



How can the web support carers?



This guide was commissioned by the Department of Health and produced by Crossroads Care and The Princess Royal Trust for Carers, leading organisations in their respective fields, sharing a vision that carers should be recognised, valued and supported.

Crossroads Care provides services to over 41,000 carers and their families via a network of more than 85 local schemes across England and Wales, enabling carers to have a break from their caring role and enjoy a life of their own while caring. By working with a wide range of third sector organisations both locally and nationally, services are developed and delivered to provide the widest choice to carers and those they support.

The Princess Royal Trust for Carers delivers comprehensive information and support to over 424,000 carers and approximately 28,500 young carers through its unique network of 144 independently-managed Carers' Centres, 89 young carers' services and two interactive websites - www.carers.org and www.youngcarers.net - which deliver support around the clock. The Trust also acts independently in the interests of carers through research, policy work and partnerships with other national organisations.

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Preface

Who is a carer?

A carer is someone of any age who provides unpaid support to a partner, child, relative, friend or neighbour who could not manage without this help due to age, disability, physical or mental illness or substance misuse problems. Anyone can become a carer; carers come from all cultures and all walks of life and can be of any age.

There are almost six million carers in the UK; that is one in 10 people - some as young as five years old. Many feel they are just doing what anyone else would in the same situation, looking after their mother, spouse, son or best friend.

Why do carers need support?

Taking on a caring role can mean facing a life of poverty, isolation, frustration, ill health and depression. 1.25 million carers care for over 50 hours a week¹. Many also work outside the home and are trying to juggle jobs with their caring responsibilities, while others give up an income, future employment prospects and pension rights in order to care. More than 80% of carers say that caring has damaged their health, and three out of four carers are financially worse off as a result of their caring role².

Carers say that access to information, financial assistance and breaks in caring are vital in helping them manage the impact of caring on their lives. But the majority of carers struggle alone and do not know that help is available to them. In fact, 33% of local authorities are providing services to less than 6% of carers within their area³.

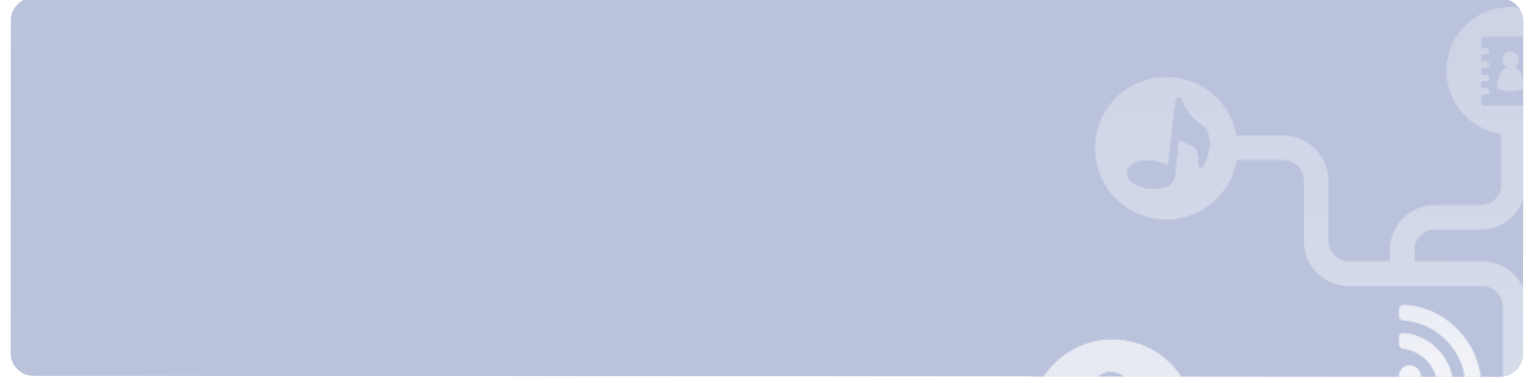
As the largest source of care and support in each region of the UK, carers are estimated to save the Government between £67 billion and £87 billion a year⁴, so it is clearly in everyone's interest that carers are supported.

¹ 'Key facts about carers', The Princess Royal Trust for Carers [online at <http://www.carers.org/node/35509>], accessed 1 May 2011

² Ibid.

³ Ibid.

⁴ 'Key facts about carers', The Princess Royal Trust for Carers [online at <http://www.carers.org/node/35509>], accessed 1 May 2011



With an ageing population, the number of carers in the UK will increase by around 60% to 9.4 million over the next 30 years⁵, making it more vital than ever to establish sustainable support structures that reach as many carers as possible.

How can the internet help?

In 2010, over 44 million people in the UK - 72% of the country's population - were online, and around 70% of households had broadband. In 2011, it is estimated that the number of internet users will rise to 45.5 million⁶, with the rate growing especially rapidly among residents aged 50 or older⁷.

This makes the internet an extremely powerful tool for reaching a great majority of people in a quick and cost-effective way, especially as 60% of adults say they go online every day or almost every day⁸.

Because nearly nine in 10 carers find it difficult to leave their home due to their caring role⁹, the internet has a very valuable role to play in providing access to services and support to those who have difficulty accessing them in the offline world, particularly as 95% of users mainly access the internet from home¹⁰.

As technology continues to develop and options for telecare and telehealth expand, the internet is likely to become an even more essential tool for carers, making the provision of online services and support more relevant and useful than ever.

⁵ Ibid.

⁶ 'Internet access households and individuals statistical bulletin 2010' (27 August 2010) Office for National Statistics [online at <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672>], accessed 30 April 2011

⁷ Karin von Abrams, UK Internet Users and Usage: Top 2010 Trends, (November 2010) [online at http://raceonline2012.org/sites/default/files/resources/emarketer_trends.pdf], accessed 1 May 2011

⁸ Internet access households and individuals statistical bulletin 2010 (27 August 2010) Office for National Statistics [online at <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672>], accessed 30 April 2011

⁹ 'Carers battling isolation can get help online', The Princess Royal Trust for Carers [online at <http://www.carers.org/press-release/carers-battling-isolation-can-get-help-online>], accessed 1 May 2011

¹⁰ Karin von Abrams, UK Internet Users and Usage: Top 2010 Trends (November 2010) [online at http://raceonline2012.org/sites/default/files/resources/emarketer_trends.pdf], accessed 1 May 2011

Introduction



Aims of the guide

This document has been written to act as a resource for all those involved in developing or providing online services for carers and their families.

Many organisations and local authorities are currently exploring how the internet can be used to reach more carers and to provide services more effectively. This guide offers advice and direction on the creation and expansion of websites and other online services for carers, based on the experiences of providers and the views of carers themselves.

This guide also includes information about barriers to accessing the internet and suggestions on how to overcome these issues; however the aim is not to advocate the replacement of real world services with websites. Online services should complement and add to the support that is already available, increasing carers' options rather than reducing them.

The following pages contain a detailed exploration of the advantages and challenges of providing carer support online, as well as the pros and cons for the main types of web services that are currently being offered or developed.

The recommendations contained in this report are the result of discussions with various stakeholders and extensive consultation with carers on what they like or dislike about particular websites and what additional online resources they would like to see developed.



Methodology

The first phase of the project involved a scoping exercise to establish what online services are currently available to carers. This was followed by discussions with the providers of many of these services, in an effort to mine their experience for recommendations based on their successes and challenges. Discussions were also conducted with various carer support organisations and other stakeholders to learn about their experiences with online services to date, and a trawl of research evidence was carried out to determine what other sources had to say on the subject.

The second phase of the project involved extensive consultation with carers across the UK via online, telephone and paper surveys, as well as a series of focus groups. The online survey, which contained questions about general internet use, particular kinds of websites and what features carers would like to see developed, was designed to take around 15 minutes to complete. It was widely publicised through carers' websites, attracting responses from 420 carers or former carers.

Carers who do not use the internet were offered the opportunity to answer questions over the phone or to complete paper surveys by post, which resulted in 31 responses to a series of eight questions about computer training and barriers to accessing the internet.



To explore some of the questions in more depth, focus groups were conducted in a variety of locations in England spanning urban as well as rural communities. Three of the groups were held in person at Crossroads Care schemes or Trust Carers' Centres, and one was held online in a chat room.

Each focus group was attended by between four and 15 carers from a variety of backgrounds and with differing levels of internet use – from regular users to those who never go online. Lasting from one to two hours, each group centred on a structured but open-ended discussion about particular types of websites followed by a brainstorming session about what new online services would be the most useful. Carers at the in-person focus groups were also given a chance to write down any thoughts they did not feel comfortable sharing with the group.

The statistics and quotations on the following pages come directly from carers; their answers to the survey and focus group questions have been used throughout this report to illustrate a range of issues, options and recommendations.



Summary of findings

The internet is an important tool for carers which can help to improve their ability to care, and increasing internet usage presents an ideal opportunity for service providers to reach a wider audience. Different carers have different needs and no one solution or type of website will suit everyone, so it is important to consider all the issues involved in offering online support and to weigh the advantages and disadvantages of each type of website.

Key findings

- The 24/7 nature of the internet makes it an indispensable resource for carers, and there are great benefits to making support services available online.
- Getting more carers online is essential to ensure that they are able to access all the information, services and support that are available.
- Online services should complement and add to the support that is already available, increasing carers' options rather than reducing them.
- Not all carers use the internet and even those who do may not always be able to access services online or may prefer to use another method. In cases where information or a particular service can only be accessed online, there is a danger that many carers will miss out.
- Consultation is the key to ensuring that online and offline services meet the needs of local carers.
- Exploring all the benefits and challenges of different types of websites can help providers design services that maximise resources and meet the needs of local carers.
- There are several existing tools and websites that may be able to be adapted to meet local need. Research and collaboration are essential starting points for maximising resources and avoiding duplication.

Key facts

- Over 98% of online carers¹¹ usually access the internet from home, with only 5% regularly using public computers.
- Almost one in 10 net-using carers usually access the internet using a mobile phone.
- More than 60% of carers who use the internet are always logged on or go online several times a day.
- 99% of online carers use email, almost 45% have used instant messaging and 20% have used video chats.
- 94% of net-using carers shop online, and over half have bought groceries online.
- Seven out of 10 online carers say that the internet saves time, and five out of 10 finds that it helps them save money.
- 64% of carers say that keeping up with friends and family is one of their main reasons for going online.
- 42% of online carers say that the internet helps to reduce their feelings of isolation.

¹¹ The terms 'online carers', 'net-using carers' and 'carers who use the internet' have been employed interchangeably throughout this report to refer to carers who identify themselves as internet users, regardless of the frequency of their internet usage.



Types of online support

- **Information websites:** More than seven out of 10 online carers use the internet to search for information related to caring, and almost half of these are searching at least once a week.
- **Forums and chat rooms:** More than a fifth of net-using carers have visited chat rooms, and the same proportion regularly access online carers' forums. Almost half of these visit carers' forums more than once a week, with a quarter visiting at least once a day.
- **Online networks of support¹²:** 14% of online carers have online networks of support to exchange information about the person being cared for, get help with tasks or receive support with caring from friends, family and other contacts.
- **Online breaks bookings:** Around 6% of net-using carers are making care arrangements online, and 4% have used a website to book a caring break.
- **e-Learning:** 30% of online carers have taken part in e-learning, but only 9% of these programmes contained content relating to caring.
- **Podcasts:** One in 10 net-using carers listen to podcasts, while almost a quarter listen to online radio.

¹² Throughout this report, the term 'online networks of support' refers to internet tools that allow carers to link virtually with people they already know in the real world, specifically for the purpose of getting emotional or practical support around their caring responsibilities. Often the other members of the network will also have a real-world relationship with the person being cared for, with the online network created for the purposes of sharing information or facilitating practical arrangements such as medical appointments. These online networks are therefore different from the supportive networks that are formed with other carers in forums and chat rooms, where the participants each care for different people and may not know each other outside the virtual world.

How carers use the internet

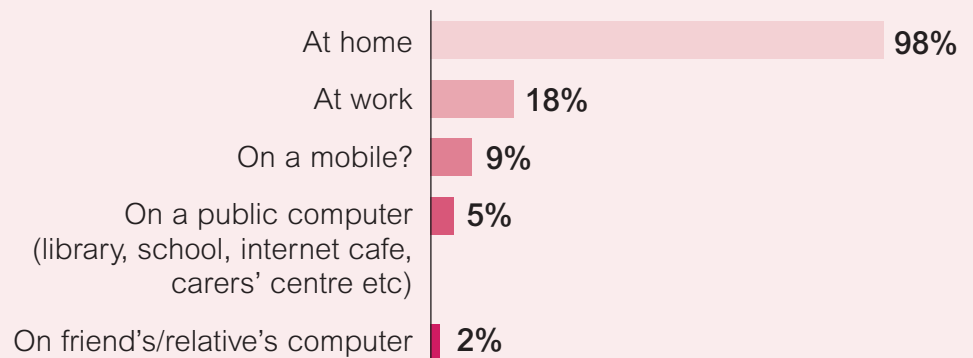
Many carers say that the internet is essential to their daily life, and there are some common trends in the way that it is used.

"I use dozens of different sites every day."

Where do carers access the internet?

Almost all carers who use the internet usually access it at home, while only a small proportion (5%) use public computers. 20% of online carers have used a mobile phone to access the internet, and almost one in 10 do so regularly.

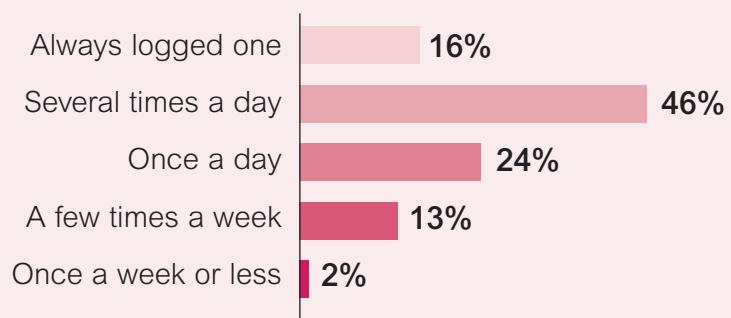
Where do you usually access the internet?



How often do carers go online?

More than 60% of net-using carers are always logged on or go online several times a day.

How often do you get online??





What do carers do online?

Carers use a variety of different websites and technologies, with email being the most widely used tool.

| Have you ever used any of the online technologies? | Percentage of carers |
|--|----------------------|
| Email | 99% |
| Online television | 56% |
| Instant messaging | 45% |
| VOIP telephone calls | 30% |
| Streaming videos | 29% |
| Internet radio or streaming music | 24% |
| Chat rooms | 23% |
| Photo sharing websites | 21% |
| Video chats | 21% |
| Accessing the internet via a mobile | 20% |
| Downloading mobile apps | 12% |
| Podcasts | 11% |
| Online gaming | 10% |



Why do carers go online?

“The internet makes a lot of things possible.”

Just as there are a wide variety of technologies being used, there are also many different reasons for going online, with checking email, looking for information and keeping up with friends and family being the most popular.

| What are your main reasons for going online? | Percentage of carers |
|---|----------------------|
| Checking email | 97% |
| Looking for information | 89% |
| Keeping up with friends and family | 64% |
| Shopping | 60% |
| Banking or paying bills | 59% |
| Keeping up with current events | 45% |
| Booking holidays or other services | 36% |
| Work or education tasks such as research | 35% |
| Social networking | 34% |
| Entertainment (games, music, television, films etc) | 22% |
| Surfing the web just to pass the time | 20% |
| Participating in discussion boards and chat rooms | 18% |
| Reading blogs | 7% |
| Making care arrangements | 6% |

Why carers need the internet



"I'd be absolutely lost without the internet."

"For me, internet access has to be an essential consideration for carers."

Many carers face common challenges, and the online world can be particularly useful in addressing these. Such challenges include:

Time and money

"Carers are very busy people and busy people need to maximise the hours in the day! I could not do all I need to do without access to the internet."

Many carers are short on time and money, and the internet can be an excellent way to maximise limited resources. Seven out of 10 carers say that using the internet helps save time.

"I like sites that give me the ability to shop around."

Almost half of carers find that the internet helps them save money. Price comparison sites can be particularly useful, and shopping online is often the cheapest way to purchase goods and services.

Irregular hours

"The internet is essential for 24 hour carers."

Many carers have unpredictable hours, which makes the round-the-clock availability of the internet particularly useful. From accessing information outside of normal business hours to connecting with others or watching television on demand, the internet provides access to a host of sites and services at any time of day or night.



Inability to go out

“When you’re caring for someone, there might unfortunately be a day, week, month or year when you can’t leave the person. So what are you going to do?”

Nearly nine in 10 carers find it difficult to leave their home because of their caring role¹³. Many carers may also have their own health issues which make it difficult for them to go out. The internet can be the gateway to a wide variety of services, support and activities that might otherwise be inaccessible to those who are housebound.

Isolation

“I feel I’m not alone.”

Over half of carers admit to feeling alone and isolated¹⁴, and the internet is a powerful tool for reducing this isolation because it connects carers round-the-clock with people, services and information. 42% of online carers say that the internet helps to reduce their feelings of isolation.

Breaks from caring

“The internet stops me thinking about caring.”

Taking regular breaks from caring can help protect carers’ health and well-being, and many carers find that going online can be a good way to take a break.

“When I get stressed, I go into my room and surf the net for a bit, which helps calm me down.”

One in five online carers say they like to surf the net just to pass the time, and one in ten like to play online games. Social networking, blogging and keeping up with current events are also used by many carers as a break from their caring responsibilities.

¹³ ‘Key facts about carers’, The Princess Royal Trust for Carers [online at <http://www.carers.org/node/35509>], accessed 1 May 2011

¹⁴ ‘Carers battling isolation can get help online’, The Princess Royal Trust for Carers [online at <http://www.carers.org/press-release/carers-battling-isolation-can-get-help-online>], accessed 1 May 2011



Socialising

“The internet has changed my social life as a carer. Before the internet I had none.”

“The internet is my link to friends, conversation and news.”

71% of online carers say that the internet helps them to stay connected to family and friends, and 64% of carers say that this is one of their main reasons for going online. Carers who are unable to meet up with contacts in the offline world can connect with their contacts online without leaving the person they care for.

“You’ve got somebody there who knows where you’re coming from.”

The internet also allows carers to connect with other carers, which can help to reduce feelings of isolation. 34% of online carers say that connecting with other carers is one of the positive ways that the internet impacts their caring role.

Flexible working

“It’s enabled me to work from home, so the internet’s been the key to freedom.”

One in five carers gives up employment to care¹⁵, but the internet has created more opportunities for telecommuting and flexible working, which can help many carers to juggle work and care. 20% of online carers say that using the internet to work from home has had a positive impact on their caring role.

Having a life outside of caring

“It enables me to pursue hobbies whilst in same room as a cared-for person.”

It is important for carers to be able to have a life of their own alongside their caring role, and the internet enables many carers to pursue their hobbies and interests as well as education and employment opportunities.

¹⁵ ‘Key facts about carers’, The Princess Royal Trust for Carers [online at <http://www.carers.org/node/35509>], accessed 1 May 2011



Entertainment

"We need fun and relaxation."

"Because I'm a parent carer, I don't get to go out in the evenings much at all. I use the internet to relax at home. It's a way of winding down from the day and switching off for a while."

One in five carers say their main reason for going online is for entertainment purposes such as watching television, playing games or listening to music. 35% of online carers listen to internet radio or podcasts, 30% watch videos on sites like YouTube and Vimeo, while 10% play games online.

More than half of online carers use the internet to watch television on sites like BBC iPlayer and 4oD that offer programmes on demand. The flexibility to watch programmes at any time, and to pause them when necessary, can be very useful for carers.

Shopping

"I buy anything I can online to save money and time."

94% of net-using carers shop online, buying everything from books and clothes to car insurance.

"You can use internet to shop when you can't get out."

Almost nine out of 10 connected carers say that online shopping is particularly useful to them as a carer, often because it is difficult to find time to go shopping or they are unable to leave the person they care for, and 58% of online carers say that the internet gives them access to products that they would not otherwise be able to find.

"I could not manage our monthly food shop without the internet as I cannot carry heavy loads. We're too far away from supermarkets or clothes shops, and I've no time to get there anyway with fulltime caring."

Over half of online carers have bought groceries over the internet, and 22% do so regularly. In addition to their caring responsibilities, some carers have their own health issues which make it difficult for them to get out of the house or to carry heavy shopping.



Information

“The internet has been a valuable resource for finding information relating to my daughter’s and husband’s medical conditions.”

Carers need access to information, and going online provides an instant connection to a wide variety of data and resources. More than seven out of 10 online carers use the internet to search for information related to caring.

“My daughter’s medical condition is very complex ... By putting all the information in and researching it, I found out about a particular disorder and then I managed to find Britain’s leading expert ... and phoned him up and got an appointment.”

Benefits for those being cared for

“My husband used the computer a tremendous amount and I was very grateful to it from my husband’s point of view. If we hadn’t had a computer, I don’t know what he would have done because he used to spend most of his time on the computer.”

The internet can provide numerous benefits for people with disabilities or health problems. It is particularly useful for those who are housebound or have mobility problems, as websites can provide access to a wide variety of services, education, entertainment and opportunities for communication and interaction.

“I do so much on the internet and it means Mark still has an input in day to day living even though he is so housebound.”

The web can also enable the cared for to be involved in making decisions and planning their own care.

Benefits of providing carers' services online



"The internet brings great benefits."

In addition to the positive impact of general internet use, the internet can offer additional benefits by acting as a platform for the delivery of specialist support and services. The specific advantages of different types of websites are outlined in detail in the section covering types of support, but there are several benefits that are common to all carers' sites including:

Reaching more carers

"The internet brings the world to us when we can't get to the world."

Many carers are short on time and money, have unpredictable schedules and may be housebound or even restricted to a single room in their home in order to stay near the person they are caring for. These restrictions may limit carers' ability to access offline services. In fact, nearly half of carers have no free time to visit support services¹⁶, so online services can provide access to a wider proportion of carers.

Maximising options

"We need a range of options."

Because every caring situation is different, carers need a variety of options for accessing services, and the internet provides opportunities for personalising the support that is being offered.

"The internet will not suit all, but I think it's a useful addition to existing ways of communicating."

The 24/7 nature of the internet can add flexibility and choice for carers about when, where and how they access services.

¹⁶ 'Key facts about carers', The Princess Royal Trust for Carers [online at <http://www.carers.org/node/35509>], accessed 1 May 2011



Laying the groundwork

“Face-to-face contact is useful but internet can give you the info you need first so you can be informed before the meeting.”

The web can be an excellent first stop for those searching for information or preparing for an in-person meeting or telephone appointment.

“There's a lot of stuff out there but if you don't know what questions to ask in the first place you won't find out about all the help you can get.”

Providing online information can help to maximise carers' use of offline services.

Benefits to organisations

Providing services online can have knock-on benefits for providers by helping to reduce costs, staff time and administration.

Challenges for providers of carers' services online



Digital exclusion

The biggest challenge facing providers of online services is the fact that 9.2 million UK adults have never used the internet¹⁷. Almost half of these are from disadvantaged groups: 39% are over 65, 38% are unemployed and 19% are families with children¹⁸.

A third of all carers are over 65, three out of four carers are financially worse off as a result of their caring role, and one in five has had to give up work to care¹⁹, which means that many fall into the disadvantaged category. As a result, they are less likely to be able to access the internet.

There are several factors that need to be overcome to get more carers online. These include:

Geographic restrictions

Some areas of the country have no broadband coverage. Many rural carers are not able to get online simply because broadband is not available in their area.

Financial barriers

Many carers are on tight budgets and may be unable to afford a computer. In some cases, carers may wish to purchase computer equipment using Carer Direct Payment or Carers' Allowance, and some areas are trialling "prescription laptops" for carers.

"A lot of carers are on a minimum financial budget and just to have that broadband package on top of the phone bill can be just that little bit too much."

Even for carers who have a computer, the ongoing costs of broadband costs can be too much. Many carers would like to see the creation of a dedicated ISP to provide free broadband.

¹⁷ 'Internet access households and individuals statistical bulletin 2010' (27 August 2010) Office for National Statistics [online at <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672>], accessed 30 April 2011

¹⁸ Race Online 2012: Manifesto for a Reworked Nation (12 July 2010) [online at <http://raceonline2012.org/node/2011>], accessed 25 April 2011

¹⁹ 'Key facts about carers', The Princess Royal Trust for Carers [online at <http://www.carers.org/node/35509>], accessed 1 May 2011



Public computers

People who cannot get online at home may be able to access the internet from a public computer, but many carers are unable to afford the charges at internet cafés and even some libraries. Carers would benefit from a voucher system that would allow them to access library computers for free.

“Carers’ time is precious and they can’t always get to the library.”

Because many carers are not able to travel or be away from home for long, there is a need for more computers with internet access in places carers frequent such as carers’ centres or even GP surgeries, with free or low-cost access and a flexible booking process that does not tie carers down to a particular time slot.

Training needs

“I have a computer and I can switch it on, but I still don’t understand it.”

There is a need for training to get more carers online, but many carers may not be able to access mainstream training opportunities due to their caring responsibilities.

“There have been courses at the local library but I have not been able to attend.”

Training aimed at carers must be low-cost and flexible to accommodate carers’ tight budgets and sometimes unpredictable schedules.

“The course was trying to cover so much in six weeks, you can’t take it all in.”

“One-to-one sessions on the topics that are useful to you would be best.”

Because carers are often short on time, it is important for courses to be as focused as possible on the skills that they actually need and want.

“When you get home, your screen looks totally different.”

“It would be good if you could bring your computer in and could have someone who could show you on that actual computer.”

Often carers would prefer training that is personalised to their learning needs and takes place in the home on their own equipment.



Risks and dangers

“I worry about making a mistake and sharing sensitive information with the wrong people.”

“I do have a computer and I’m working on a diploma in computing but I don’t have the internet at home. Why would I want to run all these risks when there are alternatives? They might be slower, they might be more long-winded, they might be more difficult, but they don’t have all those risks attached to them.”

Many carers have fears about online dangers such as viruses, hacking and identity theft, and some feel that the risks outweigh the benefits.

“If you don’t use it, you’re frightened of it.”

Training, awareness and confidence building programmes may be needed to minimise the risks and encourage more carers to overcome their fears.

Ongoing support

“People set you up with these things and then leave you to cope.”

Carers often worry about what would happen if something went wrong with their equipment or software, and these fears can cause some to avoid computers altogether. There is a need for access to ongoing support so carers know who to turn to with their tech problems.

Personal interest

“I thought the internet didn’t apply to me until I saw what it can do.”

Some carers feel that the web has nothing to offer them, but several organisations have been successful in getting carers to engage with the internet by giving individual demonstrations showcasing sites relating to the carer’s personal interests.

“There’s a whole world of opportunity on the web ... With familiarity, people can get switched on to it.”



Taking the time to show carers how the internet can be personally useful is a good way of getting them engaged.

“I didn’t use it until I found out I can talk to my granddaughter and see her on the screen.”

“My friend showed me a page about how to cook and also some videos of Indian music, and I was hooked.”

“My daughter lives in America, and I was so excited when someone showed me the webcam on the main street in her town. Now I go on the computer all the time to see what is going on near her.”



Organisations Helping Carers Get Online

“The carers we have given laptops to say it has changed their lives.”

UK Online Centres offer free computer courses throughout the UK. The website also provides support for organisations that offer free or low cost internet access to the public.

<http://www.ukonlinecentres.com/>

Digital Unite specialises in supporting older people to use digital technologies through IT training, campaigns, online learning and special events.

<http://digitalunite.com/>

Age UK offers computer training courses to older people across the UK, with an annual event – iTea and Biscuits – offering taster sessions to get people interested in technology and the internet.

<http://www.ageuk.org.uk/work-and-learning/technology-and-internet/>

SCIE Get Connected is a capital grant scheme that aims to enable providers of care for adults in England to access information and communication technology (ICT) more effectively. Applications for funding are now closed, but the website contains details of successful projects and practice examples of how organisations have used ICT systems to improve care services.

<http://www.scie.org.uk/workforce/getconnected/index.asp>



Race Online is a national initiative aiming to make the internet universally available by 2012 through campaigning, forming partnerships with other organisations and recruiting Digital Champions.

<http://raceonline2012.org/>

BT's Get IT Together offers free advice and support to individuals getting online or helping someone else to get online, and initiatives to help organisations that provide internet access and training to communities.

<http://www.bt.com/includingyou/getting-online.html>

Citizens Online is a national charity promoting digital inclusion through project work, partnerships and campaigns.

<http://www.citizenonline.org.uk/conline>

AbilityNet is a national charity helping disabled adults and children use computers and the internet by adapting and adjusting their technology.

<http://www.abilitynet.org.uk/>

Computers4Carers is a grassroots initiative that campaigns for free laptops and distributes reconditioned computers to carers. The website is affiliated with the Chill4Us community which provides a place for carers to meet online.

<http://www.computers4carers.co.uk>



Other challenges and consideration

Even among those carers who have the skills, equipment and resources necessary to get online, there may be other barriers that prevent them from accessing online services, including:

Time constraints

“Some days I won't get online at all because I'm too tired or busy.”

Carers often lead very busy lives and their caring responsibilities may make it impossible for them to find time to go online. Even those with the right equipment and training may find that it is just not possible to use the internet on a regular basis.

Accessibility issues

“I have difficulty using the mouse. My coordination has never been that good.”

Some carers may have physical problems that make it hard for them to use a computer. Others may have learning disabilities such as dyslexia which can make reading difficult.

Language problems

“It takes a long time to translate every word into my language.”

For those carers whose first language is not English, trying to absorb information or communicate effectively using only the written word may be more challenging and time-consuming because there are no facial cues or body language to aid the process.

Connection speeds

“We live in a small village and the internet speed is not good. If you try and go on during peak hours it is extremely slow or you quite often fail to get on at all.”

Many internet users complain of slow broadband or sudden losses of connection. When time is tight, such obstacles can be incredibly frustrating and might lead to abandoning the task altogether. In cases where information or a particular service can only be accessed online, there is a danger that many carers will miss out.



Computer location

“There’s no room for a computer upstairs, but that’s where I spend my time so I’m close to my husband in case he needs me.”

Some carers who have a computer are unable to use it because of its position in the home being inconvenient or inaccessible while they are caring. This may be less of a problem for those with a laptop, though sometimes space is so tight that even a laptop cannot be accommodated near the person who is being cared for.

Personal preference

“It’s not something that appeals to me ... There are a 1,000 other things I’d rather do than sit down at a computer.”

Some carers are not interested in getting online. As with any technology, there will always be some people who choose not to use it. There may also be regular internet users who prefer face-to-face contact or telephone conversations when dealing with caring issues.

“The internet is good and all that, but, whatever happened to good old face to face contact?”

Using the internet for fun

“I don’t always want my carer hat on ... I like sites that are just for fun.”

Many carers go online to take a break from their caring role, and they may not wish to use the internet to access services or information.

Increased isolation

“If everything is online we will be even more isolated.”

While some carers find the internet helps them to feel more connected, others feel that it increases their isolation. For this reason, many carers prefer to access information, support and services via the telephone or face-to-face rather than online.

“I’m reluctant to spend any more time on computer than I do already! I prefer going to a monthly carers’ group to exchange views, information etc.”



Organisational barriers

Organisations providing online services may sometimes meet with internal barriers or resistance from staff and other stakeholders. Lack of skills and staff time are a problem for many voluntary and community groups, as is apprehension about new web technology²⁰.

To ensure the success of online services, organisations must ensure that the internal structure and culture are designed to embrace change and foster a willingness to learn new skills and engage with new web technology.

²⁰ Caitlin McMullin and Stacy Pritchard for Urban Forum, Community 2.0: The use of computers, the internet and social media in the voluntary and community sector, (2011) [online at [http:// www.urbanforum.org.uk/publications/the-use-of-computers-the-internet-and-social-media-in-the-vcs/](http://www.urbanforum.org.uk/publications/the-use-of-computers-the-internet-and-social-media-in-the-vcs/)], accessed 1 May 2011

Guidelines for carers' websites



There are a number of general considerations that apply to all kinds of carers' websites. No matter what type of online service you are creating or developing, it is important to bear in mind the following issues:

Involving carers and their families

"Different groups of carers and different individuals have different needs."

As with all carers' services, the development process for online services should be based on consultation with carers. Before developing any new service, whether online or offline, it is important to involve local carers to find out what they need and what kind of services will meet those needs.

"My family and friends do have internet, so I'm more than likely going to pick up the phone and say "Would you do this for me?" That's how I use it, which is indirectly but it's just as efficient for me."

Those who do not use the internet often have family members who do, so it is a good idea to consider families as well as carers themselves when setting up carers' websites, as family members may well be the ones accessing online services on a carer's behalf.

Including the people being cared for

"What's missing is somehow the person getting cared for gets excluded. How do we make it more inclusive?"

When thinking about services for carers, it is important to take into account the people being cared for, as they can sometimes get left out of the equation. Many people being cared for are able to use the internet themselves, and it may be useful to consider how a website for carers might also be able to link to other services and support and involve the cared for in decisions about their care.

Overlap and duplication

Before creating a new website, it is a good idea to establish what already exists. In some cases, it might be possible to signpost to an existing service or to join forces with a site that shares your aim, purpose or audience.



For services like online booking or forums, there may be an existing system that you can purchase or adapt, which will save time and money in the development process.

Relevance to the local area

“The way things work in England is completely different from the way things work in Scotland or Wales. It’s not the social difference, it’s the different bureaucracies and the different way things are run.”

In many cases, it is useful for websites to be tailored to the local area. Think about whether you are aiming for a national audience or a smaller region, and be sure to tailor your site to meet the needs of your intended visitors. Many carers are particularly interested in what is available in their local area, so this may be a good place to start.

Cost to carers

“I am struggling financially so having to pay for services would be a problem.”

Because many carers are on tight budgets, it is important to consider very carefully before instituting any charges for use of a website. It is also a good idea to restrict the frequency of requests for donations on your site.

“Services must be free.”

Many carers say that they would not consider using any online service with a fee attached, as it is already a stretch to cover broadband costs.

Disability access issues

It is important to ensure that your website meets the requirements of the Equality Act. Carers and other users may have visual impairments or other disabilities that make it difficult for them to access websites that do not meet the standards of compliance.



Ease of navigation

“It is often difficult to find what you’re looking for on carer websites.”

Because many carers are short on time, it is especially important to ensure that online services have a straightforward structure, easy navigation and adequate search capabilities to make it as easy as possible for visitors to find their way around and locate the information they need.

Technical backup

Carers’ websites should be built on a solid technical foundation to ensure that the site runs smoothly with the absolute minimum of faults and problems. Users can be easily frustrated with endless error messages or functionality that does not function.

“If you get stuck, often it’s hard to find a contact number or even an email address.”

Ideally, offline support should be available if anything does go wrong. One of the top complaints from many online carers is not having access to a phone number that can be used in cases where there is a problem with the website. A phone number, or at the very least an email address, should be easily accessible from the home page rather than buried away somewhere in the depths of the site. Many carers also expressed a strong preference for a live human voice at the other end of the phone line, rather than an automated service.

Privacy and security

Maintaining the safety and integrity of data on your website is crucial to user confidence.

“As carers, we are very protective of the people we care for, and I’d feel nervous about putting a lot of those details on a website unless I knew it was really safe.”



Many carers have concerns about sharing sensitive information online, so if your site asks for personal details you will need to establish strong security protocols and spell them out very clearly in order to ensure that users are comfortable in sharing such data.

If you are providing services to young carers or other vulnerable groups, it is especially important to consider issues of safeguarding and security.

Linking services and systems

Many providers say that interfacing online services with existing systems is one of the biggest challenges when creating a website. It is worth taking the time to investigate how a website will work with your offline processes before embarking on a project. This is particularly important for services such as online booking sites involving financial transactions, as it may take some extra work to ensure that data from the website can interface with your accounting and other bookkeeping software as seamlessly as possible.

Taking these issues into account from the very beginning can reduce overall administrative time and costs for the life of the website.

Carers who do not realise they are carers

“Many carers don’t even know they are carers.”

Carers do not always identify themselves as carers, so it is particularly important to ensure that there are multiple ways to navigate to a site providing support and services. When creating a website for carers, it is often a good idea to include a page explaining what a carer is and to include links to your site on sites relevant to people being cared for.

Providing offline options

“Technology can help but it cannot replace.”

It is important to remember that not all carers use the internet and that even those who do may not always be able to access services online or may prefer to use another method. Providing offline options in addition to your online services will ensure access to the widest possible group of carers.

Types of online support



Many organisations and local authorities already offer websites aimed at carers, and others are looking to develop such services.

“For many who don't access physical carers' services it's about providing what will be most useful for them online.”

Each type of website has its own advantages and disadvantages. Below is a summary of the benefits, challenges and recommendations for each of the major types of online carers' support currently being delivered or developed.

Information websites

More than seven out of 10 online carers use the internet to search for information related to caring, and almost half of these are searching at least once a week.

Carers say that the type of information available is the most important factor in which site they use, with regular updates, links to other websites and the availability of telephone numbers for offline support also cited as important features.

| What do you like about the information sites that you use? | Percentage of carers |
|---|----------------------|
| Type of information available | 76% |
| Available at any time | 72% |
| Links to other sites and resources | 59% |
| Information is up to date | 53% |
| Breadth of information available | 48% |
| Contact details for helplines and other offline information sources | 46% |
| Easy to find what I want | 41% |
| Search function | 23% |
| Other | 3% |

“Just type anything in and you can find an answer.”



Nine out of 10 carers searching for caring information online are looking for particulars relating to a specific illness, disability or condition, while more than half of carers are searching for details of local support. Many carers also use the internet to find information about financial assistance as well as details of medical equipment and adaptations.

| What do you like about the information sites that you use? | Percentage of carers |
|---|-----------------------------|
| Information about a specific illness, disability or condition | 90% |
| Details of local support | 56% |
| Benefits advice | 52% |
| Equipment and adaptations | 50% |
| Other people's stories and experiences | 41% |
| Financial information | 34% |
| Respite care | 24% |
| How to take care of yourself | 24% |
| Carers' assessments | 21% |
| Carers' employment information | 16% |
| Bereavement | 6% |
| Other | 6% |

It is clear that a range of websites is needed to meet the demand for different types of information, and there are number of advantages, disadvantages and issues to bear in mind when creating an information website.



Benefits:

Available to anyone at any time

Information on unrestricted websites can be accessed by any carer with an internet connection, regardless of their identity or location. This means that carers and their families can instantly access a wide range of facts and resources.

The 24/7 availability of the internet makes it a particularly good resource for carers needing information in times of crisis or simply a moment of free time that does not coincide with normal business hours.

Latest information

Websites can be updated much more easily, quickly and cheaply than printed material, so the internet is often the most logical place to store or search for the latest information. Websites allow providers to disseminate new information widely and quickly, keeping up with the ever-changing world of medical research and government policy with the minimum of effort and cost.

Local needs

Information websites can be tailored to meet local needs and can be easily updated or expanded as these needs change and develop.

Reduced costs for providers

Using a website to disseminate information can be very cost effective as it can cut down on printing and postage as well as administration costs.



Challenges and recommendations:

Site navigation, searches and indexes

“I often find it difficult to narrow the search for the information I want to obtain.”

40% of online carers who do not use the internet to search for information say this is because they do not know how to or cannot find what they are looking for.

“On some websites you can spend a lot of time searching for the exact information you need. You can go down a lot of blind alleys.”

Straightforward site layout and easy navigation are very important to ensure that carers can access the information they need.

“Sometimes I don't really know what it is I do want, an index of things would be more helpful than a search at times.”

Simple and comprehensive search functions are very useful, as carers often begin their search with a keyword or phrase. In many cases, it can also be a good idea to include an alphabetical listing, index or drop-down menu that can be scanned for relevant categories by those who are unsure what information they need.

Accuracy and duplication

“I think sites carrying clinical or medical information need to be verified or ratified by an independent body. There are so many sites out there with a political or religious axe to grind!”

Not everything on the internet is accurate and reliable, and many carers find that it is difficult to know which sites and sources to trust. It is essential that carers' websites contain “good quality information”, use reliable links and are open about their sources.

“There's a lot of the same thing. You have to siphon out what you're looking for.”

At the same time, it is important to avoid duplicating existing websites. Carers often find that they have to trawl through multiple web pages or links, all of which contain very similar information.



Tone and audience

“When I was trying to find out information about MS, most of it was either very scientific or nothing about what I'm looking for.”

Carers sometimes find information that is relevant to their situation but is presented in a manner or language that is difficult to interpret or understand. This is particularly true for issues relating to medical research.

“Whatever I look for ... a lot of it is not put in simple terms that I can understand.”

It is important to ensure that your website uses the correct terminology and tone for its intended audience.

Keeping information updated

“I have gone to a site and often found that it might be months or years out of date, so I get annoyed at having to keep searching and still not get the answer.”

In the fast pace of our modern world, facts, figures and even links can rapidly become obsolete. A website can instantly lose credibility and value if it contains a lot of out-of-date information. With more than a quarter of carers searching online for caring information several times a week or more, it is essential that carers' websites are maintained and updated on a regular basis to ensure that they contain the most appropriate and timely information.

Site registration

“On some sites you have to register to get information, so I don't bother.”

Because time is tight for many carers, information websites need to be accessible as quickly and easily as possible.

“I don't like filling in forms; for me they are confusing and I just get more confused trying to answer them.”

Many carers avoid websites that require them to register before being given access to information and instead continue to search elsewhere.



“I wouldn’t search the whole internet because anyone can say anything and how do you know if it’s true or not?”

However, some carers prefer to consult a trusted source first and may even choose to be sent regular updates on particular topics. In this case, a registration process may create a feeling of confidence around the information on the site and allow carers to narrow their search and request notifications and updates for content that is relevant to them.

Being printer-friendly

“I find things online then print them out and read them that way.”

Many carers like to print information from a website to read or share, so it is a good idea to make your website as printer friendly as possible.

“Some of my family don’t use the internet, so I print a lot of information and keep it in a folder for them.”

Carers who share caring responsibilities with family members, friends or neighbours who do not have access to the internet may also need to print much of the content from a website in order that it can be shared with everyone.

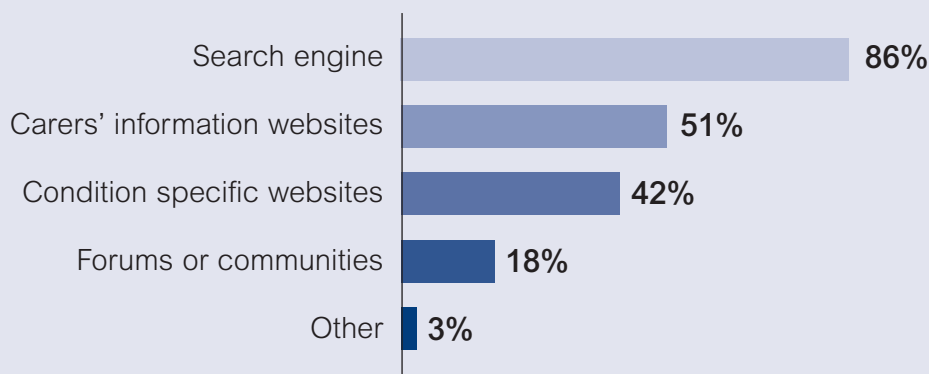
Dominance of the search engine

“I use Google because it’s easy to find what you’re looking for.”

More than 86% of carers who go online to look for caring information use a search engine as their first port of call. Search engine optimisation is therefore crucial to ensure that carers find their way to your website.



What is the main way you search for caring information online?



Carers who do not identify themselves as carers

"When I first became a carer I did not know where to go and many people are the same."

Because many carers do not realise that they are carers, it is essential to publicise your site as widely as possible and create links from other sites that carers are likely to visit. Condition-specific websites can be a good starting point for forming these links.

Offline alternatives

"I prefer to get caring information through the post and not have to search for it online. Also in paper form I do not have to switch the computer on."

Although internet usage is increasing, 39% of net-using carers still prefer to get their information another way than by searching online, so it is important to offer offline alternatives such as paper leaflets, a helpline or drop-in centre. It is crucial that the same information is available offline as online to ensure that every carer has access to the same quality of information.

"I think it's safer to ring the council when I need information."



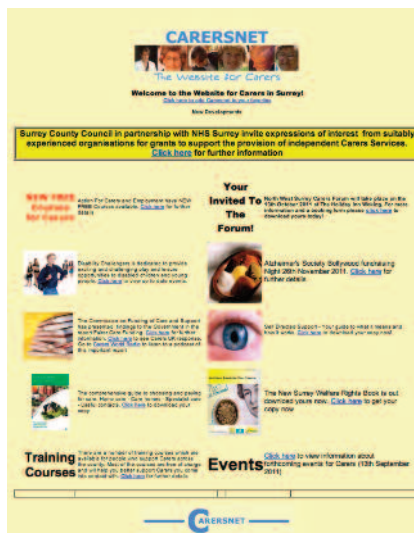
To ensure the consistency of information for all, some local authorities are developing sites that can be used internally by staff as well as externally by providers and carers themselves. This ensures that all carers have access to the same information, whether they find it online or get it over the phone.

EXAMPLE: Carersnet.org.uk

Carersnet is a county-wide website for Surrey, providing information on a wide range of topics relevant to carers in the local area. It was one of the first carers' sites and has been running successfully for almost 14 years.

Surrey County Council attributes the site's success to the fact that it is text-based, very simply built and easy to navigate, with a prominent search function. It has had the same look and format for many years, making it as easy as possible for regular visitors to find what they are looking for.

The site is updated regularly and contains information about local events, training courses, surveys, reports and publications, as well as details of carers' issues and local support organisations.



Forums and chat rooms

A forum or message board is an online discussion site where people can hold ongoing conversations in the form of posted messages, while a chat room is a part of a website where users can communicate in real time²¹. In most forums, the messages are usually archived for some time, and often there are several conversations or 'threads' going on simultaneously.

"I am able to communicate with other carers who really understand what a carer's life is like."

²¹ Internet Forum', Wikipedia [online at http://en.wikipedia.org/wiki/Internet_forum#cite_note-vBfaqFORUM-0], accessed 2 May 2011

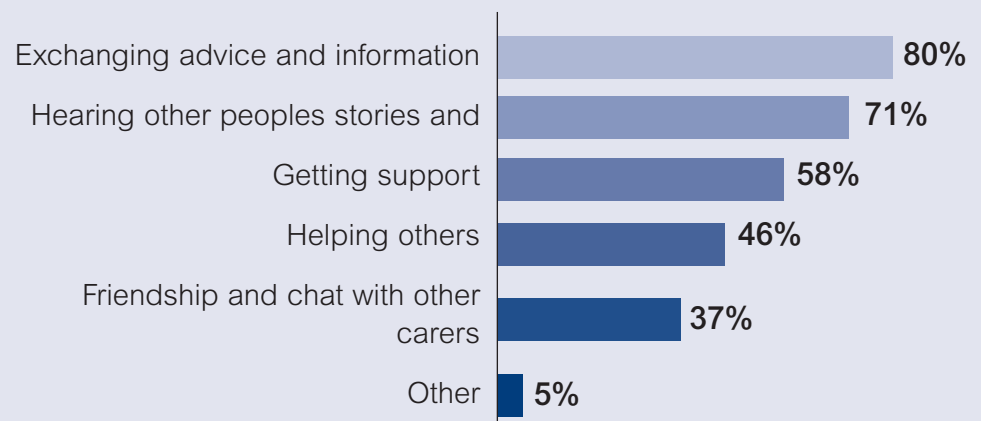


More than a fifth of online carers have visited chat rooms, and the same proportion regularly access online carers' forums. Almost half of these visit carers' forums more than once a week, with a quarter visiting at least once a day.

"You've got somebody there who knows where you're coming from."

Chats and forums allow carers to connect with "supportive people who are in the same circumstances." 80% of carers say that their main reason for using carers' communities is to exchange advice and information, while others value hearing stories from other carers.

What are your main reasons for visiting carers' forums or communities?



It is clear that forums and chat rooms offer a wealth of benefits for carers, along with certain challenges for providers.



Benefits:

Reduced isolation

“People have an opportunity to ask questions, talk about their feelings, let off steam. This can reduce isolation.”

Many carers find it useful to get support from other carers, and forums create the opportunity to interact with other people who “understand what it is like to be a carer”.

“It’s a good way to talk to people in the same situation even when there are none physically near you.”

Online communities bridge geographic borders, allowing carers from all over to share their stories and interact with each other.

“It’s someone to speak to if you are on your own and you’re very lonely.”

Many carers are housebound due to their caring role or their own health issues, and taking part in forums can be a way for them to connect to others without leaving home.

“You feel less isolated ... you are not alone in whatever problems you are trying to deal with.”

Always available

“I can access the forum at any time when it is convenient for me and when it fits in with my obligations, and there is always someone online with a wide range of experiences.”

Like other websites, most online forums are usually available 24 hours a day. Because many carers have busy schedules or unpredictable hours, it can be especially useful to have access to a community of carers at any time of the day or night.

“If I get stressed at night, I can chat online.”

Carers can feel more isolated at night when many traditional support services are unavailable, and online forums can bridge this gap to some extent by providing support 24/7.



Practical advice and information

“When you need help you can always find someone who has been down a similar route to give you some advice. It is also a place to share good news and bad, and there is always someone who will listen when you need a helping hand.”

Forums can provide carers with “instant advice and support” from people who have experienced similar situations and perhaps found solutions to common problems.

“We’re able to say, ‘Have you spoken to your local Citizen’s Advice? Did you know there’s a group locally?’”

Online communities can be a useful resource for carers to access suggestions from others who may have broader knowledge, specialist information or a different perspective on the situation, often providing a wider range of information than what may be available from a carer’s own support network or resources in their local area.

Hearing other carers’ stories

“It can help to know that others are in the same or similar situation.”

Many carers find it useful to share stories with other carers, and forums can facilitate this process. Some users may want to read stories that have been posted, while others may also find it useful to post about their own experiences.

“You can see people developing and getting better at caring. That’s the best thing about the site.”

Because of the live and up-to-the-minute nature of the internet, it is possible for carers to give updates about their situation on a regular basis, leading to a real feeling of investment in each other’s lives and more regular interaction than what would usually be possible with an offline group.



Emotional support

"It can be quite supportive if you're having a downer."

A carer's journey may include difficult emotions that need to be expressed to an understanding and listening ear. Online communities provide an ideal opportunity for this.

"If I have problems at home or need to talk to someone but can't call anyone then I could go on and talk to someone that can give me advice and not judge."

The fact that the other members are also carers can make it a safe place to share even the most difficult of emotions.

"We've got all these feelings that are really hard to share with anyone outside the situation because they might think 'She's awful for thinking that.' So it's good to be able to say what you feel."

The virtual nature of the internet makes it easier for many carers to talk about emotions or situations that might be too painful or embarrassing to mention in a face-to-face or telephone conversation. Typing rather than speaking also eliminates the worry that some carers feel about being overheard and judged by the person they care for or by other family members.

Friendship and connection

"You become part of a family, feel that you belong and look forward to everyone writing, especially as some days can be long and lonely."

Caring responsibilities can restrict a carer's ability to socialise, so many carers value the opportunity to form connections and friendships with other carers.

"I have often had bad days and being able to have a light hearted chat to people in the same situation can really help."

Forums and communities can also be a place for carers to take a break from caring and have fun. Chat room sessions or forum threads covering topics outside of caring give forum users a chance to talk about other subjects.



Helping others

“Sometimes I am able to help other carers.”

In addition to seeking support, forums also allow carers and former carers to pass on their knowledge and give support and advice to others. This can help to increase self-esteem which can sometimes be eroded by the caring role.

Challenges and recommendations:

Creating and running a forum or online community is not without its challenges. There are several issues to consider before embarking on such a project.

Target audience

Some online communities are open to all carers, while others are aimed at particular groups such as those from a common age range, geographical location or those who care for someone with a particular condition.

“I like chat rooms where people your age can talk to others who are in a similar situation somewhere else and can understand your difficulties.”

“I would be very interested in a group for carers of husbands ... It is very different caring for a spouse than caring for a parent.”

“It depends what the person you care for is suffering from. I don’t think talking to another carer without my problems would be useful.”

There is room for a wide variety of groups and forums to accommodate the different needs and preferences of different carers, but it is worth researching what already exists to avoid competing with an established forum with an identical target audience.



Using an existing tool or creating a new one

“We created a group on Yahoo.”

It may be possible to set up a new group on an established site or forum or to use a generic community tool such as Yahoo Groups or Google Groups. Many condition-specific websites may also have established forums with a dedicated section for carers, so it is a good idea to investigate these to see if it is possible to collaborate.

If your aim is to connect a group of carers who already know each other offline, you might also consider using social networking tools such as Facebook.

Navigation

“I don’t like having to search through to find the latest posts.”

Because forums have a multiple ‘thread’ structure, it is particularly important to have simple navigation methods in place. Easy navigation is essential so that visitors can find their way through the different conversations and locate what interests them as quickly and as easily as possible.

Rules and guidelines

It is a good idea to establish rules and guidelines for your community and to display these prominently on the site. This can help to put visitors at ease while preventing inappropriate behaviour.

“My assumption is that they are rather like cliques - unwelcoming to new members who don’t understand or know what etiquette is needed.”

It may also be useful to create an induction process to welcome new members, as many carers find it daunting to join an established community.

Anonymity

Some forums allow anonymous users to read and post messages, while others allow browsing but require some form of registration in order to post, and still others are entirely closed to anyone who is not registered. There are benefits and drawbacks to each of these



approaches, and it is important to consider what will be the most useful for the carers in your community.

“I only like going on websites that are secure not ones that are not.”

“I would like to access boards that are not open access.”

There are benefits to having a closed community that can only be accessed by those who are registered, but this can make it difficult to attract new members.

“I would want to remain anonymous, initially at least. I am a professional and feel that sharing my personal situation would compromise my status.”

“It would be nice to have a bit of info about the members. I would also like to know if they are male or female. Some have obscure names and could be a man or woman.”

Many carers find that the anonymity of the internet allows them to express difficult emotions, and they value the opportunity to interact without revealing any details about their identity. Other carers are wary of talking to complete strangers and may find it useful to know a little about others on the forum. It is important to consult with carers in your community to establish what would be the most useful for them.

Abuse and moderation

“I don't like aggression.”

Many carers are under stress or are in a vulnerable position, so it is essential to limit abusive language or aggressive behaviour in order to ensure that the community is a safe place for all to visit. Clear rules and regulations are useful for outlining what is expected from community members and may help to limit any problems.

“You don't know who you're talking to, do you?”

The anonymous nature of the internet can lead to situations of inappropriate behaviour or abusive language, and it is important to monitor forums and chat rooms on a regular basis. In addition to regular moderation, some sites require every message to be approved before posting and others use a group facilitator to foster positive interaction.



Funding and longevity

Building a community takes time, and it is important to think about the sustainability of your site. If ongoing or long-term financial support cannot be secured, consider carefully before creating a forum as these sites often require a high level of moderation and maintenance, as well as time and effort to get the community established. There is little point in creating a high-tech structure if you cannot invest the time necessary to get carers to visit the site, post messages and begin to form relationships.

Depending on the source of your funding, it is also crucial to consider the aims, objectives and issues of ownership for your site. One provider was offered funding from a private sector company to establish a carers' forum, but after the community had been built it became clear that the funders had their own agenda. Once the funders got what they needed, they promptly discontinued the funding and removed the infrastructure, effectively dissolving the community and terminating the relationships that carers had established.

Unlike many static websites, forums need a lot of ongoing input and support, which makes long-term planning essential before creating an online community.

Involvement of professionals

"I would be interested if there was a forum that had access to mental health professionals like councillors, CPNs etc."

Some carers value the opportunity to interact with professionals in forums or chat rooms, but it is important to consider how the involvement of professionals in a community of carers might alter the dynamic of peer interaction.

"I don't like care workers coming on the boards and acting like they're the same as carers."

It can be useful for professionals to identify themselves as such and to be clear from the outset about the level of involvement that they have on the site.



Additional features

As technology advances, so do the possibilities for interaction. Some carers and communities may wish to add video interaction or have the facility to arrange private chats with other group members.

“Not everyone has webcam though; they might feel left out.”

Each additional feature or technology has its own pros and cons, so it is important to consider carefully and consult with group members before adding additional features.

“I would like to see a facility that puts carers in contact with others who are in the same geographical region ... and are caring for someone who is suffering from the same set of conditions.”

Many carers have said that it is useful to be able to connect with other forum users offline or directly via email. There are obviously pros and cons to this, but it is worth exploring whether carers on your site would like the opportunity to extend their interaction beyond the confines of the online forum.

Young carers

There are additional safety concerns involved for communities aimed at young carers. Safeguarding becomes particularly important, as do issues of anonymity. Rules, guidelines and procedures are even more essential, and every consideration must be given to protecting the safety of users and ensuring that abuse and inappropriate behaviour are excluded from the community.



EXAMPLE: Carers' community on Carers.org

The forums and chat room on the Carers.org website offer peer-to-peer support, social events and a safe place for carers where they can be part of a community. Regular events in the chat room include online parties and web chats with experts.

The site has been running since 2002 and has attracted over 12,000 registered members. Content is moderated by a team of Online Support Workers who also offer professional advice and support.

A recent redesign added a variety of new and innovative features such as:

- enhanced profiles and search facilities to allow carers to find others in a similar situation or nearby location
- the option for carers to contact each other privately
- access to local news and events
- blogs, commenting facilities and user groups to give carers opportunities to contribute to the site.

Further details of how the site was started and how it is run can be found at: <http://www.carershub.org/content/virtual-community-carers>

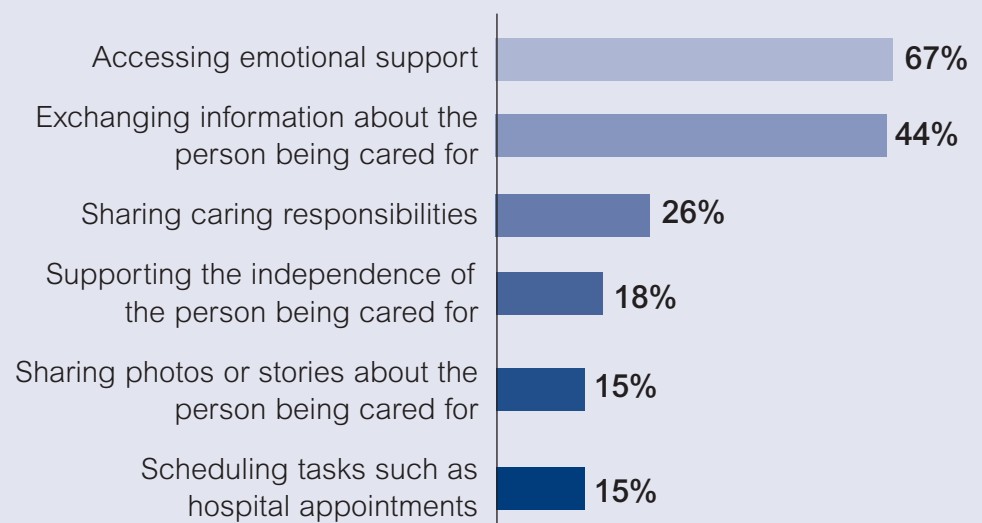


Networks of support²²

14% of online carers have online networks of support to exchange information about the person being cared for, get help with tasks or receive support with caring from friends, family and other contacts.

More than half of carers with online networks use them once a day or more, and 67% of carers say that their main reason for using them is to access emotional support.

What are your main reasons for using an online caring network?



²² This section relates to internet tools that allow carers to link virtually with people they already know in the real world, specifically for the purpose of getting emotional or practical support around their caring responsibilities. Often the other members of the network will also have a real-world relationship with the person being cared for, with the online network created for the purposes of sharing information or facilitating practical arrangements such as medical appointments. These online networks are therefore different from the supportive networks that are formed with other carers in forums and chat rooms, where the participants each care for different people and may not know each other outside the virtual world.



Benefits:

Simplification

“Everything and everyone in one place.”

The concept of creating a website or service to facilitate online networks for carers is a relatively new one, and pilot projects have struggled to identify clear benefits for carers or organisations. However, carers have reported various benefits from using online networks on sites like Facebook, including the simplicity of having everything in one place.

It is likely that online networks could be particularly useful for those carers for whom the internet is already a preferred means of communication.

Challenges and recommendations:

Immediacy

“I want to know there and then that it’s taken care of.”

There is often a need for an immediate response when making care arrangements, so many carers prefer to text or telephone rather than use online calendars, emails or other internet-based message systems.

Personal preference

“I can see the application of it, but it’s just not what I want. It’s not that I’m frightened of it or anything. It isn’t my way of making contact.”

27% of online carers say they do not want an online network because they prefer to communicate offline. Regardless of what features and technologies are available online, some carers will always choose to stick with more tried and tested methods of communication such as the telephone and face-to-face meetings.



Time constraints

“I don’t have time to learn a new system.”

29% of online carers say they would not use an online network of support because they do not have time. If you are considering creating such a site, it is important to determine how to make it as user-friendly and intuitive as possible.

Using existing tools

80% of carers who use online support networks access them via mainstream sites such as Facebook or BigTent. It is particularly sensible to investigate how these tools might be used for your purposes, instead of simply creating a new site from scratch.

“I don’t want another site to log onto.”

A third of carers said they would prefer to use a carer-specific website to create an online network, so it is also worth exploring whether a networking tool could be integrated into an established carers’ website.

Cost

“Only if it’s free.”

Less than 3% of carers said they would be willing to pay for a service that allowed them to set up a support network online, so websites with a fee attached are not likely to attract many users.

Privacy and security

“I’d be nervous about putting personal information on the internet.”

“We are protective of the people we care for and that would be too much information.”

37% of online carers say they would not use an online network of support because they do not want to share personal information on the internet. Although many carers shop and bank online, they often have reservations when it comes to sharing details about the person they care for, which can make it difficult to get carers to engage with a tool that is focused on such information.



Including the person being cared for

“If the cared for cannot engage, what’s the point?”

“A lot of people with learning disabilities need to communicate face to face. So if their support network is online, they’re going to be left out of their own network.”

Although a carer’s network of support is aimed at supporting the carer, many carers feel that the person they care for is a key element of that group. There is a danger of creating a network of support around an individual who is unable to access that network.



EXAMPLE: Howsthepatient.org.uk

‘How’s the patient?’ is a free web-based service that offers carers a secure way to stay in touch with friends and family. A carer can sign up to the site, set up a private blog and invite friends and family to join their community. Those in the community are kept up to date with news and information about the person being cared for and can send messages of support.

The site allows members to communicate individually via private message or quickly contact the whole ‘community’ by writing on the message board. All messages are stored on the site itself rather than sent by email, giving extra security and peace of mind.

‘How’s the patient?’, which was launched in November 2010, is operated by the social enterprise PatientPages LLP, working closely with NHS Patient Advice and Liaison Services. The site is funded through sponsorship and commissions from its online store which is linked to Amazon.



Emotional support by email, instant messenger or video chat

“Caring involves emotions, so that is the kind of support carers will often need.”

Emotional support is an important element in supporting carers, and the internet can be a simple and cost-effective way of extending this service to more carers. Over 99% of online carers use email and almost 45% have used instant messaging. The widespread use of email makes it a good avenue for delivering emotional support, while instant messaging can provide real-time interaction.

“It’s good to see someone at the other end.”

Video chats, which have been used by 20% of online carers, can humanise the process by allowing carers and support workers to put a face with a voice and use visual cues and facial expressions.

Below are some of the benefits, challenges and considerations for those planning to offer emotional support online.

Benefits:

Maximising choice

“I would like to be able to have a one-to-one online by written chat sometimes.”

Some carers may prefer to get emotional support face-to-face or over the phone, but the internet can offer another option for those who would prefer to meet online.

Reaching more carers

“Getting the space to offload, whilst still being ‘there’ with the person you care for ...”

Many carers are short on time or are unable to leave the person they care for, so the internet can be used to offer emotional support to those who might not otherwise be able to access it.



Privacy

“I get a call once a week from my support worker, but my husband can hear every word so I can’t say what I’m really feeling. With email, I can type whatever I want without hurting him.”

Email, online chats and instant messages can offer more privacy for carers who are unable to talk on the phone without being overheard by the person they care for or other family members.

Out of hours support

“I would love there to be somewhere that I could occasionally offload the feelings that I have as a carer of my very ill daughter. I can deal with crisis; it’s after the crisis that I have problems.”

It may be possible for some organisations to offer online support outside of normal business hours. This is particularly useful for carers who have unpredictable schedules or those who are juggling work and care.

Challenges and recommendations:

Language problems and access issues

“English is my second language, so it takes too long to figure out how to write what I want to say ... The phone is much better for me”

Email and other online interaction may not be a viable option for carers whose first language is not English, or for those with dyslexia, visual impairments or any other condition that makes it difficult to communicate via the written word. It may be worth investigating options such as voice recognition software or providing support in other languages if there is a need in your local community.

Establishing a relationship

Many carers feel that it might be difficult to establish a supportive relationship with “the anonymous person at the other end of an email” as there are no visual cues or even tone of voice to help humanise the interaction.

“If it’s somebody I know, I don’t have to go through the whole rigmarole.”



Some carers feel that it is more useful to get support from someone they already know. Once the relationship has been established by phone or in person, online interactions can feel more meaningful and supportive.

The value of face-to-face interaction

“There is no warmth in a computer.”

Because many carers often feel isolated, face-to-face interaction can be more supportive than online contact.

“It's the highlight of the week if a nurse or social worker visits us.”

Carers receiving emotional support from a visiting professional often value that time very highly, and the visit can be beneficial to the person being cared for as well. In these cases, it would be disadvantageous to eliminate visits in favour of online contact.

“Nothing beats face to face in real life but the more choices the better I guess.”



EXAMPLE: YCNet (www.youngcarers.net)

This online community for young carers offers email support and one-to-one chats from a small team of Online Support Workers.

Carers who email their questions or concerns receive a reply from one of the Support Workers within one working day. If further support is needed, the carer is invited to a private online chat at a pre-arranged time, usually lasting 45 minutes and giving the carer an opportunity to talk through the issues and be linked with local services when appropriate. Carers may be offered up to eight chat sessions, on a weekly or fortnightly basis.

Because support is provided by a very small team, with two of the workers having been with the site for more than five years, carers can get to know the workers as individuals and build relationships with them over time, leading to a more personal service.

Further details of how the site was started and how it is run can be found at: <http://www.carershub.org/content/online-support-young-carers>



Online breaks booking

As half of carers say they do not have any free time to visit support services²³, it is no surprise that many organisations are developing systems to enable carers to book breaks online. Currently around 6% of net-using carers are making care arrangements online, and 4% have used a website to book a caring break.

Many online breaks booking sites are simple systems allowing a carer to make an appointment with their usual care worker at a suitable time, while others function like an online database of care workers offering their services. It is clear that both types of sites could be very useful, particularly for those carers who already use the internet on a regular basis.

When exploring the possibility of creating such a site, there are numerous benefits and considerations to bear in mind.

Benefits:

Time-saving

"It allows me to book a break any time of the day."

For those carers who already spend much of their time on the internet, online booking can be a much faster way of making arrangements than by telephone or in person, and the ability to access a booking website at any time of day or night is particularly useful given the unpredictable hours that many carers keep.

Choice and control

The ability to book a break online can give carers more choice and control over the process, and may also allow the cared for to be involved with arranging their own care.

²³ 'Carers battling isolation can get help online', The Princess Royal Trust for Carers [online at <http://www.carers.org/press-release/carers-battling-isolation-can-get-help-online>], accessed 1 May 2011



Flexibility

Some of the existing breaks booking systems give carers more flexibility about the timing and duration of their breaks.

“I sometimes just would love an evening to go to the cinema.”

For example, instead of being tied down to a particular time each week, some sites allow the carer to search staff availability to find a time that is convenient, sometimes even at short notice.

Payment options

Some online booking systems have been developed to accommodate a range of payment methods including personal budgets, direct payments, voucher schemes and self-funding.

Benefits for staff

Many online systems enable staff to have more flexibility about when they work and for how many hours. Some websites allow staff to create a profile and update their availability, and automated systems such as email and text message confirmations can provide instant updates about any bookings.

Benefits for organisations

In the long-term, online booking can lead to a reduction in an administrative time and costs for organisations, particularly if the online system is integrated with bookkeeping software and other offline processes.

Challenges and recommendations:

Awareness

“I am not aware of this support being available to me.”

Over three quarters of carers do not receive any respite from social services, and over a third of carers are unaware that they are even entitled to breaks²⁴. The aim of online booking systems should be to close this gap, offering breaks to as many carers as possible.

²⁴ ‘Carers battling isolation can get help online’, The Princess Royal Trust for Carers [online at <http://www.carers.org/press-release/carers-battling-isolation-can-get-help-online>], accessed 1 May 2011



“I’ve had carers’ respite because it was suggested to me face to face. If it had come up on screen or on a piece of paper, I probably would have just ignored it.”

It can be hard to raise awareness when interacting with carers solely via the internet, so offline support and outreach has a crucial role to play in guiding carers to the service.

Cost

It is important to remember that many carers are on tight budgets, meaning that it may not be possible for them to make use of services that have a cost attached.

Existing tools and websites

There are some established systems such as Slivers of Time or Shop 4 Support that may be able to be adapted to fit your needs. This could cut out a lot of the time and money needed to develop a site from scratch, but it is important to be sure that the system you choose meets the needs of carers in your area.

Some organisations with online breaks booking sites may be interested in extending their websites to include care workers from other organisations. Multi-organisation sites can be a good way of cutting costs while maximising choice for carers, but it is important to consider data protection, different operating procedures and other issues of compatibility between organisations.

Stability for the person being cared for

“I would want to book a specific person.”

Many carers want to use the same care worker every time they have a break, and it is important that online booking sites can facilitate this process by allowing carers to choose a care worker that they know and trust.



Groundwork

“If I needed to book care for my mother in my absence, I would want to get a local person and be recommended to them and get to know them before I could use their service.”

The traditional model of domiciliary respite care usually involves risk assessments and matching particular care workers with the needs of the person being cared for, often followed by an opportunity for the carer and cared for to get to know the care workers who will be providing their care before the actual break takes place. In most cases, these stages will need to proceed offline in the usual way, with the online booking service only becoming useful at the point when there is an established relationship between carers and care workers who can then be booked online.

Safety, security and references

If a website is open to care workers who are not already known to your organisation, it is essential that procedures are in place to carry out CRB checks and verify references. Some websites allow staff to set up profiles giving details of their experience and availability, while other sites have a facility for carers to rate care workers or provide feedback and reviews which can be accessed by other carers.

Burden on carers

Sites that allow carers to choose from a wide pool of care workers may increase the burden on carers by requiring them to wade through lots of information in order to find the best person for their needs. This danger should be weighed against the obvious benefits that come from offering wider choice. Organisations that have an offline relationship with carers and are able to carry out assessments and make recommendations can often minimise the burden on carers while still offering choice.



People being cared for

“My husband would be quite capable of arranging his own care but it had been given to me.”

Sometimes people being cared for are willing and able to be involved in arranging their own care, but they often get left out of the equation. When creating an online booking system for carers, it may be useful to consider how your website might also be able to involve the cared for in the process.

Ease of use

As with all websites, it is important that online booking sites are easy to navigate with a straightforward structure and streamlined booking process.

Booking confirmation

“I’d like instant confirmation by email that the booking has been made.”

Carers need to be certain that an online booking has been confirmed, and that the care worker will arrive at the appointed time. It is essential that all bookings can be verified and fulfilled. There is no room for technical glitches when a person’s care is at stake. Such concerns can make carers wary of using a new service, as they may feel more secure speaking to someone on the phone. Creating a solid paper trail and a proven track record can increase carers’ confidence in the service.

Security of personal details

Booking sites are likely to contain a carer’s personal details such as address and payment information, as well as information about the person being cared for, so robust security protocols must be put in place.

“Everyone knows about hacking and identity theft and stuff like that. When it comes to personal details like issues of money, I’d rather go and do it face to face than do it over the internet.”

Some carers may be reluctant to use a site that requires them to enter a lot of personal information unless they are certain that it is safe.



Additional features

“It would be good if you could do it by text as well.”

Some sites offer additional functionality such as live availability for each care worker, or the ability to book via text message. Before investing in such features, it is a good idea to consult with local carers to find out what functions would be the most useful.

Organisational challenges

It may take some planning to ensure that a booking website can interface smoothly with your other systems such as accounting and payroll software. Getting the different systems to talk to each other may be difficult in the short term, but can cut down on administrative time and costs over time.

Some staff may struggle with the increased reliance on IT, and care workers may need support and encouragement to set up profiles on the site, so it is useful to get them involved in the process as early as possible.



EXAMPLE: Bookyourownbreaks.com

Crossroads Care Hertfordshire North and Crossroads Care Hertfordshire South teamed up with Hertfordshire County Council, the Department of Health and social enterprise Slivers of Time to create a site that gives carers more control and flexibility in the type of break they book.

Carers who get breaks from Crossroads Care can use the online system to choose their care worker and the time of their break. The site provides live, real-time information about care workers' availability, so carers can book a break at a time that suits them. Care workers receive a notification by email and text message when a booking is made, and they can set their hours and update their availability online.

Carers can still book via the telephone, but the site has proved very popular as it is available 24/7 and takes the administrative hassle out of booking a break. The online booking system has been so successful that it is likely to be extended to other services such as mobile chiropody and personal assistants.

More information about the service, including case studies and interactive demonstrations, can be found at: <http://www.bookyourownbreaks.com>

e-Learning

The flexibility of online learning makes it a particularly useful way for carers to gain skills and knowledge, but there are currently very few e-learning programmes aimed at carers. 30% of net-using carers have taken part in online learning, but only 9% of these programmes contained content relating to caring.

When asked about what topics they would like to see covered in an e-learning course on caring, many carers mentioned practical skills such as moving and handling and how to get the most out of professionals, while others wanted information about financial and legal issues such as benefits, rights and the support that is available.



75% of online carers said they might be interested in an e-learning programme covering such issues, so it is worth considering the following advantages and obstacles.

Benefits:

Saves time

“I like face-to-face learning but it takes more time than I have.”

Carers who are unable to attend training sessions in person may be more able to access online courses.

Flexibility

“If it’s accessible at any time, I can fit it around caring and other responsibilities.”

Online courses allow flexibility for carers to access the course at a time that fits with their other commitments.

Repetition

“It would be a good reminder, a backup.”

With e-learning, it is often possible to repeat a lesson or module, so carers could revisit material as many times as necessary.

“Someone could show you how to do it, and then you could get on the computer and it would jog your memory.”

Online learning can also be used as a supplement to classroom training, as videos, diagrams and other online resources can be a good way of revisiting or reinforcing other methods of learning.

Ability to update or adapt content

Unlike printed material, online resources are relatively easy to update or adapt for a particular topic or community, so offering e-learning might make it easier to make changes to course content over time.



Challenges and recommendations:

Learning styles

"I doubt I want to be trained to care online."

"I think learning and human interaction is linked."

"e-learning is good for information provision, but real education requires actual participation to be effective."

28% of net-using carers prefer to learn in other ways than through e-learning.

"I prefer a paper based version as it is easier to refer back to afterwards."

Some carers may also rather have a hard copy of information rather than an online version.



Caring with Confidence - Online



Welcome to the Caring with Confidence online sessions

Caring with Confidence helps unpaid carers make a positive difference to their life and that of the person they care for. If you, 'carer' or 'service' family member, friend or neighbour with a long-term physical or mental health condition, disability or problem related to old age, Caring with Confidence can help you develop your skills and knowledge for your caring role.

Caring with Confidence online sessions for you:

- ▶ Learn simple techniques to help you care
- ▶ Work at your own pace and at a convenient time
- ▶ Come back to us B2B at a time as you want
- ▶ The feedback of organisations that can give you further information and advice
- ▶ Build up a collection of useful resources and notes

Click on the Start your session button to go to the main Caring with Confidence courses. Each course has several parts, which you can complete in order or skip to whenever you have time.

For more information about being a carer, go to the Carers Direct website or call the Free Carers Direct Helpline on 0800 822 9202.

[Start your session now.](#)



Start your session ▶

EXAMPLE: Caring with Confidence

This online interactive learning programme aims to give carers a better understanding of the problems they face and help them find new ways to tackle these issues. The programme is a series of seven courses that carers can download and complete in their own time.

Topics include:

- How the care system works

- How caring affects your life
- Communicating effectively with the person you care for as well as health and social care professionals
- Taking control of your time and finances
- Understanding the emotions you may feel when caring and finding practical ways to handle them

The course is available online at:

<http://www.caringwithconfidenceonline.co.uk>

Further details about the development of the course and resources for providers can be found at: <http://www.nhs.uk/CarersDirect/carers-learning-online/Pages/Welcome.aspx>

Other Applications



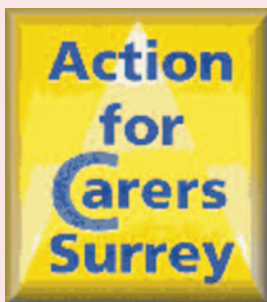
Consultation

The internet can be a very useful tool for involving carers in decisions about services and issues that affect them.

Online surveys can be a fast and effective way of gathering opinions, and several providers have reported an increase in the number of carers replying to web surveys as the number of carers using the internet continues to grow.

Online video conferencing tools can be useful for carers who are not able to travel to meetings, such as those who are housebound or unable to leave the people they care for, or those who are not available for meetings during normal business hours because they are juggling work and care. Almost a third of online carers have used VOIP systems such as Skype, and one in five has taken part in an online video chat.

Using video conferencing tools has the additional benefits of keeping the phone line open and reducing costs for the carer and the organisation.



EXAMPLE: Giving Carers a Voice in Surrey

Giving Carers a Voice is a consultation group that uses virtual meetings, online surveys and electronic feedback forms to gather carers' views.

Visit the website to see the online feedback form and a list of current campaigns: <http://www.carersnet.org.uk/actionforcarers/afc.html>

Further details of how the group was started and how it is run can be found at: <http://www.carershub.org/content/meetings-phone-conferences-and-online-feedback-forms-gather-input-carers>



Podcasts

One in 10 online carers listen to podcasts, while almost a quarter listen to online radio. Some organisations - particularly those aimed at young carers - have experimented with creating one-off podcasts, but there seem to be very few regular podcasts for carers. It may be worth exploring whether carers in your area would be interested in this type of content.

Carers World Radio
Radio With A Purpose

Do you look after someone?
If you provide help and support to a partner, child, relative, friend or neighbour who could not manage without your help due to age, physical or mental illness, addiction or disability you are a Carer

HOME ABOUT US CARERS WORLD CHATROOM CARERS LIVES CONTACT US

September 2011 programme
In this months programme we'll be talking to one of the organisers of the Care Show which takes place in London in October. Also on the programme we look at a great new web based service especially for people in care homes and older people to stay in touch with their families who are increasingly web and email dependant via the website Finerday. We also go to Western Australia to look at a new tracking device for people who are at a risk of wandering and getting lost.

 [Click here to download the podcast of the programme](#)

EXAMPLE: Carersworldradio.com

Carers World Radio produces a monthly radio programme covering carers' issues such as policy changes, reports and special events. The current month's programme can be streamed from the site or downloaded as a podcast and is archived at the end of the month.

The site includes a chat room which is sometimes used as a way for carers to interact with live broadcasts by posting questions and comments.

What carers would like to see developed



Free internet

“I think carers having free internet - and PCs or laptops - would be a great idea.”

“They need to set up an ISP especially for carers.”

When asked what online services carers would like to see created, suggestions often related to the provision of equipment and free internet access.

Gateway website or one-stop shop

“I have trouble knowing where to start to find what I’m looking for.”

“When I first became a carer I did not know where to go, and many people are the same.”

Several carers suggested a site that could act as a gateway to information and services. It would be an ideal place for new carers to start, and would also be useful for those who are not quite sure what they are looking for.

“If I had an Aladdin's lamp, my wish would be for an internet site called [questionstoaskifyou'vejuststartedthiscaringlark.org](#).”

“Someone said there should be a website called something like [justbecomeacarerandhavntgotacluewheretostart.com](#)”

Such a site could include links to national carers’ organisations as well as condition-specific sites and local resources. Many carers also felt it would be useful to have sections for different groups of carers such as parent carers or young carers, listing all the support and services available to them.

Local information

“There are things you can chat about nationally, but the local knowledge – certainly when you’re a new carer, there are a million things you need to know. It can be quite daunting.”

“You don’t want to hear about how wonderful it is somewhere else.”



There is a demand for information that is tailored to local areas, and a gateway website that included sections for every borough would be particularly useful.

“You can find out all kinds of information about my son’s disease, but what you don’t have is something that’s specific to where we are and what is there to help you and to help them, all on one site ... Something that’s specific to the condition but also specific locally.”

Such a site could be based around a directory of services including registered care agencies in the area, voluntary organisations, telephone and online information resources, support groups, activities and criteria for assessment and support. Carers suggested creating a template that could be completed by local authorities and tailored to fit specific communities.

“There’s loads of information that carers are giving to each other.”

An interactive element to the site would also be useful, so carers could exchange suggestions and resources.

“Like post-it notes, carers could go in and type in whatever you’ve found out about the local area, from the horse’s mouth. Pin it up on the board and refresh it every week or so.”

This would allow carers to share their own local knowledge and add that to the official listings of what is available.

Online services booking

Carers who use the internet to manage direct payments for the person they care for said it would be useful to be able to book more services online.

Benefits information and support

Many carers say that they need more information about benefits and assistance with completing forms. Some say that it would be helpful to have an interactive tool that could calculate which benefits are applicable, what they are worth and how to apply.



Some carers suggested that there should be more information online about personalisation and personal budgets, with resources, examples of what other carers have done and answers to questions like ‘Where do I find a personal assistant?’.

Guidance for carers who want to start their own groups

“I run a cycling group for people with disabilities ... We get approached very often and asked how we set it up.”

Carers who want to start their own groups and activities said it would be useful to have a site where they can share information and resources about practicalities, challenges and successful methods.

“If you could give another carer an idea, information about how to get it going and where to look for funding, then they could get it going.”

Such a site could also be useful for people being cared for who want to start their own groups.

“I think there are a lot of people with learning disabilities who could set up clubs that match their interests.”

Conclusions



The impact of the internet on carers is wide-ranging and dramatic, and with internet use on the rise, there is an opportunity for service providers to reach more carers than ever before by offering a range of websites and online support that complement and add to offline services.

As more services are offered online, it is crucial that internet access is extended to include as many carers as possible and that offline options are available alongside websites to ensure that every carer is able to access services and support.

Consulting with carers, working with other organisations and exploring all the benefits and challenges of different types of websites can help providers design services that maximise resources and meet the needs of local carers.

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Appendix: Demographics of survey respondents

How old are you?

| Answer Options | Response Percent | Response Count |
|----------------|--------------------------|----------------|
| Under 18 | 0.5% | 2 |
| 18 to 24 | 0.5% | 2 |
| 25 to 39 | 7.7% | 31 |
| 40 to 54 | 38.5% | 156 |
| 55 to 64 | 29.9% | 121 |
| 65 to 74 | 16.3% | 66 |
| 75 to 84 | 5.7% | 23 |
| 85 or older | 1.0% | 4 |
| | <i>answered question</i> | 405 |
| | <i>skipped question</i> | 15 |

What is your gender?

| Answer Options | Response Percent | Response Count |
|----------------|--------------------------|----------------|
| Male | 24.8% | 99 |
| Female | 75.2% | 300 |
| | <i>answered question</i> | 399 |
| | <i>skipped question</i> | 21 |



How would you describe your ethnic category?

| Answer Options | Response Percent | Response Count |
|-----------------------------------|--------------------------|----------------|
| White - British | 89.3% | 357 |
| White - Irish | 1.8% | 7 |
| Any other White background | 3.8% | 15 |
| Mixed - White and Black Caribbean | 0.3% | 1 |
| Mixed - White and Black African | 0.0% | 0 |
| Mixed - White and Asian | 0.3% | 1 |
| Any other mixed background | 0.3% | 1 |
| Indian | 0.8% | 3 |
| Pakistani | 1.0% | 4 |
| Bangladeshi | 0.0% | 0 |
| Any other Asian background | 0.0% | 0 |
| Caribbean | 0.5% | 2 |
| African | 0.5% | 2 |
| Any other Black background | 0.0% | 0 |
| Chinese | 0.0% | 0 |
| Any other ethnic category | 0.5% | 2 |
| Not sure / Prefer not to say | 1.3% | 5 |
| | <i>answered question</i> | 400 |
| | <i>skipped question</i> | 20 |



Which area do you live in?

| Answer Options | Response Percent | Response Count |
|---------------------------------|--------------------------|----------------|
| North East England | 1.5% | 6 |
| North West England | 10.4% | 42 |
| Yorkshire and Humber | 3.5% | 14 |
| East Midlands | 2.7% | 11 |
| West Midlands | 19.3% | 78 |
| East of England / East Anglia | 10.9% | 44 |
| Greater London | 7.4% | 30 |
| South East England (not London) | 26.5% | 107 |
| South West England | 4.5% | 18 |
| Scotland | 3.0% | 12 |
| Northern Ireland | 0.2% | 1 |
| Wales | 6.9% | 28 |
| Don't know | 0.0% | 0 |
| Other (please specify) | 3.2% | 13 |
| | <i>answered question</i> | 404 |
| | <i>skipped question</i> | 16 |



What is your current employment status?

| Answer Options | Response Percent | Response Count |
|---|--------------------------|----------------|
| Employed full-time | 14.9% | 60 |
| Employed part-time | 15.4% | 62 |
| Self-employed full-time | 2.2% | 9 |
| Self-employed part-time | 4.7% | 19 |
| Retired | 30.3% | 122 |
| Caring for home /family/ dependants full-time | 34.5% | 139 |
| In education full-time | 0.7% | 3 |
| In education part-time | 1.7% | 7 |
| Unemployed / Looking for work | 2.0% | 8 |
| Left work to care | 16.4% | 66 |
| Unable to work due to long-term illness or disability | 4.5% | 18 |
| | <i>answered question</i> | 403 |
| | <i>skipped question</i> | 17 |

How many hours a week do you spend on caring responsibilities?

| Answer Options | Response Percent | Response Count |
|--------------------|--------------------------|----------------|
| Up to 20 hours | 16.4% | 63 |
| 20 to 40 hours | 17.7% | 68 |
| 40 to 60 hours | 10.7% | 41 |
| More than 60 hours | 55.2% | 212 |
| | <i>answered question</i> | 384 |
| | <i>skipped question</i> | 36 |



How many ill, frail or disabled people do you care for?

| Answer Options | Response Percent | Response Count |
|--------------------------|------------------|----------------|
| 1 | 83.0% | 322 |
| 2 | 13.7% | 53 |
| 3 | 2.8% | 11 |
| More than 3 | 0.5% | 2 |
| <i>answered question</i> | | 388 |
| <i>skipped question</i> | | 32 |

Who do you care for?

| Answer Options | Response Percent | Response Count |
|--------------------------|------------------|----------------|
| Grandparent | 0.8% | 3 |
| Parent / Parent-in-law | 26.9% | 105 |
| Spouse / Partner | 44.4% | 173 |
| Son / Daughter | 32.1% | 125 |
| Brother / Sister | 1.5% | 6 |
| Friend | 2.8% | 11 |
| Other | 3.8% | 15 |
| <i>answered question</i> | | 390 |
| <i>skipped question</i> | | 30 |



Why do you look after them?

| Answer Options | Response Percent | Response Count |
|-----------------------------------|------------------|----------------|
| Physical disability | 43.3% | 169 |
| Mobility problems | 53.3% | 208 |
| Sensory impairment | 16.2% | 63 |
| Frailty | 18.7% | 73 |
| Long-term health condition | 44.4% | 173 |
| Degenerative disease | 16.2% | 63 |
| Dementia or other memory problems | 26.9% | 105 |
| Learning disability or autism | 25.6% | 100 |
| Mental health problems | 20.0% | 78 |
| Alcohol or substance misuse | 2.3% | 9 |
| Other | 6.9% | 27 |
| <i>answered question</i> | | 390 |
| <i>skipped question</i> | | 30 |

In addition to any ill, frail or disabled people you care for, do you also care for any young children?

| Answer Options | Response Percent | Response Count |
|--------------------------|------------------|----------------|
| Yes | 19.6% | 75 |
| No | 80.4% | 308 |
| <i>answered question</i> | | 383 |
| <i>skipped question</i> | | 37 |

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