DRAFT GUIDELINES FOR STAYING SAFE IN ONLINE SUPPORT FORUMS

Internet chat rooms and forums can provide a very valuable source of support for patients and carers which can be accessed at any time and wherever the person can use a computer.

"They offer patients and families the chance to share their hopes, fears, and knowledge with others experiencing life as they are. These online groups can counter isolation and serve as bastions of understanding, deep concern, and even affection." Marc D Feldman

However there is potential for abuse of this. The attached provides some guidance for staying safe in this type of forum.

Types of Support Sites

- **Chat rooms:** for live discussions between people. This is like phoning except that you type rather than speaking. Messages are not archived.
- **Discussion boards / groups / internet forums / message boards:** for discussions that are not necessarily live where you leave message which may or may not be replied to. These tend to be archived for a period of time. Sometimes messages have to be approved by a moderator before they are posted.
- **PM:** private messaging between 2 people
- **Blog:** pages by someone with their thoughts, their diary
- **Live online support groups:** where members can meet weekly at a set time for real-time chat and support, may be facilitated by a professional

Key Guidance Points

Never join in straightaway
Read mailing list or discussion board postings for a week or more without responding or posting anything yourself. In chat rooms, just sit quietly for at least 30 minutes to see if the discussions that are going on are truly something in which you wish to engage. Don't respond to private messages in that time, either. Take your time to get the 'feel' of the group.

Look at the small print
First check if there are any 'house rules' or 'community guidelines' on the site
You can get a sense of a site by looking at their 'house rules' or guidance on how to behave online. A reputable site will cover most of the points in this document. If a site has no 'house rules' or very limited ones then treat it with extra caution.
Who is the site owned by?
Is this a well known, reputable organisation? Are there contact details for it?
Is it UK based?

If it is not then be mindful that there may be differences in treatments, attitudes, culture.

Always balance sharing with circumspection
Remember that all may not be as it seems:
'Even in the relative intimacy of health support groups, individuals may choose to mislead others by pretending to have illnesses they do not... While most people visiting support groups are honest, all members must balance empathy with circumspection" (Marc D Feldman writing on Munchausen by Internet: for tips on spotting a faker please go to
http://www.healthyplace.com/faking-illness/munchausen/munchausen-by-internet-faking-illness-online/).

Never take a support group's recommendations instead of medical advice
Your case may appear the same as someone else's online, but in practice there may be differences. Always contact your healthcare professional for medical advice. A reputable site will make it clear that they recommend this and will be supportive of the doctor / patient relationship, rather than trying to undermine it.

Watch what you "say" online.
When you do participate online, be careful--only type what you would say to someone's face. If you wouldn't say it to a stranger standing next to you in an elevator, why would you "say" it online?

Don't give out any personal information
Never give out your real name, address, contact details, where you work, financial information, family details. Be careful what you put in your signature file also.

Additional Guidance

Ask more questions of the site:
Is there a **privacy policy?**
Check this out to see if you are happy with it
Is the site moderated? Who by? Is this done reactively (after messages are posted) or proactively (before messages are posted)?
Is there a **complaints mechanism** for alerting re abusive / offensive / spam posts?
Is there an option to send **Private Messages** so private conversation does not have to be via the site for all to see, or via email which breaks your confidentiality
Are the **aims and audience of forum** clear?
Is there a policy on child use including **minimum age**?

If you decide to join

Select a gender-neutral username, email address, etc. Avoid anything cute, sexual, diminutive, or overtly feminine.

Block or ignore unwanted users if there are any. Whether you are in a chat room or using instant messaging, you should always check out what options/preferences are available to you and take advantage of the "Block all users except those on my buddy list" or adding unwanted usernames to an Ignore list in chat. If anyone bothers you and won't go away, put them on block or ignore!

Don't allow others to draw you into argument. That may mean that you don't defend yourself from personal attacks. It's safer to ignore them and keep yourself above the fray. When the person realizes that they aren't getting a reaction from you, in most cases they'll move on.

If a place becomes stressful, leave it. There are many stressors we cannot avoid easily in our lives, so why put up with those we can avoid? If someone is being annoying in a chat room or on a discussion board, there are countless others that are likely to be more pleasant.

When you change, really change! If you need to change your username or email address, using a variation on your real name or anything you've used in the past leaves tracks allowing someone to find you again fairly easily. If you've always been "Kitty" and you change your handle to "Cat," you haven't really changed.

Never give your password to anyone. Your ISP will never, ever ask you for your password while you are online or via email. In fact, they shouldn't ever contact you to ask you for your password, period. They can get it from their own records, if they really need it for any reason. If you call them for support, there are a few rather rare instances in which the support person might ask you for your password - but you called them, right? So you know it's really a support person from your ISP that you're talking to. There's no legitimate reason for anyone to ever contact **you** to ask for your password.

And finally…

Personally monitor children's internet use, even if you have trained them in what information they can and cannot give out. There is no software in the world that can replace the active involvement of a concerned parent. For more on keeping children safe online see the guidance on the Childline website.

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