slept through would make us frightened to go into her room in the morning, scared of what we might find.

Adolescence brought its own problems: as a parent you want to encourage independence when your child grows up physically, but when they still have a mental age of around five – your instincts are confused. Life became harder for Katherine: she saw her brother and sister enjoying parties and outings and felt excluded. She became increasingly depressed and withdrawn, and her mental health was not properly addressed until a couple of years ago. We were given an insight into how the constant underlying epileptic activity affected Katherine when for 17 weeks over the Millennium, she became seizure free. It was wonderful to see her blossom, and begin to interact in a normal way. And terrible when her seizures started again. But we had all had a glimpse of how life could have been for Katherine if she had not had epilepsy.

A particular difficulty of caring for someone with complex epilepsy is having to explain their condition, and how it affects family life to friends, relatives and teachers. This is even more difficult when you have not been given a full diagnosis and the treatment is a sequence of experimenting with drugs that have unknown and unwanted side effects. Not understanding her condition meant that our acceptance of how different her life was going to be took longer. And our feelings of guilt at not making her healthy or happy were prolonged.

Yet there are good times too: Katherine is loving, funny and the focus of our family. Her sister said this year – during our 14th visit to Eurodisney – it makes everyone happy just to see Katherine smiling. We see Katherine at home for one night a fortnight, and we spend time doing what she wants to do. And after 24 hours she is happy to return to her community where she feels safe and has a good social life. We feel she is being cared for by people who enjoy her company, care for her wellbeing and share our desire for her to look forward to another day.

It has not been easy. Part of being the parent and carer of someone with Katherine's condition is knowing when to let go, and when to ask for and accept external help. There were many times in the past when we were too exhausted by Katherine's illness, both by the epilepsy and the mental health and psychosocial problems that come with her epilepsy, to recognise that we desperately needed more help. Support is not forthcoming without fighting more battles, and without proper diagnosis and care plans it is difficult to know what to fight for.



did we achieve our aims?

Our project set out with three main aims. Here we outline the outcomes of these aims and what we achieved along the way.

Aim 1: to identify the experiences, needs and aspirations of people who care for someone with epilepsy, through engaging with carers directly.

We were able to engage with carers in two important ways.

- Running an online survey allowed us to reach out to over 150 carers in a short space of time. This provided a large enough number of responses to draw some very interesting observations. It was also an opportunity to raise awareness of the project and what resources and services we already have to support and inform carers.
- Running the focus group allowed us to ask in-depth questions about people's experiences, providing some qualitative responses.

We were also able to engage with individuals with epilepsy, to understand caring from their perspective of being 'cared for'. This gave us valuable insight into the issues *they* felt were important for carers.

Aim 2: To identify ways in which Epilepsy Society can continue to best support people with epilepsy and their carers.

The project enabled us to highlight some of the services we already have for carers, such as information on the website and in print, the helpline and a dedicated area on our forum. In addition, it gave us an opportunity to explore other ways to help support and inform carers in our future work (see section 5, page 43).

The project also enabled us to visibly show our support to carers: to recognise and acknowledge the vital role they have in supporting individuals with epilepsy.

Aim 3: to give feedback about the Carers' Strategy to the Department of Health, reflecting the views of carers of people with epilepsy.

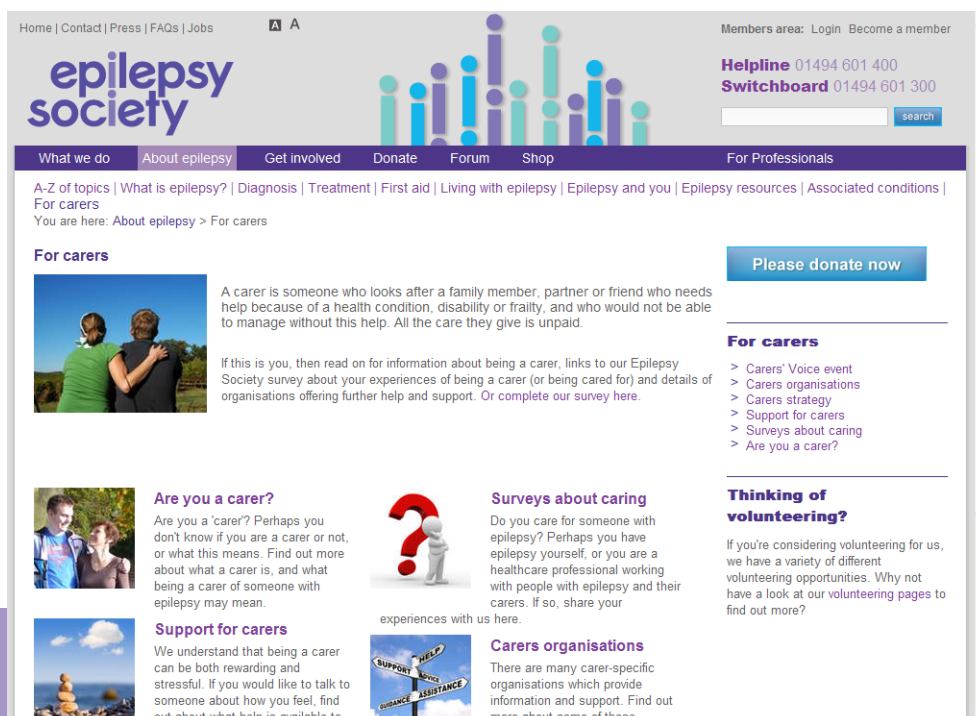
We submitted a report from the project to the Department of Health, through which we were able to demonstrate both the impact of caring for an individual with epilepsy on the carer, and why epilepsy is a condition which places unique challenges on carers.

We also wanted to deliver several specific outcomes.

1. To help carers of people with epilepsy to recognise themselves in a caring role, and to help them understand what help and support is available to them. To develop a section of our website specifically for carers of people with epilepsy, focusing on providing information and signposting to appropriate agencies and to support them as individuals.

Through the project we created a new section on our website specifically for carers. As well as containing links to the project surveys, it contains carer-specific information on the following topics:

- what a carer is, what caring for someone with epilepsy includes, and recognising the role of carers (so that individuals would be encouraged to see themselves in this role if appropriate);
- the support available to carers (including links to the carers' section of our forum and to information about our helpline);
- the Carers' Strategy, including a link to the Department of Health website; and
- how to get in touch with carers' organisations and the services they offer.



2. To develop a new information card to signpost carers to sources of help.

We adapted our existing and popular first aid card to include references to help and support for carers. We have now adopted this 'carers' version of the card as the only version: to recognise the fundamental role that carers play in supporting individuals with epilepsy.



3. To develop and deliver a survey amongst carers of people with epilepsy, to understand what they do for the individual, what information, help and support they want and get, and to understand the issues unique to supporting someone with epilepsy.

This was achieved and is reported on in section 2 of this report.

4. To engage with carers through focus groups to get in-depth feedback on the Government's Carers' Strategy and to see whether this supports carers of people with epilepsy.

This was achieved and is reported on in section 3 of this report.

what next?

Throughout the project we aimed to identify the needs of carers, for themselves and to help them within their caring role. But it is not enough to listen to the experiences; we need to act on what we have heard. Here we outline some of the ways in which we want to support carers within existing services and into the future.

Informing carers

The new carer-specific section of our website contains:

- information about being a carer to encourage people to recognise whether they are a carer;
- information on benefits and entitlements for carers, with signposting to further sources of information; and
- links to carer-specific organisations that provide additional help, support and advice.

This section will be kept up to date with information for carers, to inform, empower and support them. We can also highlight other areas and issues of potential interest to carers, by signposting to carer-specific agencies.

Supporting carers

Our helpline takes over 5,000 calls each year, with around 25% of calls coming from carers. We will continue to ensure our helpline workers are able to support both carers and individuals with epilepsy. We plan to improve access to the helpline in 2012 by piloting opening it earlier in the morning and also in the evenings. This should offer additional opportunities for people caring for someone with epilepsy to call us, at a time that fits in with their caring responsibilities.

Connecting carers

Carer-specific areas on online forums was highlighted as important for carers for mutual peer support. We will continue to have a specific area for carers on our forum, to address this need.

Focusing on carers

We will keep the needs of carers firmly in sight when delivering on our vision of ‘a full life for everyone affected by epilepsy’. They will continue to be a focus for our membership schemes, for our annual conferences, and information resources.

Including carers

We will continue to include carers within our work, and commit to giving a voice to carers.

The carers role in seizure control

Alongside healthcare professionals and the medical treatment and management of epilepsy, carers are a key part of effective seizure control for many people with epilepsy. However, this often goes unrecognised.

Many carers provide daily support for an individual, including managing seizures, helping with taking medication, recording when seizures happen, and supporting the individual to manage their condition. And for many individuals their epilepsy will be a long-term condition, that needs ongoing support over many years. For individuals with epilepsy support from their carers, both practical and emotional, can be vital.

As part of our ‘Targeting Seizures’ campaign during 2011 - 13, we will look at the role of, and impact on, carers to seek what contribution they make to seizure control and how this can impact on their lives too.

The impact of carers

The contribution of carers, not only to the individual with epilepsy but also to society, is far-reaching. For example, supporting an individual with epilepsy might help reduce the number of times they are admitted to hospital. Helping an individual manage their treatment so that they become seizure-free may help them to find or stay in work.

If resources permit in the future, we would like to work with the health service, employers and other agencies to raise the profile of carers and measure the value of carers in society. We would like to look at the impact of caring on the *carer's* potential to find or stay in work and participate and contribute to society. In addition, we would like to identify what support would enable both the carer and the individual with epilepsy to feel like full members of society and reduce the need to rely on health and social care services and the benefits system.

Survey 1 - carers of people with epilepsy

This survey focused on the needs, experiences and views of carers themselves.

153 carers completed a survey. Most respondents were female.

143 carers were currently a carer of someone with epilepsy, and 10 had been a carer in the past. For this report we analysed the responses from the 143 current carers.

Results

- Most respondents were between 41 – 59 years of age, but ranging from under 16 to 84.
- Over half of the respondents (55%) work alongside their caring role (either full time, part time or volunteering), with the remainder neither in work nor volunteering.
- Most respondents (74%) did not have any care or support needs themselves. This is interesting as the Department of Health* identifies that “those providing high levels of care are twice as likely to have poor health compared with those without caring responsibilities”.
- Most respondents (55%) have been a carer for more than 10 years, with only 6% having been a carer for less than one year.
- Most respondents (90%) live with the person they care for. This is largely because most (94%) were caring for relatives that you would normally expect them to be living with (such as their partner or spouse or their child).
- The age range of the person with epilepsy was 0 to 84 years, with 90 individuals aged between 5 and 59 years.

Co-morbidities

The majority of the carers (72%) were caring for an individual with other medical conditions or disabilities (co-morbidities), alongside their epilepsy, for which they need care and support. For people who have other conditions alongside their epilepsy, their epilepsy may be more difficult to treat, have a greater impact on their life and need for care, than people without other conditions alongside their epilepsy.

“I love being a carer”

*Carer of an individual
with epilepsy*

Types of care that carers give

Respondents were asked in what ways they help the individual with epilepsy. The majority (from 63% to 99%) helped in the following ways (either daily, weekly, monthly or as needed):

- look after them during a seizure;
- look after them after a seizure;
- help with seizure-related injuries;
- call for an ambulance or go to A&E with them because of seizures;
- give emergency medication if they have prolonged or repeated seizures;
- go to clinic appointments with them;
- have input into decisions about their epilepsy and its management;
- help them to take their medication;
- help them with transport (for example, driving them around);
- help them with daily living (for example, preparing meals);
- help them develop their individual education or health plan; and
- help them with their personal finances or benefits.

The respondents often help the individual in the same ways, and the vast majority of respondents are giving this help.

Many of the ways in which carers help are perhaps 'obvious' ways of supporting someone who has seizures: helping during and after a seizure, going to hospital with them or giving emergency medication. The results also show that help and support is also given in the overall management of the individual's epilepsy, such as helping with medication and being involved in treatment decisions. However, the results also show that most carers help with daily living, transport and finances on an ongoing basis.

"[I also] fight and challenge poor decisions made by social services and government"

Carer of an individual with epilepsy

"I worry about them 24 hours a day, 7 days a week."

Carer of an individual with epilepsy

Information that was given when epilepsy first developed

Respondents were asked about what information and help they needed when they first became a carer, and whether this was available.

The majority of respondents were not given information and help, although they would have found it useful.

"I had to find out for myself – I felt so alone and scared"

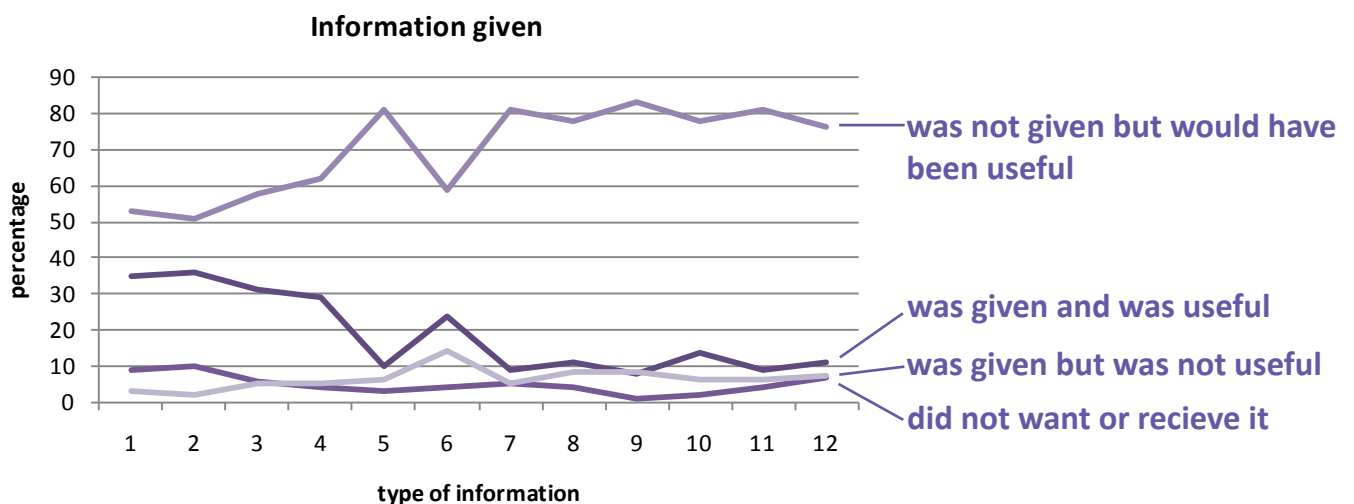
Carer of an individual with epilepsy

Information that may be immediately important for the safe care of someone with epilepsy at diagnosis:

1. information about epilepsy;
2. information about medication;
3. information about first aid and managing seizures;
4. information about safety and risk;
5. information about regulations and entitlements; and
6. training for their carer in emergency medication.

Information which may be important in the longer-term for the holistic care of someone with epilepsy:

7. information about charities and forums;
8. information about epilepsy helplines for the person with epilepsy;
9. information about epilepsy helplines for them;
10. information about financial support and benefits;
11. information about carers' organisations; and
12. information about help from social services.



The graph on the previous page shows that the carers were frequently not given information to help and support them, or the person they care for, at the point when they become a carer. Also, it shows that this information was wanted, and when it was given it was helpful.

In addition, 85% of respondents were not given information about looking after themselves, but would have found this useful and 71% of respondents were not given information about respite care but would have found it useful.

About being a carer

Respondents were asked what impact being a carer has on them. For each statement they were asked to respond 'a little bit', 'a lot' or 'not at all'.

Many people said being a carer affected them 'a lot' in these ways:

- 'it affects my employment';
- 'it affects my social life /leisure activities';
- 'it affects my lifestyle and the way I would like my life to be';
- 'it restricts how I live my life';
- 'it affects what time I have to myself';
- 'it affects my mental wellbeing';
- 'it affects me/us financially'.
- 'I find caring rewarding'; and
- 'I enjoy being able to care for the person'.

This shows that the carers find caring both a positive experience (rewarding and enjoyable) and a negative experience (affecting their life and health).

Commonly, carers did not feel that being a carer affected their physical health, their education, or their friendship or relationship with the individual they care for.

In comparison, most individuals with epilepsy felt that caring affected their carer's friendship with others and their mental wellbeing 'a bit'. Also, individuals were 'unsure' whether their carer finds caring rewarding or that their carer enjoys caring for them.

"The brilliant information sheets and leaflets from Epilepsy Society were not made aware to me by any medical professionals. I came across them at a local town hall seminar where they had presence."

Carer of an individual with epilepsy

How it feels to be a carer

Respondents were asked to say how they felt about being a carer.

Most (64%) answers were negative words, such as 'stressed', 'tired', 'undervalued' and 'restricted'. However, some answers (26%) were positive such as 'rewarding', 'blessed', 'needed' and 'happy'. Some were neither positive nor negative, such as 'content', 'a challenge' and 'responsible'.

The Department of Health* agreed that "being a carer provokes a complex mix of emotions. It can be both rewarding and frustrating." Overall, the answers reflect the 'complex mix' and shows the demanding, frustrating, tiring and negative impact that being a carer has on individuals, alongside the rewarding parts of caring.

Other comments about being a carer included the following.

- "Always wondering if you are doing the right things, not forgetting something, if you are helping your child enough".
- "Caring for my youngest child is rewarding but it is hard work and I also feel most of the time that I neglect my other children due to the amount of time I spend caring which leads to the old guilt settling in."
- "My daughter is not the problem, the system that is meant to support her is. I am constantly having to justify her and my existence to people who haven't a clue about our lives... this system is set up to support itself not vulnerable people or their carers."
- "I find that being a carer means that you have to be constantly fighting on behalf of the person you care for."
- "I don't feel like her mum, I feel like her carer. This upsets me as I would love to be just a mum."

These comments demonstrate the very complex nature of caring for an individual with epilepsy, and that the services designed to support people can often be difficult to contact, navigate and negotiate. Indeed, some of the comments suggest that carers find the system, and some people administering the system, hard to work with and insensitive.

"A very demanding role with huge financial implications on the family."

Carer of an individual with epilepsy

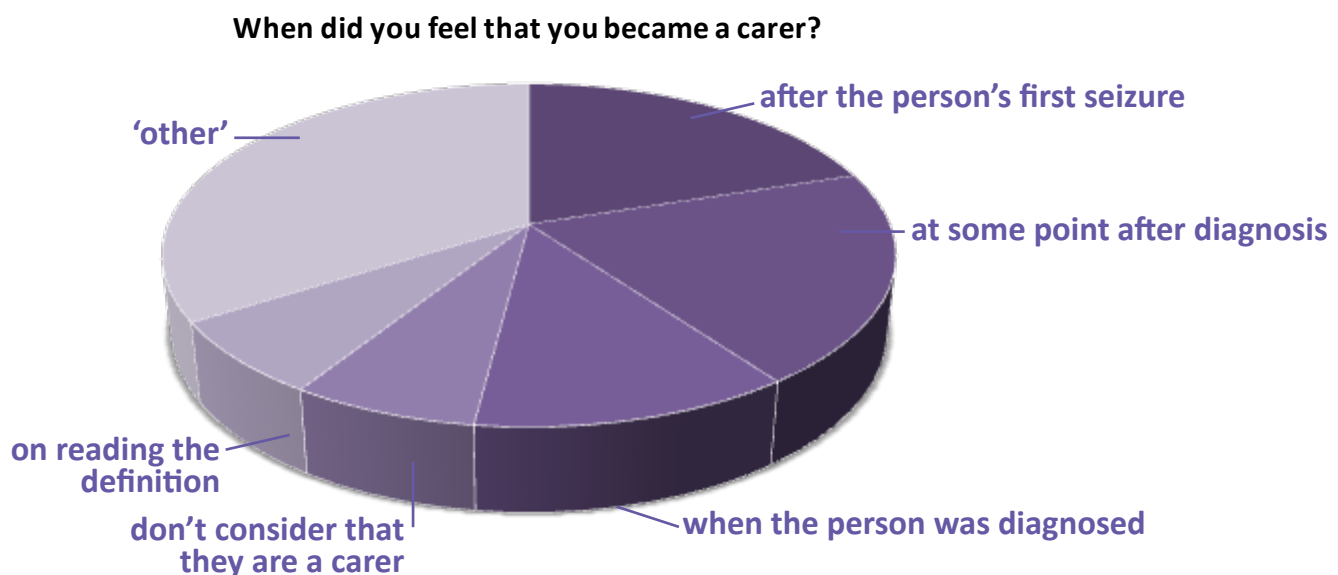
"[I feel] scared at times."

Carer of an individual with epilepsy

When does someone become a carer?

Respondents were asked at what point they considered that they were a carer. The responses were quite mixed.

- 20% said after the person had their first seizure;
- 20% said at some point after the person was diagnosed;
- 12% said when the person was diagnosed;
- 7% said when they read the definition; and
- 7% said that they don't consider themselves to be a carer.
- 34% gave other explanations, including because they are a parent, when they had to give up work because of the individual's epilepsy, and when someone pointed it out to them.



The Department of Health* identified, as a priority, “supporting those with caring responsibilities to identify themselves as carers at an early stage”. In our survey, only 32% of respondents recognised themselves as a carer at an early stage (after the first seizure or when the person was diagnosed).

Similarly, amongst the individuals with epilepsy, only 15% said that they considered they needed a carer early on (after their first seizure or when they were diagnosed).

Support for carers

Respondents were asked whether they had, at any time, looked for help and support for themselves or the person they care for. They were asked to select 'I have done', 'I would consider' or 'I would not consider'.

Most people **had asked for** the following help or support.

- 48% of respondents had asked for help from social services for the person they care for.
- 76% of respondents had applied for welfare benefits for the person they care for (such as Disability Living Allowance).
- 54% of respondents had applied for welfare benefits for themselves (such as carer's allowance).

Most people **would consider** asking for the following help or support.

- 45% of respondents would consider contacting a carers' organisation for information or help for the person they care for.
- 49% of respondents would consider contacting a carers' organisation for information or help for themselves.
- 47% of respondents would consider contacting an epilepsy helpline for information or help for the person they care for.
- 55% of respondents would consider contacting an epilepsy helpline for information or help for themselves.
- 61% of respondents would consider contacting a self-help or self-management group for the person they care for.
- 57% of respondents would consider contacting a self-help or self-management group for themselves.

These results could show that carers have not needed to access this help and support, or that they were not aware of the help and support available.

Most people **would not consider** asking for the following help or support.

- 46% of respondents 'would not consider' finding out about respite care to give themselves a break.
- 39% of respondents would not consider asking social services for help for themselves (such as for a carer's assessment).

These results show that a significant percentage of carers would not ask for help such as an assessment for themselves nor for respite care in order to have a break from caring responsibilities.

Survey 3 - healthcare professionals

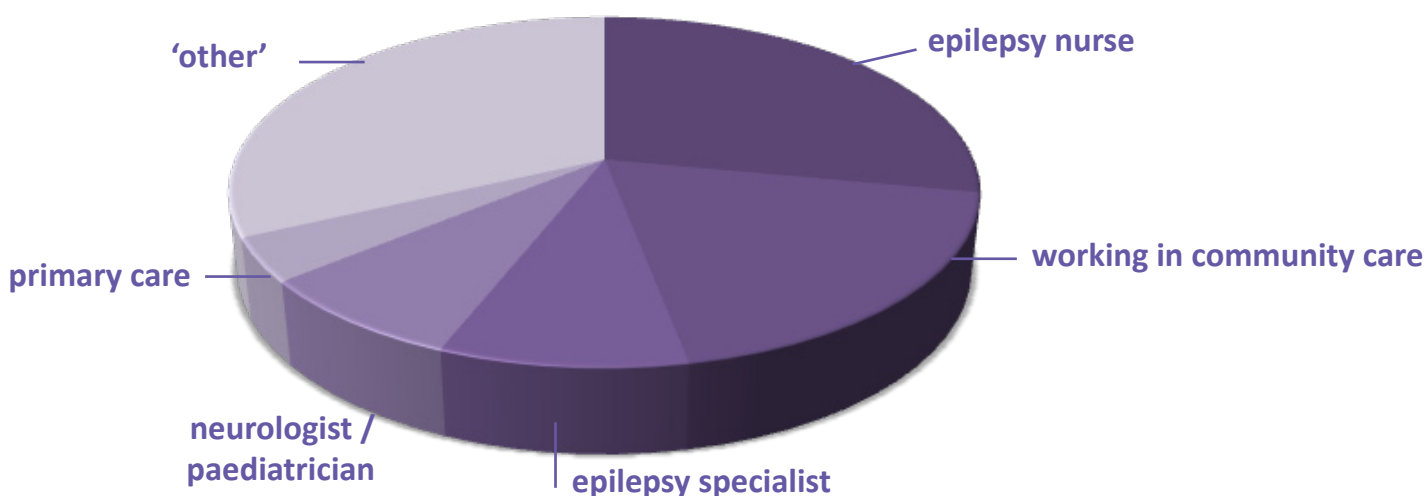
This survey focused on the experiences and views of professionals working with individuals with epilepsy and their carers.

54 respondents completed the healthcare professional's survey.
68% of respondents worked with adults with epilepsy, 32% worked with children with epilepsy.

"Their vital role is often invisible – they are a precious resource that is often neglected and undervalued."

Healthcare professional

Type of healthcare professional



About carers

Respondents were asked whether they invite carers of people with epilepsy into appointments with the individual. 95% of respondents said that they invite carers to appointments (74% always invite carers and 21% invite carers depending on the individual's wishes and consent). This is encouraging because the Department of Health* reports that "carers can often feel excluded by clinicians – both health and social care professionals should respect, inform and involve carers more as expert partners in care." The professionals responding to the survey were including carers wherever possible.

Do people identify themselves as carers?

Respondents were asked whether carers identify themselves as 'carers'. 45% of respondents said that carers do not identify themselves as carers.

When they see a carer who does not recognise themselves as a carer, 60% of respondents talk to them about what a carer is so that they can recognise themselves in the role. 42% give the carer information about being a carer, and 33% refer them to a voluntary organisation for carers. These results reflect the Department of Health's* view that people should be encouraged to identify themselves as carers.

"They may not wish to be labelled as carer. They may not recognise the advantages of being recognised as a carer."

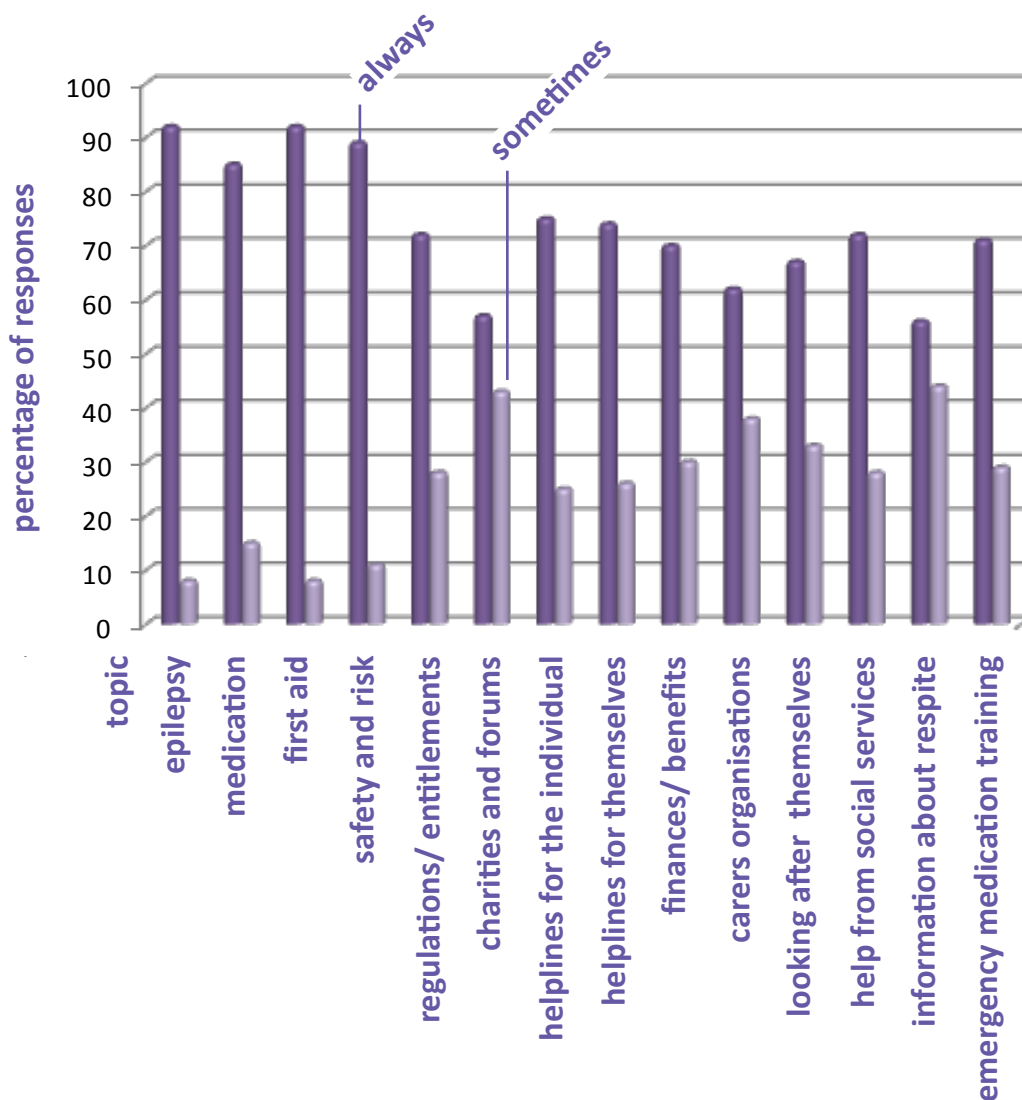
Healthcare professional

The information needs of carers

Respondents were asked what they thought carers of people with epilepsy need information about. This was broken down into 14 topics, and respondents were asked whether people would need information 'always', 'sometimes' or 'never'. Every respondent felt there was a need for information on each topic (either always or sometimes).

- 92% said carers always need information on epilepsy.
- 85% said carers always need information on medication.
- 92% said carers always need information on first aid and seizures.
- 89% said carers always need information on safety and risk.
- 72% said carers always need information on regulations and entitlements.
- 57% said carers always need information on charities and forums.
- 75% said carers always need information on epilepsy helplines for the person with epilepsy.
- 74% said carers always need information on epilepsy helplines for themselves.
- 70% said carers always need information on financial support and benefits.
- 62% said carers always need information on carers' organisations.
- 67% said carers always need information on looking after themselves.
- 72% said carers always need information on help from social services.
- 56% said carers always need information on respite care.
- 71% said carers always need training on giving emergency medication.

The information needs of carers



These responses showed that the healthcare professionals recognise that carers have information and support needs. Where they responded 'sometimes' this may be because they recognise that the needs of carers vary from one carer to another, and information needs to be tailored to the individual. The results support the Department of Health's statement* that "access to relevant and timely information and advice is vital throughout the caring role".

"I think how they perceive or label themselves is not as important as whether they are fulfilling a role they are happy with and also feeling supported themselves."

Healthcare professional

What challenges do carers face?

Respondents were asked what challenges they thought carers of people with epilepsy face. Responses included the following areas.

- The fear of seizures, managing seizures and seizures returning.
- The risks of injury or complications of seizures and epilepsy.
- A lack of emotional support and understanding from others.
- A lack of respite support and needing a break.
- Financial problems and difficulty finding work.
- Lack of involvement in decision-making about epilepsy management.
- Concerns about the future, and when the carer is not able to provide care.
- Getting the balance between safety and independence for the individual with epilepsy.
- The unpredictability of epilepsy.

These responses reflect the varied role of carers of people with epilepsy, and the varying needs that arise from this: from emotional support to help with social care, from lack of involvement to the need for financial support. It also reflects the vast impact that epilepsy can have both on the individual with epilepsy themselves and the carer.

What is the impact of caring on the health of carers?

Respondents were asked what impact they thought being a carer has on the carer's health. Responses included the following.

- Physical, mental and emotional stress, which is often long-term.
- Mood issues such as anxiety and depression, which can be made worse by stress, tiredness and lack of sleep.
- Feeling isolated, and neglecting their own health and needs.
- The impact of physical moving and handling, which affects their health.
- The impact that a caring role can have on relationships.
- The impact is not always negative: "caring can be rewarding and enriching, and with the right support carers may be prompted to check their health because of the caring role".

"Lack of support, loss of income, loss of independence, needing to have a break themselves."

Healthcare professional

"Carers are often not included in any decision making process or given accurate information, which impacts on how they can care and support the child and themselves. Many find this lack of information upsetting and stressful."

Healthcare professional

What is the general impact of caring on carers?

Respondents were asked what impact they thought being a carer might have on the carer *in general*. Responses included the following.

- Becoming isolated or lonely.
- Losing their freedom and how caring can be all-consuming: affecting lifestyle, social life and the carer's chance to fulfil their own ambitions.
- The impact on the carer's job when unpredictable seizures might mean that they suddenly need to leave work. And the financial impact of this.
- The impact on relationships and the wider family.
- Carers may not take up the support or advice that is offered to them.
- The emotional impact, including feelings of anger and frustration.

These two questions on the impact of caring reflects some of the issues identified by the Department of Health* about the impact of caring on the carer's physical and mental health: "carers can neglect their own health because they are so busy supporting someone else. But other health problems can arise that are directly associated with the caring role. Stress and anxiety can be related to concerns about the person who is being cared for, frustration about a lack of information and advice and 'battling' with systems and organisations to obtain help and services. Supporting carers to remain physically and mentally well is therefore a key part of the prevention and public health agenda."

Carers' rights and entitlements

Respondents were asked whether they tell carers about their rights and entitlements (such as benefits and free prescriptions). 17% always tell carers about their rights and entitlements and a further 63% tell carers about this if appropriate. Some refer carers to other professionals for this information. This suggests that the respondents are individualising what information they give to carers according to their personal situation, rather than 'as a standard'.

"They often feel responsible for everything negative that happens to the person in their care."

Healthcare professional

What information is given to carers?

Respondents were asked whether they provide information for carers. For every topic listed, most give the information ‘as appropriate’, and in a few cases, they refer carers to another professional, such as the GP or epilepsy nurse, for information.

For the carer themselves

- 84% give contact details for carers’ organisations.
- 91% give contact details for epilepsy helplines.
- 78% give information about help from social services, such as a carer’s assessment.
- 67% give information about benefits, such as Carer’s Allowance.
- 70% give information about self-help or self-management groups, such as the Expert Patients Programme.
- 82% give information about respite care.

For the individual with epilepsy

- 85% give contact details for carers’ organisations.
- 94% give contact details for epilepsy helplines.
- 84% give information about help from social services.
- 69% give information about benefits, such as Disability Living Allowance.
- 73% give information about self-help or self-management groups, such as the Expert Patients Programme.

Much of the information listed may be seen as more ‘holistic’, covering topics around lifestyle and wellbeing (such as self-management, social care and emotional support) as well as ‘traditional’ information about epilepsy.

Engaging services on behalf of carers

Respondents were asked whether they engage other services on behalf of carers (such as social services). 64% of respondents do engage other services on behalf of carers, and many do so either through their medical staff colleagues (such as an epilepsy nurse) or by working closely with social health professionals.

“A tremendous impact mentally, emotionally and physically.”

Healthcare professional

Notes

- In this report, all statistics are rounded up or down to the nearest percentage.
- Unless otherwise stated, the figures in brackets are absolute values.
- 'Majority' is taken to mean over 50%.
- Some people did not answer all the questions in a survey, so values given are the percentage of those who did answer any specific question, unless stated otherwise.
- Statistics are listed as number or percentage 'of respondents' to reiterate that the results are only that of the people who completed the survey and do not necessarily extrapolate to 'the population of carers (or people with epilepsy or healthcare professionals) in the country'.
- Where quotes are used, the respondent has given their consent to be quoted.
- Where respondents refer to 'NSE' this is an abbreviation of The National Society for Epilepsy, our registered charity name. Epilepsy Society is the working name of the charity, officially adopted on 1 January 2011.



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