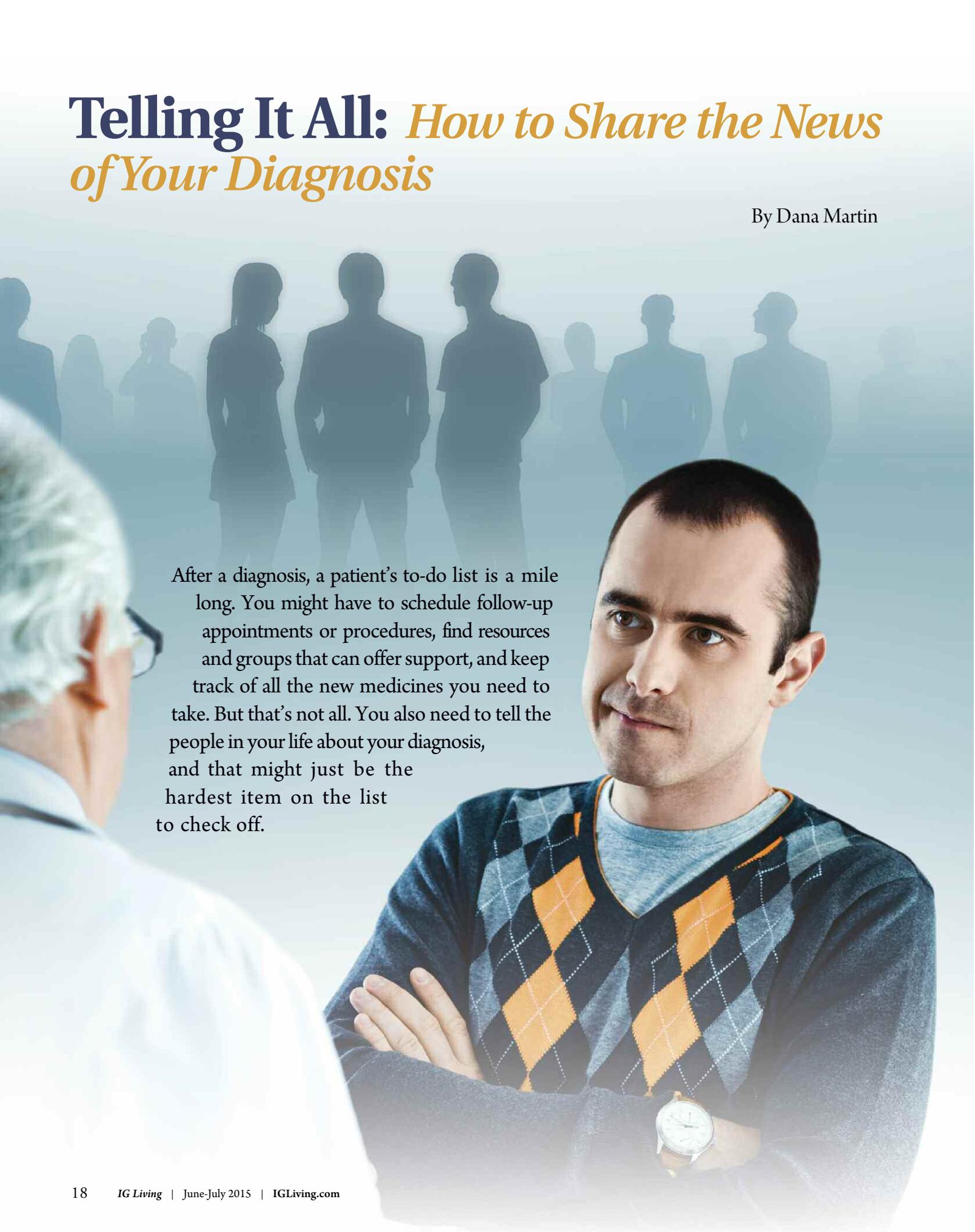


Telling It All: *How to Share the News of Your Diagnosis*

By Dana Martin

A photograph of a man with short dark hair, wearing a blue and orange argyle sweater over a grey t-shirt, looking towards a doctor whose back is to the camera. The doctor has white hair and is wearing glasses and a white lab coat. In the background, there are several blue-tinted silhouettes of people of various ages and genders standing in a line.

After a diagnosis, a patient's to-do list is a mile long. You might have to schedule follow-up appointments or procedures, find resources and groups that can offer support, and keep track of all the new medicines you need to take. But that's not all. You also need to tell the people in your life about your diagnosis, and that might just be the hardest item on the list to check off.

FOR MANY PEOPLE living with a chronic illness, life can be divided into two parts: before diagnosis and after diagnosis. Even when symptoms have been present for months or even years, the point of diagnosis is a significant milestone. It's as if you've been cleaved in half: You now stand squarely in the "after-diagnosis" half of your life, while the "before-diagnosis" life drifts into the distance. And, as that old life is carried away, you may fear it will take many of your relationships with it.

Your immediate family and closest friends will most likely be the first to know about your condition. But how do you break the news? And how do you tell others such as friends with whom you have less contact, classmates, extended family members, congregation members and other community members?

It might be tempting to keep silent in the hope that those who aren't in the know won't have an altered sense of who you are. This is a way of shielding others from your after-diagnosis life, as well as preserving those relationships in a past that might feel safer and more secure than your present or future. But reaching out to those you have shared aspects of your life with might be one way to help bring your past and present together. This, in turn, may help you alleviate the feelings of isolation that so many people living with chronic illnesses experience. Reaching out even more by being public with your condition might also be a therapeutic approach to processing your diagnosis and living with your illness.

Below are some tools to consider when sharing your diagnosis with those who are part of your life and with the larger community.

Stay Centered

Staying centered works on two levels. The first is to share your diagnosis with others by placing yourself at the center of the process and envisioning working your way out. On a piece of paper, mark yourself at the center. Then draw consecutive rings around you. Each ring represents a different group of people in your life that you want to tell. Loved ones will most likely be in the ring that's closest to the center. Close friends might be in the next ring. Distant family members might be in a ring that's farther from the center. Add enough rings to represent everyone you want to talk with about your condition, and make sure their proximity represents how close they are to you. Now you have a guide for working your way out from the center. Depending on your situation, you might have to make some adjustments in terms of the order in which you share your news, but the diagram gives you a basic blueprint to work from.

The second way of staying centered is exactly what it sounds like: As you go through the process of informing other people about your condition, remember that you are at the center of

this news. Patricia Anderson, an emerging technologies librarian for the Health Sciences at the University of Michigan, is a patient advocate who is also very public about her own health issues. She points out that many people who have chronic illnesses spend a long time hiding the manifestations of their conditions before they are finally diagnosed correctly. During that time, they might ask themselves how much they can cover up so they don't lose their jobs or place their relationships at risk. Anderson says a common theme among those with chronic illnesses is: "How far can I fake it?"

Making the transition from faking it to talking openly about your condition is an accomplishment in itself. As you make this shift, remember that your life is the one most affected by the diagnosis, and you are the person who needs support and understanding during this time. Keep this in mind and honor what you need, including how much energy you can give to any one person and what pace you can adopt when informing others about your condition. People will naturally have questions about the news you are sharing. They might even have misconceptions about what you are trying to relate. The act of communicating and clarifying can be exhausting on top of a condition that may already be draining your energy. Think of each act of communication as a sprint. Warm up for it. Don't go longer than you are able. Honor the signs your body sends that tell you you've done all you can do in one sitting or with one person. Even if you haven't crossed the finish line in a given conversation, know when you need to pause and say, "I think we've talked about this enough for now. Let's come back to it again another day," or something to that effect.

Another way to stay centered is to make sure you have all the support you need before you embark on telling people about your diagnosis. Solicit the support of those closest to you first. Find support groups that can help, including those in your area and those available online through organizations that serve people with your condition. You might even consider talking with a therapist for a period of time to help you process the diagnosis and the steps you are taking to communicate that diagnosis to others.

Tell It, and Tell It Again

Be prepared to tell your story more than once to the same person. Medical conditions can be complicated and difficult to understand. As you are sharing your news with someone, he or she is likely trying to process it on an emotional and intellectual level. There's so much to take in and contextualize that it's almost impossible to be the recipient of such news without having follow-up questions or needing further clarification.

Be as patient as possible. Be as understanding as possible. If you can, have information in print or online that discusses your



Sharing in a Group Setting

In some situations, sharing with a group such as your children or a few close friends might be best. Try to have someone with you for support if you go this route. Otherwise, you could become overwhelmed by everyone's collective response to the news. When you share with several people at once, try to follow up with each person individually. In a group, people might not feel comfortable asking questions or sharing all their feelings openly. Offering to talk one on one can give each loved one that opportunity. With children, one-on-one conversations can also be tailored to their developmental stage.

Sharing at Work

Sharing your condition in the workplace is a personal decision. If you choose to have those conversations, know your rights as an employee before you discuss your condition. Legally, you are not obligated to disclose the nature of the condition, even when asking for leave or an accommodation. The Equal Employment Opportunity Commission (www.eeoc.gov/facts/ada18.html) and the Americans with Disabilities Act (www.ada.gov/qandaeng.htm) both have web pages that answer frequently asked questions about disability rights.

condition. Make those reference materials available during or shortly after each conversation. If you know of support groups for loved ones dealing with your condition, share that information as well. If you seem to be sharing more information than someone is comfortable with or able to understand, reduce the message to its core. If someone wants to know more and you are comfortable with that level of sharing, feel free to go into more detail. Talking through the diagnosis in depth can help you process it, which can in turn promote your own healing.

In addition, keep in mind that you might not be the only one telling your story. Anderson points out that loved ones and others advocating for your health may also need to communicate information about your illness, and most likely more than once. Like you, they should be prepared to tell your story as well as possible and as often as needed.

Create Your Elevator Pitch

There will be situations in which you and those advocating for your health will need to convey the essence of your diagnosis quickly and succinctly. This is where having an elevator pitch comes in handy. In marketing, an elevator pitch is a short summary used to quickly define a profession, product or service. It's supposed to be no longer than an elevator ride, hence the name.

For a medical condition, your elevator speech might be: "I have a rare, genetic condition that affects my immune system" or "I have pain all over my body that limits my activities." Everybody's elevator speech will be unique, and you can use variations in different settings. For instance, if you choose to

share your diagnosis during an interview, you could add a second sentence that speaks to your ability to perform the functions of your job. Melanie, who was diagnosed with common variable immunodeficiency (CVID) in 2010, recommends using words that other people are likely to understand when giving a summary of your condition. Rather than saying she has a "primary immunodeficiency," she tells people she has a "genetic immune deficiency" because people are more likely to understand the term genetic as opposed to primary. "Telling people my condition is genetic helps them understand that it isn't contagious," explains Anderson, "which can be one of the first questions people ask when I tell them I have CVID." Anderson also chooses her words carefully when crafting her elevator pitches. For her methylenetetrahydrofolate reductase (MTHFR) deficiency, rather than going into the detailed complexities of the condition, she tells people she has a genetic enzyme deficiency that means her body can't properly get nutrients from green leafy vegetables. (For more on elevator pitches, see Ilana Jacqueline's *Life as a 20-Something* column in the April-May 2014 issue of *IG Living*.)

Choose Your Scope

It's up to each person to decide how open they want to be about their condition. Some people might want to tell only their immediate family members. Others might want to tell the world. Many will want to aim for something in between. There's no right or wrong in this regard. Some people who receive life-changing diagnoses go on to become community educators and health advocates. Others keep their diagnosis more private and

share it selectively.

Though you will most likely experience a great deal of love and support during the process of sharing your diagnosis, you should also be prepared for those who don't understand what you're going through. The more open you choose to be and the greater the number of people you include in your communications about your condition, the more likely you are to run into a few naysayers. Anderson cautions: "You can't assume that everyone will just be kind. Some folks will think you're crazy, or that your diagnosis is wrong, or your doctors are stupid. Sometimes, being public means you have to defend yourself, your treatment choices and your lifestyle."

Melanie was reticent at first to be open about her condition. Over time, however, she became more comfortable sharing information in the hope that it would help educate others. She now posts about CVID openly on Facebook, and she maintains a blog called CVID Awareness (cvidawareness.org), which she took over anonymously in February and still maintains semi-anonymously. She recognizes that many people with CVID are afraid of the ramifications of revealing it publicly, but she also sees the need to educate the public and be visible to others who also have the condition.

When you consider scope, you might also want to think about whether to discuss your condition with people from the past. Before diagnosis, many people with chronic illnesses spend years being misunderstood or treated as hypochondriacs. Finally having a diagnosis could help those from your past have a better understanding of what they couldn't make sense of at the time. When Melanie was diagnosed, she chose to reach out to an ex-boyfriend who hadn't understood why she was always ill. She says he appreciated knowing about the diagnosis, and the conversation provided a sense of closure that had been lacking before. To give another example, if you missed work and people believed you were making excuses for your absences, it might be helpful to get in touch with the supervisor at that position to update him or her about your health and provide context for your missed workdays. This can be especially helpful if you rely on that supervisor for a reference. The downside of reaching out to those from the past, whether they are former friends, partners or employers, is that they may or may not be open to what you are communicating.

Harness Social Media (and Avoid Its Pitfalls)

Social media can be part of your communication strategy, but be careful. The allure of social media sites is that we can broadcast messages to a large group of people. This can be a tempting way to announce a medical condition because it removes the pressure of a one-on-one conversation and requires less energy than more

traditional ways of communicating personal news.

Melanie says she especially appreciated Facebook at the time of her diagnosis because it gave her a convenient way to message acquaintances that she had passing or infrequent contact with. This prepared those acquaintances to see her posts on the subject without being confused about their content. Depending on how comfortable you are with social media, Melanie's approach might work for you. But for family members and close friends, discussing the diagnosis privately is important. You don't want someone you know well and care for deeply to learn about your medical condition by reading a post on your Facebook timeline. That could be hurtful and confusing, as well as lead to feelings of resentment that linger.

Social media can also be used effectively to continually educate people about your condition. You can link to research articles, news from organizations that specialize in your condition, and other information that, over time, will give those who follow you a deeper understanding of your condition. At the same time, you should consider the potential effect such information could have. If you aren't careful with privacy settings, for example, your posts could be seen by a current or potential employer, and you might not want that level of sharing. You also can't assume your friends are seeing all your posts about your condition. Most posts on social media are seen by a fraction of those they are shared with. Don't be surprised if you post an update and it seems like people missed it. They probably did. If you don't continue to touch base with people individually about your condition, they might lose touch of where the diagnosis and treatment stand.

Anderson has made a personal commitment to transparency and openness in order to educate and support others. Her "strategy," she says, is by necessity a combination of "can't tell a lie, can't keep a secret, and don't ask, don't tell." Her communications on social media allow her to share with and learn from others, which is part of her healing process. "I've noticed my friends who keep their conditions secret tend to suffer the greatest emotional trauma from it," Anderson says. In her case, being open about her health, online and offline, has led to more support in all areas of her life.

Whatever approach you take and however widely you decide to cast your net, know that sharing your diagnosis is an act of bravery and strength. Soon, you won't be in it alone. With a considered approach to communicating about your illness with others, you can engage a band of supporters to help you make your way through the process and help you bridge your life before and after your diagnosis. ■

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