Managing Communications With Family & Friends

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Dear Patient,

One of the many decisions you face after a cancer diagnosis is how to communicate health updates to your family and friends. These days, you have lots of options. It helps to know the pros and cons of each. Whether you share your diagnosis with only one person by phone, the whole world on social media, or anything in-between, here are insights and tips to help you benefit from the best method for you, for now.

Do you have to share updates?

No, you don't *have* to share anything. That said, keeping family and friends in the loop helps you benefit from their support—and helps minimize stressful interactions due to miscommunications. Many patients tell us that such support was invaluable in helping them through treatment and recovery.

Who should be the one updating family and friends?

This is your treatment and recovery, and you have a right to tell your story your way. That's why patients who want to do the communicating usually take charge of updating others. Other patients prefer that someone else do it, with them reviewing and approving each update before it goes out. If for any reason you can't or don't want to, find someone who's willing to take over the task. Rest assured you can change who does the updates as your preferences change.

What are common ways to communicate updates?

- *Group emails.* If comfortable with email, sending group updates to your select group allows you to craft the message exactly the way you want it to sound. You save energy by sharing news only once, instead of repeatedly. Remember to use the blind copy address bar ("bcc") to protect others' privacy unless you prefer everyone know who's on the list. Also, remember to find a way to update people who aren't online and won't receive your emails.
- *CaringBridge (caringbridge.org).* This free computer app is designed to "build bridges of care and communication." Only the people you invite can see your updates. *CaringBridge* also makes it easy to let people know your needs. Whenever you feel like it, you can post updates and read others' encouragement and offers of help. You have the option to add journal entries or photos.
- *Phone calls.* Phone calls (and FaceTime) allow you to share your thoughts and feelings in real-time conversations. The intimacy and immediacy may be just what you need to process what's happening and not feel alone. Along with letters, phone calls are the usual way to communicate with family and friends who aren't online.

Don't be surprised if phone calls tire you. It takes energy to repeat news over and over—even when the news is good. Another risk is being caught off-guard by a comment or topic that upsets you. On the spot, you must figure out how to respond. You also run the risk of your callers getting emotional, making you feel like you need to support them, which is draining.

What are advantages of providing periodic updates about your condition?

Advantages include…

- *Retaining control over the message.* You decide which medical details you share, if any, and when you share them. That preserves your physical and emotional energy, while decreasing the risk of people passing along misinformation or spreading rumors.
- *Obtaining assistance.* Your updates provide an easy way for you to spell out what kinds of support you want and need—or don't want or don't need.
- *Addressing the needs of your friends and loved ones.* Your friends and family can do a better job supporting you if they have some sense of what's going on. Your guidance on what you find helpful or harmful as your situation evolves enables them to adjust what they say and do. Importantly, updates also help them manage their own expectations and needs.

What information belongs in an update?

The purpose of updates is to help you address your needs every step of the way. In general, you benefit by (1) letting others know where you are in your treatment and recovery and (2) guiding others to helpful responses to your current needs.

Common topics to cover include…

- Your condition: How you feel. What kinds of assistance you need.
- Your treatments: How treatments are going. Whether things are on schedule.
- Your expectations: The next steps in treatment or recovery. How you expect to feel.
- Your needs: Meals. Errands. Rides to treatment. Childcare or eldercare. Messages and cards. Prayers.
- Your hopes: Short-term health-related hopes. Non-illness-related hopes.

If you prefer privacy right now, be direct—even if others won't be happy about feeling shut out. One way to phrase it is: "*Right now, you help me most by respecting my privacy. I'll let you know when I resume emailing or want phone calls or visits. Until then, I appreciate your understanding and patience.*"

How much detail belongs in an update?

Whichever amount serves you best. In general, the most basic information is enough. For example, "*Hi, everyone. I'm half-way through my chemo. Except for the 2-3 days following treatment, I'm doing all my usual activities. I expect more fatigue as the treatments continue. My daily walks should help. Thanks for the meals twice a week. They really help. I appreciate all the cards and emails, too—both of which are better for me than phone calls.*"

It's up to you if you want to add details about setbacks or your side effects, fears, anxieties, or stresses at home or work. When considering what to include, ask yourself, "How does sharing those details help me? How does adding those details help others respond to my needs better?"

What if people close to you complain that you're sharing too much or too little?

People have different communication styles and needs. It's common for a patient's spouse, partner, parent, or adult child to prefer sharing less—or more—than the patient. Keep in mind that your illness affects those who care about you, which is why we encourage you to discuss this issue upfront with those closest to you. Bottom line: you have a right to communicate the best way for you.

A warning: You lose control *forever* over anything you share in public forums such as Facebook.

What if you change your preferences about what you share and with whom?

Do what's best for you now. It's common for patients to change who is on their update list and how much they share. If you want more privacy, simply post less often (or not at all) while continuing to email and/or call the people you want to keep in the loop. Your job is taking care of your needs, not everyone else's.

What now?

Talk with those closest to you about your options for updating friends and family. Finding the best way for you is one way to help you get through and beyond treatment. OT