



# Web-Savvy Caregiving

Using the Internet  
to Care, Connect and Cope

Individuals and families coping with Alzheimer's disease (AD) and other forms of memory loss have a lot of questions. What's happening to my loved one? What can I expect in the coming months and years? How can I meet my caregiving responsibilities while also taking care of myself? Does anybody out there have any idea what I'm going through?

The answers, according to one expert, are right at your fingertips.

"Going online is such a great way to find what you need because you don't often have the time or availability to go out looking for help when you're providing care to someone in the home," says Andrew Schorr, a noted patient advocate and author of *The Web-Savvy Patient: An Insider's Guide to Navigating the Internet When Facing Medical Crisis*. Rather than allowing yourself and your loved one to become isolated, Schorr recommends using the Web to find what you need for all aspects of caregiving.

"You're not the first family dealing with Alzheimer's. None of this is new; it's just new for you," Schorr explains. "So why not draw from the wisdom that's out there?"

But the Internet can feel overwhelming, particularly to newer computer users and to those who haven't ever conducted online research. What are the best ways to wade through the seemingly endless number of Web pages to find what you need? And how can you distinguish helpful from potentially harmful content?

Mr. Schorr offers the following "Insider's Tips" to AD caregivers who are interested in becoming Web-savvy:

#### • **Insider's Tip #1: Define the condition.**

"Watching a loved one suffer from memory loss is like having a ton of bricks fall on a family over a long period of time," says Schorr. "But you don't have to take it lying down. Knowing how much support is out there on the Web helps people pick themselves up off the floor and deal with it." The first step, he insists, is identifying the problem before you kick off an online research project. This is especially true with memory loss, which can take many forms, each manifesting itself in slightly different ways. Make sure you have a clearly defined diagnosis from your loved one's doctor before you begin searching for information online about it. Alzheimer's disease, mild cognitive impairment and brain trauma are distinct diagnoses and typically call for slightly different treatment and caregiving approaches. Before you turn to the Web, tailor your search to the precise health issue you and your loved one are facing. "Deal with the medical stuff first, then begin hunting for support networks for the patient and the family," says Schorr. "It's all there. You just have to learn how to find it so that everyone involved can continue to experience the joy of living."

#### • **Insider's Tip #2: Connect with other caregivers.**

"These days, there is absolutely no reason to feel alone. The online connection can be a real salvation to caregivers," says Schorr. Using the Web to find others who are in your shoes can be one of the greatest gifts you give yourself as a caregiver. Since opportunities to attend in-person support groups are more limited to those caring for AD sufferers, you can interact virtually with people as a way of participating in a community of like-minded people. Exchange coping strategies, share anecdotes, do a little venting. The point is to communicate with people who understand what you're going through. You can even continue conversations online with people you've met in person at doctors' offices or in support groups as a way of keeping discussions going. Ask your doctor, nurse or social worker for the Web addresses of local and/or national caregiving groups that you might explore. "Many of us have to shift our perceptions of what makes a conversation," advises Schorr. "Conversations that happen online through email, social networking sites and website chat rooms are still conversations. And it's that sense of community that really matters."

#### • **Insider's Tip #3: Keep family and friends in the loop.**

The Internet offers numerous ways for caregivers to communicate with the people they care about—not just to stay in touch but also to ask for support. Email, instant messaging, Facebook, Skype, Twitter and other tools allow caregivers to interact with others and stave off the threat of isolation. Use these easy, often free channels for casual as well as more official purposes. Write informal notes to grandchildren, exchange newsy letters with friends, and summarize the latest medical reports for extended family. Equally important, says Schorr, is using the Web as a way to manage the help of others. "It can be debilitating for caregivers to do it all on their own," he notes. "So don't be shy about using some of these tools to delegate a portion of your caregiving duties to the folks who want to pitch in." You can marshal the efforts of all those good people who want to bring meals, help with errands and give you a couple of hours away from the house.

#### • **Insider's Tip #4: Get to your computer regularly.**

The best way to ensure that you get what you need from the Internet is to return to it as often as possible. "Carve out time for it. Add it to the list of things you ask for help with; have someone else sit with your loved one so you can focus," says Schorr. "Maintaining those connections and staying engaged with the world beyond your four walls will benefit you and the person you're taking care of," he adds. This is especially

true if you are researching your loved one's condition, since online content is ever-changing and you may make new discoveries each time you return. However, Schorr cautions to establish boundaries when it comes to interacting with online communities. "Don't get sucked into more than you can bear," he warns. "Devote a certain amount of time to connecting and chatting with others—even if it's just in ten-minute blocks—but honor that limit if it gets to be too much." (If anything or anyone makes you uncomfortable, or if your online activities begin to interfere with your caregiving responsibilities, then it's time to reevaluate your approach.) The Web can and should be a source of comfort and connectivity that helps recharge your caregiving batteries.

• **Insider's Tip #5: Share your story.**

"The Internet is a two-way street," reminds Schorr. "Don't just use it to learn from others; use it so others can learn from you." Along your journey as a caregiver, you will make many discoveries. You find it helpful to hear about coping strategies that have proven successful for other families caring for AD patients, so why not do the same for individuals just starting down a path that's similar to yours? "You're learning as you go and you have so much to share. It can be extremely rewarding to offer your new-found wisdom to fellow caregivers," says Schorr.

• **Insider's Tip #6: Protect your privacy.**

Use common sense while establishing accounts and communicating with others online. Think twice before using your full name (or that of your loved one) and identifying your hometown when visiting public Web spaces. You always have the option of using an alias or a nickname for any moniker that is visible to others. But don't let your desire for anonymity prevent you from diving into whatever resources you can find. In *The Web-Savvy Patient*, Schorr writes, "There are plenty of ways to find what you need without divulging your identify or your personal information unless you want to do so. Remember that everyone who explores the Internet in search of answers and support is in the exact same position as you and shares your interest in privacy." Final note: Do not ever give out credit card information or social security numbers to a non-verified source.

Caring for someone with memory issues is a job characterized by uncertainty, variability and occasional loneliness. According to Andrew Schorr, that makes it a lot like life. "Sometimes it's easy for caregivers to see a black cloud rather than the breaks in the cloud—those rays of sunshine and hope," he acknowledges. "But the Internet offers a huge community of people who have been there

## Online Resources for the Web-Savvy Caregiver

**www.ALZInfo.org**

News and tools from the Fisher Center for Alzheimer's Research Foundation

**www.ALZTalk.org**

Free online site, like Facebook, for the online Alzheimer's community

**www.Caring.com**

Alzheimer's caregiver resources and connections

**www.StrengthForCaring.com**

Support and community for caregivers of all kinds

**www.PatientPower.info**

Free Web-based patient education programs on AD, dementia and a variety of other disease categories

**www.LotsaHelpingHands.com**

Free, private, Web-based communities for organizing the assistance of friends, family and colleagues

**www.CaringBridge.org**

Free communication tool for people who want to provide journal-style updates to friends and family

**www.Facebook.com**

Social networking channel



**www.Skype.com**

Free Web-based phone and video chat services

**www.Blogger.com**

Easy-to-use, free blogging tools from Google

**www.Twitter.com**

A free Web-based medium to provide short updates and messages



and felt all those things. There are real people out there—doctors, nurses, social workers and caregivers just like you—who want to help for free simply because they've been through it. They know they can help you avoid some of that pain so that you can get to a more positive place." Then, Schorr says, the Web-savvy caregiver can turn around and give the same gift to others. ■

*Mary Adam Thomas, a frequent contributor to Preserving Your Memory, is the collaborative author of Andrew Schorr's The Web-Savvy Patient: An Insider's Guide to Navigating the Internet When Facing Medical Crisis. More information and excerpts from the book are available at www.WebSavvyPatient.com.*