



A Shared Space &
A Space for Sharing



Information Sheet

ONLINE HEALTH FORUMS

Key messages for people living with health conditions seeking support

● **BACKGROUND TO THE INFORMATION SHEET**

This information sheet has been developed as part of a research project called “A Shared Space and a Space for Sharing”, which examined how people, living with, or affected by serious health conditions use online health forums to gain support from other people. The information in this sheet is based on findings from the study.

● **WHO WE ARE**

We are a team of researchers based in the Information School, at the University of Sheffield (UK). Our contact details are at the end of this information sheet.

This information sheet is designed for people living with, or affected by, health condition(s) who are thinking about joining an online health forum, but are unsure what forums can offer them, and may have concerns about doing this. In this sheet we tell you about the types of support offered by online forums, give advice about choosing the right forum for you, how to stay safe online, and describe some of the possible negative aspects of forums.

● WHY JOIN AN ONLINE HEALTH FORUM?

People who join online health forums are mostly people who have been diagnosed with a health condition themselves, or are family members of people living with the condition. You will find people at all stages of the health condition, from those recently diagnosed, to others who have longer experience of living with the condition and may have fully recovered. Online forums can be helpful because you join others who share and understand the experience of living with a health condition:

- People provide information and support by sharing experiences and emotions of living with health conditions and treatments, with others going through similar experiences.
- Joining a forum can help people feel less alone in facing their health condition (this may be especially valuable for people living with rare or disabling conditions).
- Forums can be sources of reassurance and hope - it can be comforting to find other people who have got through the early stages and ongoing challenges and are living with the condition.

If you do not have Internet access at home, you can often do so at your local public library.

● UNIQUE SUPPORT

Online forums offer a special sort of support because the support comes from forum members who have their own unique and personal understanding of living with a health condition. They can offer several types of support that may help you.

1. INFORMATION

Users share information on forums about their knowledge of health conditions and their experiences of living with it, for example, the symptoms, available treatments, support services, and everyday life. This can be very helpful especially if you are recently diagnosed, or have reached a new stage in the health condition, and are uncertain about what will happen to you in the future. If you are beginning a new treatment, for example, chemotherapy, or medication, you may have worries about what this involves, for example, what you might expect, how you might cope, or how it might feel. The experiences shared on the forum can help you feel less uncertain; help in planning for the future; and inform your decision making. The informal support provided by forums can also help you think about the questions you may wish to ask health professionals.

2. EMOTIONAL SUPPORT

Forum users know what it feels like to live with a health condition and understand the emotional impact on them and their family. This can be helpful because you may feel more able to share fears and worries with others who know what you are going through. You are likely to find out that other people feel similar things to you – this can be comforting. People may share ways to cope with fears, and offer reassurance in dealing with difficult emotional problems.

Online forums are generally available all day, every day. Your worries may seem greater during the night, and forums offer a place to turn to at any time to share your fears and get support from others. People within the forum can help you to feel better about your situation, when they share their own experiences.

3. FRIENDSHIP AND COMPANIONSHIP

Health forums can also provide a source of companionship or friendship. You can get to know others and make friends on the forum. You may develop friendships based on shared experiences of the health condition, or you may find other connections that draw you to a person or group of people. Some forums are set up to bring together groups of people sharing the same experience, for example, Breast Cancer Care has groups for people starting chemotherapy at the same time.

Online friendships can be very supportive. Some people describe feeling the same emotional connection to forum friends as they do with friends in everyday life. They provide relationships in which to share both good and difficult experiences. Some people develop very strong relationships and share intimate details of their life with a particular friend or friendship group. Some people even decide to meet up and get to know each other over a coffee.

● DECIDING ON YOUR OWN LEVEL OF ENGAGEMENT

Everyone is different and people use forums in their own ways. You may wish to only get information from the forum; or just to seek emotional support and friendship and post messages to others. Some people never actively join in forums; they just read through the posts and gain support that way. It is up to you to choose the level of engagement you are comfortable with.

● FINDING THE BEST ONLINE HEALTH FORUM FOR YOU

If you search on the Internet you will find lots of online health forums set up to support people living with many health conditions. It can help to narrow these down by considering two key questions - how relevant are the forums to your needs, and how safe are the forums?

You are more likely to gain useful support from forums that are set up for people living with your particular health condition; or offer spaces within the main forum for your specific illness, treatment, or circumstances. Forums that are hosted within your home country are likely to offer more useful support, because the information shared about treatments and health services will be more relevant to your own situation. A good starting point for finding a reputable health forum is to either ask advice from a health professional, or to find out whether well-known and trusted health charities provide online forums.

● ARE ONLINE FORUMS TRUSTWORTHY?

There are two key questions around how trustworthy forums are. Firstly, are forums a safe place to share experiences? Secondly, can the information provided by the forum be trusted?

● SAFE SHARING PRACTICES

It is safer to choose health forums which are hosted by a reputable charity/organisation and are moderated. Moderators are people who are employed to oversee the safe running of the forum. They check posts to make sure that users are following safe sharing rules and treating others with respect, they welcome new users, and sign-post to sources of help.

When sharing information about yourself on a health forum it is wise to follow some simple rules to keep yourself safe.

- **Do not share information that would identify you as an individual or anyone that you refer to** (such as friends, family, or health professionals), for example, do not share names, addresses, or other personal details.
- **Be aware that some forums are open for anyone on the Internet to read.** Read the terms and conditions of the forum to check whether this is the case. If forums are open, you need to be aware that conversations are also searchable by search engines such as Google, and may appear in search results. There are good reasons why forums are open to anyone to read, as this enables more people to gain support - but you need to be aware of whether this is the case, so that you can share with this in mind.
- **Take things a step at a time.** It is a good idea to spend time looking through the forum before starting to post. Read through posts to assess whether you think the content will be useful to you and to get a sense of whether you feel you can trust the other people using it (in the same way that you might behave when getting to know a new group of people). Users in our study used the same instincts that they use in everyday life. This will also help you learn about any informal rules and etiquettes of sharing and being part of the forum.
- **Think about the sensitivities of others before you post.** If you are sharing information about another organisation or person, such as your friends and family, consider whether they would be happy for you to share this on the forum. Think about who will be reading the post, especially if you are writing about sensitive topics that may upset others in the forum. For example, if you are writing about a bad experience with a treatment it might be insensitive to share this post with others who are waiting to start that treatment. Messages can sometimes be misinterpreted. Before posting read through messages carefully to check the wording.
- **Private spaces.** Some conversations take place off the forum, such as in emails, or users may set up their own closed Facebook groups. These offer the opportunity to converse in private spaces about issues that users might not wish to share on the wider forum; however, there are some risks to sharing in private spaces (see Trustworthiness overleaf) and these tend not to be moderated by professionals.
- **Medical advice.** It can be helpful to share experiences of medications, or treatments; but it is not appropriate to give medical advice to others.



● TRUSTWORTHINESS

The information provided on moderated forums is likely to be more trustworthy than in forums where there is no one overseeing the postings. In the forums we researched, moderators intervened and corrected any factually incorrect posts. In private spaces such as email and unofficial Facebook groups no one formally checks the accuracy of posts.

● POTENTIAL RISKS

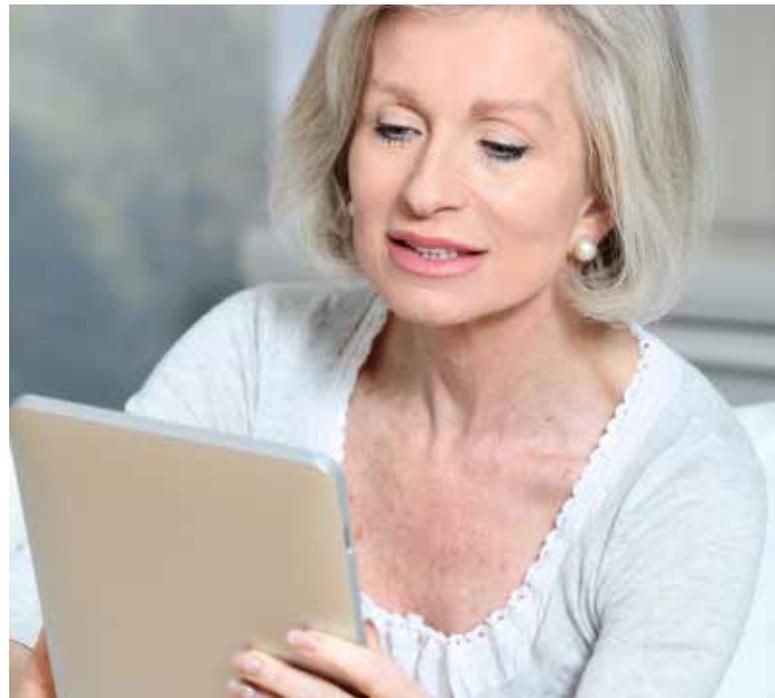
There are some risks to taking part in online health forums, but the people who took part in our studies found that the benefits far outweighed the risks.

- **Health forums are anonymous spaces and there is a risk that people online may not be who they say they are** – in our study we found an example of people going on the forum to sell things. However, these people were soon found out, and were removed from the forum by the moderators.
- **There is a small risk of being upset by the actions of other forum users.** People sometimes find out things from other forum members that they would prefer not to know, due to insensitive sharing. On occasion, users may disagree with each other, or feel pressurised or even bullied by others, and, in very rare instances, an argument may break out. This does not happen often, as generally people act with care and consideration for each other. Forum moderators may help to resolve any arguments. If you feel upset about something that is posted, you can always let the moderator know.
- **Sorrow for others.** It can be very upsetting if someone that you have become friends with on the forum becomes very ill, or dies. These feelings are natural, but nonetheless it can feel painful.
- **Feeling overwhelmed.** Problems can feel magnified within the forum. People may be more likely to share negative stories such as side-effects from treatments. If you should ever need to, remember that you can always take a break from the forum and come back to it later.

- **The amount of support available at any one time will depend on which other users are logged onto the forum at that moment.** There may be times when no users are available to help especially if it is a small forum or group, but other users will generally reply to messages when they go online.
- **Treat with caution any medical advice offered by forum users.** Always check medical advice with a health professional. If you have any concerns about your health, seek advice from a health professional.

● KEY MESSAGES

Online health forums can be helpful because they are easy to access from the home, and provide informational and emotional support, and friendship/companionship from others living in the same situation. Whilst there are some risks to joining forums, users in our study found them to be an invaluable source of help and any risks can be reduced by following simple rules of being safe online.



For further information about our project or for more copies of this information sheet please contact:

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**breast
cancer
care**

mnda
motor neurone disease
association

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