

Virtual communities



Access to 'virtual' or online communities is available through the Internet. Through these people with shared interests can overcome time, cost and distance to communicate with each other. Virtual communities are an ideal way for people with disabling conditions and rare disorders to talk to each other.

How do they work?

- Different communities offer different features:
 - email lists
 - discussion boards
 - polls
 - live chat room
 - review pages
 - group areas
 - personal profiles
- Normally, users must register for membership before being allowed to join the community and contribute.
- If you are setting up a virtual community, make sure that users agree to your 'acceptable use' policy.
- Some communities are moderated: before any contribution is published, a trusted party must check it meets community standards for decency and legality.

contact a family

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What are the benefits?

Online communities can bring many benefits:

- Users will spend longer at your site and return more frequently
- They can be a low cost way of sharing and archiving information
- Existing networks can be enhanced by an online presence
- You gain an awareness of the real needs and interests of your users because they are given the opportunity to talk amongst themselves

Taking care

- Users need to think carefully about the amount of personal information they give. In chat rooms, use an email address you reserve for that purpose
- Remember that there will be a range of different views presented ranging from orthodox to complementary treatments
- People with the same disorder may be affected differently
- If children are to use chat rooms, either generally, or about a specific disorder, check these websites that can alert you to pitfalls:
 - <http://www.thamesvalley.police.uk/chatsafe/parent.htm>
 - <http://www.thinkuknow.co.uk> for children to learn about Internet safety
 - <http://www.chatdanger.com> contains sections for parents, youngsters, school & general background safety on the Internet
 - <http://www.childnet-int.org> International Internet safety site

The latter three sites give instructions on how to insert a *Safety on the Internet* banner on your website.

For families with children and teenagers the AOL Internet Service Provider (ISP) includes safety provision which places the limits on the use of the Internet decided by parents. For those not using AOL, Net Nanny <http://www.netnanny.com> and Cyber Patrol <http://www.cyberpatrol.com> software will carry out the same function.

What are the costs?

Software and hosting can be expensive, especially if you require many features. Moderation is very labour-intensive, but mature communities can often be self-policing. However, the legal ramifications if anything goes wrong can be immense.

Where can I find examples?

- <http://www.mswebpals.org> Julie's Joint 'people with Multiple Sclerosis supporting each other'. This site has been created by an affected person who is a professional expert on website quality.

A number of support organisations cited in the Contact a Family Directory have established bulletin boards, forums and chatrooms. These include:

- <http://www.jtsma.org.uk> Jennifer Trust for Spinal Muscular Atrophy (JTSMA)
- <http://www.marfan.org.uk> Marfan Association
- <http://www.rarechromo.org> Unique – the Rare Chromosome Support Group

How do we set one up?

- Define your goal and audience
- Identify which features serve your purpose and audience
- Think about how you want to host or facilitate your community
- Build it
- Draw in the members by seeding discussions, attracting links and posting in other communities
- Nurture

A good starting point is <http://www.fullcirc.com/community/communitymanual.htm>
This site has a comprehensive range of information including:

- <http://www.fullcirc.com/community/purposecheck.htm> A check list to guide community builders.
- <http://groups.yahoo.com> Very helpful site listing a huge number of groups and easy instructions to start a new one.

This guide is part of the Contact a Family Group Action Pack. For more information please visit www.cafamily.org.uk or telephone 020 7608 8700.

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