Patients undergoing treatment for infertility often go online in search of medical information and social connection. This article outlines some of the benefits and limitations of searching for infertility-related information online, and aims to highlight the potential risks associated with the overuse of web-based medical information.

Online Information about Infertility

What Types of Infertility Information Do People Look for Online?

People generally go online seeking information about infertility for three main purposes:

1) They want to learn more about the general medical and treatment aspects of infertility and its treatment (e.g., “What is IVF?”), and/or
2) They want to learn more about their own specific diagnosis and treatment plan; and/or
3) They want to connect with others and understand more about the emotional and psychological aspects of infertility and its treatment (e.g., “How do people cope with IVF?”).

Having access to this information can empower patients. It enables them to take an active role in their understanding and management of their fertility treatment and can assist them to feel more confident about speaking to their doctor and knowing what questions they want/need to ask during their appointments. Patients also report that learning about other people’s experiences of infertility helps them to feel prepared for their own road ahead.

Where Do People Find Infertility Information Online?

The amount of information published online can be overwhelming – if you type “IVF” into Google alone and it will give you over 31 million hits. The internet gives you access to information from government or healthcare agencies, commercial websites (e.g. drug companies), clinic/doctor’s websites, the websites of various patient associations, and online forums/chat rooms. Making sense of it all and knowing where to access good quality infertility information can be a huge challenge.

It is important to evaluate all of the information you encounter online to ensure that you are not accepting outdated, unreliable, or irrelevant information. A great range of general tips for assessing health information online is given by the Australian Government’s HealthInsite website:

http://www.healthinsite.gov.au/topics/How_to_Assess_Health_Information_Online

When going online in search of infertility-related information, always be sceptical and don’t believe everything that you read. Most importantly, always check what you learn with your doctor or treatment team to so they can relate the information specifically to your own treatment.

Overuse of Online Information – How Much is Too Much?

For most people, accessing information about infertility on the internet is valuable and helps them to feel more informed and in control of their situation and treatment. However, there are times when searching the internet for information is not only unhelpful, but may be harmful by creating unnecessary worry or concern.

Signs that may indicate that your internet searching is no longer helpful include:

- You feel upset, stressed, or anxious about something you have read online;
• You spend time searching and reading through websites but do not feel like you’re getting anywhere;
• You feel confused about what you have read and what it means for your own treatment and experience; or
• You continue to spend a lot of time searching for information online instead of doing other important things in your life (like spending time with your partner, friends, family, etc).

Some general tips for managing your use of the internet as you progress through your infertility experience are to (a) limit the amount of time you spend searching online, stopping if it is feeling as though you are getting nowhere, (b) stop searching when you encounter conflicting information on different websites, and (c) limit your searches only to topics that are directly related to your own current experience and treatment, and (d) recognise the limitations to the type of information you are actually going to be able to find online.

Many times when a patient is feeling anxious or stressed after going online, it is because they are actually searching for information or an answer about their own personal circumstances – something that no internet site can give you. To help ensure that your internet searching is not going to be in vain, you may want to spend some time before you go online to write down the things you are going to be searching for. Then, consider whether it is a general or a personal question/issue. Remember, the internet can provide some general information, but can never give you individualised medical advice or information about your treatment. If the information that you are really after is specific to your own situation, then it is best to speak directly with your doctor or treatment team.

Some examples of questions that you may have and whether you may find an answer on the internet:

<table>
<thead>
<tr>
<th>Issue/Question</th>
<th>Personal or General?</th>
<th>Can I find this information online?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does IVF treatment involve?</td>
<td>General</td>
<td>Yes</td>
</tr>
<tr>
<td>What will my IVF treatment involve?</td>
<td>Personal</td>
<td>No</td>
</tr>
<tr>
<td>How do other women cope with IVF treatment?</td>
<td>General</td>
<td>Yes</td>
</tr>
<tr>
<td>How will I cope with my own IVF treatment?</td>
<td>Personal</td>
<td>No</td>
</tr>
<tr>
<td>What other treatment options exist for infertility?</td>
<td>General</td>
<td>Yes</td>
</tr>
<tr>
<td>What are my other treatment options?</td>
<td>Personal</td>
<td>No</td>
</tr>
<tr>
<td>Why aren’t I pregnant yet? Will I ever get pregnant?</td>
<td>Personal</td>
<td>No</td>
</tr>
</tbody>
</table>

*What to do When the Internet Doesn’t have all of the Answers*

Because of the general nature of information on the internet, many questions that you have just won’t be able to be answered online, and trying to find an answer might only end up leaving you feeling frustrated and confused. When this happens, be honest with yourself and acknowledge that there are some things that you just can’t know yet (e.g. how you will respond to your medication, how your treatment will go, and of course, whether you will get pregnant). It can be
difficult to let go of trying to control certain parts of your infertility experience, especially when the ultimate goal in IVF (having a baby!) is so important.

If you find that you are struggling to handle the many unknowns that come with infertility and its treatment, you may wish to make an appointment with your doctor to ask further questions about your situation. You may also find it helpful to speak with one of Melbourne IVF’s counsellors who can assist you in exploring and managing the underlying anxieties that are a common part of the infertility experience.

A SPECIAL NOTE ABOUT ONLINE FORUMS/CHATROOMS

Online forums (such as Melbourne IVF’s “FertilityFORUM”) provide an opportunity for people to connect with others in a similar situation. Reading about what other people have experienced can help you realise that you’re not alone on the emotional rollercoaster that is infertility and its treatment.

However, because of the wide range of individual experiences that exist, reading information posted in online forums can sometimes lead to an increase in anxiety, confusion and concern about your own experience. If you access these sites, it is important to remind yourself that nothing you can read on an online forum will relate precisely to your own unique circumstances – no one will have the exact medical and infertility history and treatment plan that you do.

In addition, keep in mind that the people who contribute to those chat rooms may be vulnerable at the time of posting their thoughts online, and their views do not always reflect those of the wider infertility community. A forum presents only a snapshot of all of the possible experiences people may have. Use these chat rooms if you feel they provide you with valuable information, support and encouragement, but balance this with the help and support of people from your treatment team and your friends and family.

Summary

It is important that you feel that you are well informed and confident about your fertility treatment. Your doctor and your treatment team should be the first point of call for any questions or concerns that you may have about your own unique situation and experiences. The internet can provide some useful general information about infertility and its treatment, however this should never be taken above any medical advice that you have been given. Always check any information that you find online with your doctor to ensure you have understood it correctly and have them relate it to your own treatment.