

Taking Charge

A Cancer Resource for Friends

By Amber Masso

Program Director

American Childhood Cancer Organization

Advice for Friends of Adolescent and Young Adult Patients

Your friend has been diagnosed with cancer, and you're worried, scared, and confused. This is tough, because most people don't think about teens and young adults having cancer. Now, it has happened not only to someone close to you but also to someone your age. You may not be sure how to respond or react, and you worry about saying or doing "the wrong thing." Truly, this situation can be frightening, confusing, infuriating, saddening, and even embarrassing at the same time. You may find yourself dealing with heavy thoughts about life and death, and you might even struggle with the temptation to pull back from your friendship so you can avoid of the new feelings you have because of your friend's diagnosis.

First of all, it's perfectly normal to feel this way. You just need to remember that your friend needs you now more than ever. Cancer is scary to everyone, but the companionship of friends can help make the journey much more bearable. While you may feel powerless, please know that there are actually many things you can do to help your friend and to help yourself during this difficult time.

Be prepared.

Knowing what to expect can make it much easier to be there for your friend. For example, you might already know that your friend could lose hair as a side effect of cancer treatment, but are you familiar with some of the other side-effects? Do you know what cancer treatment actually entails? Find out as much as you can. Do some research about your friend's cancer and the types of treatments and tests he or she will receive. Maybe your friend will share some of this information with you. If not, contact your friend's parents, caregivers, or social worker with questions or concerns.

You should also be prepared for your own reactions to your friend's treatment. Your friend's cancer will take a toll on you as well, so try to be aware of your own emotional needs and limitations. You might discover that the hospital makes you nervous or that you feel uncomfortable about being seen with a friend who looks different or has to do things differently. You want to be there for your friend, but you may find yourself feeling overwhelmed by certain medical issues or feeling awkward once you notice strangers looking your way. It's okay to feel uncomfortable, and it certainly doesn't make you insensitive or a bad friend. That said, you should definitely come to terms with any issues you may have, and you should seek support accordingly. Find a relative, friend, or teacher to confide in. You can't be there for your friend if you aren't meeting your needs too.

Aside from hair loss, some additional things to expect *might* include:

Embarrassment and Lowered Self-Confidence and Self-Image.

Your friend may feel embarrassed or awkward because of treatment side-effects. He or she may no longer look "normal" or "healthy," and he/she may no longer be able to do the same things as others. Try to find ways to help your friend cheer up and feel as "normal" as possible. Cancer doesn't change who we are and what we like to do! As mentioned previously, you should be prepared for your own reactions as well. If you are having a hard time, your friend may notice and may feel even more uncomfortable. Find someone to talk to.

Weakness, fatigue, and lack of endurance.

Cancer treatments can make even the smallest things a big struggle — like walking up (or down) stairs or carrying schoolbooks. Your friend may suddenly become too tired to a lot of the things you used to do together. Sometimes, he or she may even be too tired to talk on the phone. Let your friend take things at a comfortable pace. State that you understand how draining treatment can be, and indicate that you are willing to accommodate your friend in any way necessary. However, you shouldn't automatically assume people with cancer won't always want to go out and do things. Let your friend make the call, but be understanding and supportive if the exertion proves too much. Try not to show frustration if an activity is cut short.

Vomiting and nausea.

This is quite common. Don't be offended if you've brought over a snack that doesn't get touched. Your friend isn't trying to be rude. He or she is probably having trouble keeping food down. Try to find out what he or she can eat, and bring that instead. Because of the nausea, your friend may no longer feel comfortable about going to restaurants or anywhere that he or she may have to run to the bathroom. This can be an embarrassing and distressing situation for both you, so try to keep that in mind when you make plans. Your friend may feel guilty or may not want to feel like a burden. Be very clear that you understand that this is a treatment side-effect. You may also notice a change in your friend's eating habits. Certain foods are no longer a good idea because they are harder to digest or because they cause irritation in the throat and intestinal tract. The lining of your throat and intestinal tract consists of cells that are particularly susceptible to certain chemotherapy drugs. Because the drugs damage these cells like they would damage cancer cells, your friend may have ulcers or sores in his or her mouth or digestive tract.

Difficulties in school.

Your friend may fall behind in school because of extended absences, lack of energy, or even physical or mental damage caused by the cancer or the treatments. It is very easy to feel disconnected when you are away from school for a long time. Try to help by picking up and turning in assignments and homework. Help keep teachers and classmates updated, and collect notes and postcards to take back to your friend.

Changes in personal relationships.

Understandably, people with cancer are often sad, anxious, afraid, and even angry. On top of that, some treatments have side effects like fatigue or mood swings. This can cause stress for caregivers and friends, and it can strain relationships. As a cancer patient during a major transitional period of life, your friend is dealing with a major illness on top of a lot of issues related to developing an identity as an adult. This is often a time when young people think about or begin careers, go to college, and even start considering whether or not they want to start a family. Because of cancer, your friend is being forced to re-examine his or her path and identity. Things don't feel certain or secure anymore, and that is pretty scary! If he or she is particularly moody or doesn't feel like visitors, be patient. Don't take it personally and give up; try again another day.

Be there.

This should seem obvious, but it's also extremely important. Adolescents and young adults with cancer often feel isolated and alone, especially if they're in the hospital or away from school for long stretches of time. It is also easy to feel isolated because they may be the only person their age at the treatment clinic. You can help by visiting as often as you can. This may be difficult for you too (understandably), but fight the urge to stay away because you feel uncomfortable or scared. Your friend needs you now more than ever. He or she is still the same person inside, and your presence can bring a sense of calm and normalcy. Even if you aren't sure what to say to your friend, just being there to show your support will mean so much. If distance or your schedule makes it hard to be there in person, stay in touch by sending notes and cards or by emailing, calling, texting, and using Facebook or Twitter. You should try to set an example for other friends. If someone else is uncomfortable or worried, be there for them too. By sticking together, everyone can be a great support network for the friend who is going through treatment.

Keep everyone in touch.

Keep in touch and help others stay updated. By acting as a "point person," you can help your friend spend less time updating people by phone or email. Help out by offering to relay messages to friends, teachers, and others on a regular basis. Make sure you have the phone numbers and email addresses you need, and then create a list so you can text or email everyone at once when there is news to report. Set up an email list or a listserv using a service like Google Groups. Use Facebook, Twitter, YouTube, Blogs, CaringBridge, and other sites to keep everyone in touch and up to date. Be sure to read "Internet and Social Media Survival" for some great tips about keeping in touch and maintaining the privacy of medical information.

Make a care package.

Find out what things your friend could use. When people are sick, their tastes and senses can change, so certain things might seem more or less appealing in terms of taste and smell. Your friend may have some new favorite, comforting foods. Other items like scented lotions or body spray probably aren't a good idea anymore, since strong smells can trigger nausea. Either way, be sure to find out what things might be particularly comforting right now. Put together some fun things for your friend to do while alone, perhaps popular new novels or games like Sudoku. Wrap up your package and bring it to the hospital or your friend's home.

Step in with siblings.

If your friend has siblings, spend some time with them. They probably feel a lot of the same things you do, so you might be able to help each other through it.

Help out with schoolwork.

Offer to help your friend with homework — everything from passing along assignments to tutoring your friend or working together if it's appropriate. Even something as simple as taking really good notes (or asking someone else to do so if your friend is not in your class) can be a huge help.

Talk and Listen.

Talking things out can be great for your friend and for you. Be prepared and ask questions if you need to. It can also help to talk about the future and to make plans in a realistic, compassionate way. It is definitely okay for both of you to express fears. Be patient and empathetic. Even if you are uncomfortable, try not to shrug off or avoid talking about your friend's fears or concerns, particularly about death. Instead, try to offer realistic specific examples of other people who have survived cancer, especially if they are examples of those who survived your friend's type of cancer.

Keep Humor High.

Do whatever you can to keep spirits high. If your friend is feeling down or low on energy, bring in some fun! Don't be afraid to be silly. Humor can be an excellent distraction! Just do you usually do to make your friend laugh. Movies, board games, thumb wrestling, inventing private stories about the hospital staff, the possibilities are endless.

Practical Advice for Family Friends and Co-Workers

Cancer is scary for just about everyone, whether it's the patient, their friends and family, or their family's friends. In general, it's not an easy subject to talk about. Often, people struggle with the urge to distance themselves, because they are afraid of doing or saying something wrong. This is not really the best idea. While others may feel uncomfortable, the patient and family feel isolated, forgotten, and excluded-on top of the other emotions related to their situation. Friends and co-workers should keep in mind that, no matter how uncomfortable it may be to discuss things, not acknowledging the family's situation also means not acknowledging their pain. Is this really the intended message? It may be difficult for both sides to reach out. In reality, a tongue-tied awkward silence is the enemy. Once that is overcome, everyone benefits from being there for each other. Certainly, if you have fears and concerns of your own, find someone you trust to help you talk about it. You can't be there for the family if you don't take care of yourself as well.

Some communication tips:

Refrain from saying things like, "I don't know how you handle all of this, I couldn't do it." The family is doing everything they can to make sure that cancer does not win. Often, the burden is so great that they may not view themselves as "handling" things at all. Many people plow through the constant parade of appointments, surgeries, and treatments because it is necessary. Often, they feel exhausted, scared, and isolated, but they focus on getting through one hour at a time because that is all they can do. Some people may not show their true mental state until they get behind closed doors, especially if they feel the need to make things more comfortable for those around them (and if you have just given them a complement on "handling things"). Instead, say something like, "I know you are dealing with so much. I'm here for you." It is a way of acknowledging what they are going through, but it also gives them the opportunity to open up about how they really feel.

Try to ask about other things besides the patient's status from time to time. Ask about the parents, siblings, work, and hobbies. Constantly talking about cancer is exhausting for everyone.

In addition to discussing the child or adolescent's condition, cancer families may understandably have difficulty talking about their own needs. The same can be said of an adolescent or young adult patient who is active in or managing his/ her treatment. With everything happening to them, it isn't easy to pick one specific need from the multitude on an ever-growing list. They are not used to needing help from others, so they sometimes do not know that they need it or how to say yes to help that is offered. Often, "I'm fine" or "We're doing okay" may not necessarily mean that the person/ family isn't in need of help. It's important to note that saying, "Call me if you need anything" won't suffice in most cases. That call simply won't happen. If you really want to help, be specific.

"While I'm taking care of mine, I'd be happy to drop off and pick up your dry cleaning for you."

"You and your husband should take a break. We'll be happy to babysit for a few hours."

Remember, any supportive undertaking needs to be done in a way that respects the family or patient's wishes and honors their privacy. Once you've identified an area of concern, work **WITH** the family to help them solve the problem. You should not decide to undertake a large effort, like a fund-raiser or monthly meal calendar, on your own without talking with the family first. As well-meaning as many efforts can be, they may not always be serving the family's most urgent needs. It is also important to remember that cancer is **not** a short-term problem. The hierarchy of needs shifts for a family as cancer treatment progresses. A flood of offers to help during the first few weeks can fade into less than a trickle as time goes on and some friends and family members fade out of the picture. Even if it is just a phone call or an email a couple times per month, do not lose touch. Try to check in to see how needs may be changing over time.

Some Ways to Help Young Cancer Patients and Their Families:

- * When news of the diagnosis begins to spread, the family/patient can be flooded with phone calls and emails from concerned friends and family. People want to check in, lend encouragement, or see how they can help. While they have the best intentions, they may not realize that they are causing stress. Talking about the situation 100 times is overwhelming and exhausting for the patient and the family. To help alleviate this, become a "point person" and help the patient/ family update others. Collect phone numbers and email addresses to shoot out a quick email or text message when there is something new to report. You could also help set up a secure blog or a private Facebook group, where you or the family can post updates. Anyone who is interested can get information there instead of making direct contact.
- * Another great option is Google Voice (<https://www.google.com/voice>). This is a free service that can be used to create a custom voicemail box for friends and family to call for updates. Google Voice lets you choose a phone number and even create multiple outgoing messages that can be customized for different callers. It's a great option that avoids the necessity of changing the outgoing messages on existing voicemail boxes. This service connects a new number to an existing phone, but you don't have to leave the ringer on. Just update the outgoing voicemail message when something new happens. Of course, this can be achieved with an answering machine or someone's existing voicemail box. Turning off the ringer can certainly lessen the stress of a constantly-ringing phone, and concerned friends and family will still be able to get updates. They can even leave you a message of encouragement if they wish.
- * You could also create a private YouTube channel that achieves the same goals. Help the patient and family make a video diary or, or help them periodically post video updates. Consider their privacy. Discuss what they are comfortable sharing, and create privacy settings accordingly. This can be therapeutic for everyone, because friends will get updates, and they can leave notes of encouragement in the "comments" section for the patient and family.
- * Assist with house cleaning and chores. It is essential for the patient's surroundings to be as clean as possible, because chemotherapy weakens the immune system. He or she will be much more susceptible to infections, even from common household germs. This is especially helpful if the family has been at the hospital for a while. Parents are so busy with other things that cleaning the bathrooms may not be as high on the priority list as it should be.
- * The major credit card companies make gift cards, and they can usually be purchased at grocery stores or at general retail stores like Target or Wal-Mart. Everyone could pitch in for a card. This is of great help, because the gift card can be used anywhere that major cards are accepted.
- * Drop off and pick up their dry-cleaning with yours.
- * Pets will need some attention too. Walk their dog, offer to clean the fish tank. Pet-sit while the family is at the hospital.
- * Parents will need a break every now and then; they need to maintain their sanity in order to be there for their ill child. Provide a night or day of babysitting.
- * Give puzzle books, reading books, and activity books. These are lifesavers in waiting rooms and hospital rooms.
- * Make a "Survival Kit" for the patient or parents. Include things like toiletries, favorite snacks, photos, books magazines, and anything else YOU would want if you had to be away from home for days or weeks at a time.

- * Get them a gift certificate for video rentals or give them a gift subscription to Netflix. For less than \$20 per month, a group of friends can give the family a great source of entertainment. Netflix gives the option of ordering physical DVDs or watching movies online, so it's a versatile solution. The online "Instant View" option for movies is especially helpful if the family is away from home because of treatments. If they have a laptop and an internet connection, they have thousands of movies to choose from.
- * Buy music for the patient/ siblings/parents. There are multiple options! If you know they already have an iPod or other MP3 player, give them a gift certificate to iTunes or Amazon.com. You could also load up an iPod or an MP3 player with the person's favorite songs, or create new playlists for them.
- * Create an account for them on Pandora.com or Rhapsody.com. They would be able to listen to music for free. These services are great because they suggest music based on favorites. Many phones have apps for these services, and the accounts can be accessed from anywhere with an internet connection. For some people, discovering new music is a real mood-lifter.
- * Visit the parents in the hospital. It is possible for them to be scared, bored, and tired at the same time, so company will help. Bring food, a new magazine, and lots of news and stories to make them feel less left out of normal life. If you can, stay with the patient so they can go get something to eat or have a shower and a nap at home.
- * If the treatment center is far from home, families can really spend a lot on gas. Pitch in for a gas card. It can also be expensive for them to make calls if they will incur long-distance charges, so a pre-paid phone card is another great idea. If the family will have access to internet, you could help them set up a Skype account to keep in touch with loved ones.
- * If the patient is an adolescent or young adult, provide transportation so that friends can come to the hospital. Staying in touch with friends and having their support is REALLY important at such a scary time.
- * If the patient is still in school, offer to take notes and/or pick up and drop of assignments and homework. Collect a few postcards from teachers and classmates too.
- * Enlist people to send cards, movies, and other fun things to the patient and/or the family. A little fun and laughter can go a long way toward alleviating stress, anxiety, and sadness. Be the "fun" friend who shows up at the hospital room or at the patient's house with board games, video games, play-doh, or anything else to lighten the mood. Life with cancer is scary and stressful enough for everyone without having every visitor walk in with a look of pity across his/her face!
- * Start a competition with the patient or the entire family. Examples: compete to see who can read a certain book the fastest, or see who can go the longest without saying a certain word. Frivolous goals are a great distraction, which would be greatly-welcomed amidst everything else going on.
- * Commit yourself to look after the needs of the siblings. Be someone they can call on when they need to talk or when they are feeling left out. If you can't fully commit yourself, help find someone whose special job it is to give them attention, time, and little treats. They're scared and left out, and they need people to take their places and listen to them. Help make them feel important too.
- * If you know the patient's dietary restrictions, look up recipes online and compile a cookbook for anyone who would like to help with meals.

Increasing Awareness at Schools and Businesses

Young cancer patients, survivors, and their families are not just struggling against the disease and its treatments, they are also struggling against the lack of public knowledge about the issues that cancer has created for them. This lack of knowledge and awareness can mean a serious lack of support. According to the Food and Drug Administration, all forms of childhood cancer are considered "rare diseases," so funding for research that could develop life-saving drugs for these young patients is extremely low. To the drug companies and those who fund research, the miniscule proportion of funding spent in this area is justified, because children comprise a small percentage of the overall "cancer burden." The outcry against the lack of progress in the development of new treatments could be **much** louder, but people cannot protest an injustice they are unaware of. Sadly, funding for research on less-toxic drugs is not the only deficient form of support.

To elaborate, on a local level, families deal with financial crises brought about by expensive treatments that span an average of two years. In fact, expenses resulting directly or indirectly from the child's cancer amount to an average of 38% of a family's gross annual income. Looking beyond finances, support for siblings is often lacking. These children can develop emotional and behavioral problems due to the instability of their roles in their siblings' cancer journeys. Additionally, schools can be ill-equipped for the needs of young cancer patients and survivors, whose capability to learn in a classroom may have been damaged by cancer or the "cures" for it. Furthermore, after treatment is over, young survivors face a shortage of long-term support that is specifically geared toward the unique challenges facing them.

Undoubtedly, while the battle over research funding wages on, an increase in community-level awareness and support is a very attainable goal. The American Childhood Cancer Organization has educational [resources](http://acco.org) on acco.org for advocates to use to spread awareness. ACCO also has two awareness events that are fun, effective, and easy to organize:

PJammin for Kids with Cancer is based on schools, businesses, clubs, and groups of friends hosting a pajama day or pajama party in honor of young cancer patients, who spend a lot of time in pajamas while on treatment. In exchange for \$1, participants wear pajamas in honor of and in reflection of our nation's youngest cancer patients and survivors. Pjammin.org provides customizable templates for letters, flyers, posters, and other materials needed to host a successful event. The website also provides informational slideshows and classroom-appropriate discussion questions. Since PJammin started in 2009, over 100 schools and businesses across the country have worn their pajamas and raised over \$60,000.

Go Gold is the American Childhood Cancer Organization's newest awareness program. It is based on raising public knowledge about the symbol for childhood cancer awareness, the gold ribbon. Participants use free materials on acco.org/gogold to plan gold-themed events in their communities. Event ideas range from "office gold ribbon day," to gold ribbon bake sales or gold ribbon awareness walks.



Internet and Social Media Survival



Today, the internet is an integral part of life. It's usually the first stop when we don't know the answer to something. Let's face it; the internet is also the first stop when we think we have the answer to everything. It's our very own soap box, and most of us don't hesitate to step up and speak out. We have a multitude of choices at our fingertips, and we are more connected with each other than ever before. The down side is that we have a multitude of choices at our fingertips, and we are more connected than ever before. Without question, the internet is a valuable tool for finding answers and sharing news about a friend's cancer, but it can only be of greatest use to you if you are smart about how we use it.

To clarify, the vast amount of information on the web can't be of much help unless the pertinent information is easy to find *and* reliable. It is essential to know where you can find help specifically for a certain type of cancer and specifically for children, adolescents, and young adults. In the past few years, dozens of organizations have been formed to specifically serve the childhood cancer and young adult cancer communities. All of them have websites, and most of them also use blogs, YouTube, and social networking sites like Facebook and Twitter. It really has never been easier to connect directly to people who understand and can answer your questions. Furthermore, these resources are often interconnected, with organizations utilizing the multiple platforms in different ways. This means that you can find what you need in the best format for you to utilize it. Alternatively, while it has never been easier to find resources on the internet, it has also never been easier to access inaccurate information. Today, we depend more-heavily on online sources for health-related information. Many doctors, social workers, and healthcare facilities are making the shift into the online realm as well. All that said, check and double-check anything and everything you read while doing research online. Is the information presented by a reputable source (or cited from one)? Are you reading researched, proven facts, or someone's opinion and commentary? If you are not certain about something, print it out and take it to a professional, like a doctor or social worker.

Additionally, with increased accessibility should also come increased responsibility on the user's part. Stop for a moment and ask yourself how much of your friend's business should be shared with the world, especially when it comes to health. Be very mindful of the privacy settings on any site where you or your friends post content. Is your friend comfortable with strangers, insurance companies, and current and future employers seeing all posts or pictures related to the cancer journey? Once something is posted on the internet, it's out there, sometimes for good. This advice goes for parents too. I've seen many parent blogs and YouTube channels dedicated to a child's cancer battle. Truly, it's a great way to keep friends and family informed, but it's not necessarily good that I could see these while just surfing the web. I'm not saying that parents shouldn't do this. In fact, I'm sure it helps them with the situation. In General, it's a very good idea to discuss privacy with the patient and parents before any updates, pictures, or videos are posted online. Come to a mutual understanding about what is important and what is off-limits. Down the road, the patient will want to be completely in control of the way he or she discloses information related to cancer treatment, and being aware of how much is shared online is one of the first steps. All social media sites have varying degrees of privacy for content. For instance, Facebook allows people to create private groups. If your friend wants to keep everyone updated but doesn't want to make his or her entire profile private during treatment, you could help create a "hidden" Facebook group. You could easily invite people that are already "friends" on Facebook, and you could post pictures and updates safely and privately. Another great option is Google groups, especially if some of your friends and family don't have Facebook. Again, the groups could be hidden, and you would control invitations by adding the email address of anyone you would like to receive your updates. Undoubtedly, there are hundreds of ways to stay connected with those who care about your friend and want to know how he or she is doing. Please keep in mind that there are also many ways to achieve this while maintaining privacy.