Language Matters: What Supporters Say Is Not Always What People with Cancer Hear

For Steve Buechler, terms like “journey” and “battle” fail to describe his experiences with leukemia. Other people with cancer agree.

February 22, 2023 By Leukemia & Lymphoma Society and Steve Buechler

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A note from the Leukemia & Lymphoma Society: This column is by Steve Buechler, who produced our first LLS Community member written content. We are excited to provide this opportunity to other members of our online network as well. Steve shares his own experience as a person diagnosed with AML in the article below.

In 2016, I was diagnosed with acute myeloid leukemia. I underwent five months of treatment culminating in a double umbilical cord blood stem cell transplant followed by another six months to fully recover. From the beginning, I wrote lengthy email reports to people following my treatment. With some light editing and additional writing, these reports were published as a memoir in 2018.

Paying Attention to Language

Choosing a title for my book sensitized me to the use of language surrounding cancer. Since I had playfully named my donor “Ralph” and his DNA became my own, the main title seemed obvious: “How Steve Became Ralph.” For a subtitle, I pondered “A Cancer/Stem Cell Journey (with Jokes).” After reading other cancer memoirs, I found the term “journey” to be an over-used cliché. But more importantly, I realized that the word connotes a degree of choice, a sense of adventure, a promise of pleasure, and a desired destination that are foreign to cancer treatment. I’ve been through a profound experience, but “journey” is a little too rosy to capture it. These thoughts led me to the term “odyssey.” A longtime colleague concurred with my choice of this term, noting that “it is less volitional, especially in the sense that events beyond your control (fate, and potentially fatal events) forced this journey. The word also has a stronger connotation of a learned quest in conjunction with those unforeseeable hardships and uncertain outcomes.”

I also became uncomfortable with metaphors about cancer that see it as a war in which a heroic

patient valiantly battles an evil foe. This also did not ring true for me. For starters, we have enough militarized aspects of life without extending the imagery to illness. This metaphor also concedes too much to cancer. It is not a conscious, willful antagonist. Cancer is just a biological process originating within the body that simply is what it is and does what it does. And although I felt like many things throughout my treatment, heroic warrior or combat victim were not among them.

Once I was attuned to "cancer talk," I heard dubious expressions everywhere I turned. Ironically enough, some of the most questionable words and phrases are spoken by caring people who mean well but don't fully appreciate how their words are heard by a person with cancer. I became intrigued with these mismatches between what well-meaning people say and what people with cancer may hear. One would hope that medical training would sensitize doctors to how language matters, but they are not immune to this problem. As I have counseled patients, I've heard many stories reflecting an asymmetry between what doctors say and what patients hear. One subtle example arises when patients and their loved ones hear a doctor's speculative musings as definitive advice, sometimes leading to crucial treatment decisions that they later regretted. Other problems with "doctor-speak" are more explicit. I once heard a doctor say that when his patient "failed their front line therapy, we turned to salvage chemotherapy, but the patient lost their battle anyway." My immediate thought was that if your patient really is a failed loser on a scrap heap, this is an accurate description. Otherwise, it leaves a lot to be desired.

It was this last comment that inspired me to explore language usage further. Doing so led me to favor the term "person with cancer" to "cancer patient" or "cancer survivor." The latter two phrases seem to put the illness front and center as defining the whole person, whereas "person with cancer" sustains an identity that is larger than the disease. Building on these insights, this article has three objectives. First, I want to give voice to people with cancer themselves. Second, I want to sensitize others to how their well-intentioned words may be heard in very different ways by people with cancer. Third, I hope to spark some broader reflection on the importance of language in shaping our (mis-)understandings of the diverse range of cancer experiences and how we can better communicate about them.

To be sure, there are subjective differences in how certain words or phrases are understood by a person with cancer. That makes it all the more important to sample a larger group of people that reveals these differences and respects the diversity of ways that people narrate and comprehend their cancer experience.

An Informal Research Project Emerges

I therefore embarked on an informal research project to investigate these issues. I posed a question to three different online audiences in the cancer community. The first was The Leukemia and Lymphoma Society's LLS Community. They routinely post a "Question of the Day" twice a week and they graciously accepted my question inviting people to describe language usage in the cancer community that they dislike or find objectionable. This question garnered over 60 responses in the first few days it was posted. A second audience was followers of the Facebook

page “Adult Acute Myeloid Leukemia.” The same question was posed to this private group of over 1,000 members and yielded additional responses. The third audience was members of my local Gilda’s Club in the Twin Cities. The question was posed to all members through a monthly newsletter as well as forms that were available at the club. These additional responses broadened the sample beyond blood cancers to include people touched by all types of cancer. In two of the three groups, respondents could see prior answers, which sparked additional exchanges about why certain expressions were troubling to people. Combining all three sources, this question prompted well over 100 responses.

The Findings

While some respondents provided lengthy explanations of why they found certain terms offensive, others simply listed the problematic word or phrase and left it at that. If there is a pattern in these responses, it is that the problematic phrases or expressions minimize or deny the severity, risk, or duration of cancer, its treatment, and its aftermath. Despite the wide variety of responses, some common themes recurred. So I have grouped responses into inductive categories of things people with cancer often hear. Not all the comments fit neatly into these categories, and some fit more than one category. Keeping in mind that these expressions are meant to be supportive and helpful by those who say them, here are some noteworthy expressions that one or more respondents did not hear that way.

“Combat Metaphors”

The most frequent answers by far referred to terms like battle, warrior, fight, and the like. This was partly because I included the word “battle” in the question as an example for them to consider. But the volume of responses and the rationales provided for them suggest there is widespread dissatisfaction with these terms throughout the cancer community. Many respondents challenged the rationale or the implications of “fighting” metaphors. Several noted that battles and fights can be won or lost, so do patients become “losers” if the battle does not go well? Is there an implicit criticism of those who perish as not fighting hard enough or battling effectively enough?

Other respondents noted that “lost their battle” is a common cliché in obituaries and can be an especially unkind way of noting a death. One respondent poignantly anticipated this outcome in saying “I don’t like the various battle, struggle terms. I have stage 4 cancer and it will likely kill me. So the battle is ultimately lost. I am living with cancer and on a journey. My motto is Carpe Diem.” Another respondent provided a related example saying that they disliked being told they “failed” a particular treatment. They wrote “I did not fail, I took it every day as directed, it simply didn’t work for me, or I had intolerable side effects from the drug. The drug failed me!” Yet another respondent noted that blood cancers “permeate every cell of my body” so that “battling my cancer (means) I’m battling myself.” This respondent preferred to “befriend” his cancer as a more effective way of healing rather than “battling it as an enemy.”

In the same spirit, another respondent said, “I can’t stand using the word ‘battle.’ I don’t like to think that I’m at war with myself.” Still another respondent rejected “warrior” and instead wrote a “love song” to their tumor. One of the lines is “They told me ‘be brave, be strong, you’ve got to fight to survive,’ well I had no choice, you had to leave.” They concluded “none of it made me feel brave or strong.” Others noted that being a warrior holds up a standard that patients sometimes can’t attain or don’t aspire to. One said they “always disliked the term ‘warrior’ like it’s something I chose to fight and I’m strong [and] powerful. That’s not true a lot of days, I was just basically just trying to survive most days.” In a similar vein, another respondent noted that such terminology makes them “feel more burdened and tired … and I am tired a lot.” Another respondent said they “struggle with journey, fighting, battle, victim, warrior etc. I loathe thriver. I hate being told I’m strong or a hero, I’m none of that, I’m no different than anyone else: I just have something harder to face at this time. I do relate to fuck cancer, that expresses my feelings without tying me to an identity.” Yet another respondent rejected militaristic metaphors by saying “call me a peacenik – I don’t like words like fight and battle. I prefer struggle.” Another respondent said “I prefer living with cancer over survivor or fighter … I am not battling either just trying to live each day.”

But there was not unanimity on this question. One patient saw their transplant team as “an army at war in my defense, with generals, specialists, tactical weapons, all that. It was humbling that all of that was put into action for me, and I am grateful.”

“Questionable Trips”

A close second for the most disliked term was “journey,” which was also used in the question as an example. One respondent said “journey” implies enjoyment; another said, “journey is what my wife and I take when we go to Europe”; yet another said, “a journey is a choice while we do not choose to have a blood cancer”; still another said hearing the word journey is “like fingers on a chalkboard.” One respondent suggested the more neutral term “process” while several others simply saw “journey” as an overused cliché. Another respondent chafed at hearing her experience described as an “adventure,” which has many of the same problematic features as the term “journey.” If cancer can be likened to a trip, it is one that these respondents would clearly choose not to take.

But there was at least one dissenting voice that pointed out that “journey” is a pleasant word and something that comes to an end, thereby suggesting that cancer too may come to an end.

“Loaded Medical Terms”

Another cluster of terms involved potentially misleading or deceptive descriptions of various stages of illness and potential recovery. One term that several people disliked was “cure.” One said that there “remains no cure for cancer” though some cancers respond to treatment in ways that make it seem cured. But the term cure “may lure some into denial of the possibility of recurrence” and give “a false impression to those who have not (yet) experienced cancer.”

Another patient cited their oncologist who counseled them to never use the word cure for its potential to mislead people about medical science's ability to definitively eliminate cancer in a given patient. Yet another patient noted that allogeneic transplants are sometimes billed as "cures" for acute leukemia, but this was belied by the number of people in their support group who experienced recurrences after transplant. Still another respondent noted that cure is problematic because even if one cancer is successfully banished, many treatments increase the risk of secondary cancers. This person concluded that "I'm not sure anyone is 'cured' from cancer. Just because you don't currently see evidence of it, doesn't mean you're cured."

These reservations about the term "cure" extended to the term "remission" for some respondents. One noted that remission is often just a temporary pause or reprieve that gives people false hope, while another noted that for some cancers, remission can only be of short duration before the next relapse. Still another noted that when oncologists say patients tend to stay in remission after a particular treatment, that is not a guarantee and patients still understandably worry about a relapse. One respondent identified the term "prognosis" as problematic, which sparked a lengthy thread about how that word is used and heard by doctors and people with cancer. This respondent pointed out that "prognosis" is a mathematical construct based on a collection of data points and does not apply to any given patient so it can be highly misleading and create a negative impact on a patient's will to live. This sentiment was echoed by a respondent who was uncomfortable with "people putting a timeline on life expectancy."

But others responded that knowing one's prognosis can be helpful to people who want to plan for whatever probable future their prognosis suggests. With that knowledge, people can make more informed decisions about retirement and other life course options. Yet another noted that the context for this information is important. They said that "if a patient asks and the medical professional reasonably believes that the patient can handle the answer, s/he should provide it, but with appropriate qualifications." Those qualifications include educating the patient about how to interpret prognostical information and noting that the statistics upon which prognoses are based are inevitably dated and may not reflect recent improvements in the treatment of some cancers.

"Equating Identity and Illness"

A few respondents took issue with terminology that equated someone's identity with their cancer. This includes many people's hesitations about terms like "warrior" or "fighter" noted earlier. Still others questioned the term "survivor." Several noted that people survive all kinds of things over a lifetime and defining oneself as a survivor with respect to cancer can exaggerate its role relative to other life challenges that people also survive. The term survivor can also harken back to the militaristic metaphors that troubled some patients and put them in a win-lose situation. Thus, one respondent simply said, "I prefer 'living with cancer' over survivor or fighter." Another respondent identified what they called a "bias toward survival" in a poignant passage where they said "I find comments about surviving acute myeloid leukemia hard - the stories of someone who has survived not least because the dead are not around to give their opinion so there always seems to be bias

towards survival rather than acceptance that for many that we may die. The overall prognosis for acute myeloid leukemia remains poor even if … improving year-on-year."

In a related vein, several people objected to other phrases that collapsed their identity and their illness like "your cancer" or "my cancer." One emphatically noted that "… it is not mine, I didn't buy, order or choose it and no one gifted it to me!" Another recounted a first visit with an oncologist and said "there was a poster on the door, and it said 'my cancer' on it. Immediately I had this reaction that 'Heck no' this is not mine. I did not choose this as my own." Two respondents mentioned references to their age. One fit, active respondent said being called "elderly" struck them as "a slap in the face [that] implies fragile, frail, really at the far end of life." They added that "being called elderly really leaves me feeling like I should just give up." On the more positive side, another respondent playfully noted that "being called 'young' at 54 just makes me very giggly."

Finally, one respondent spoke for others as well in noting that they simply disliked anything negative and emphasized that positive comments can have beneficial effects on wellbeing and recovery.

"Generic Clichés"

Several respondents called out overused words and phrases that one respondent found "placating and insulting" because they are commonplace cliches that are obvious and convey virtually no information. Included here are phrases like "everyone is different" and "take it one day at a time" which led one respondent to note "I think these phrases go without saying." Another said "I know it's true, but WE KNOW THIS! It feels like, 'well there's nothing else you can do but take another day.' Which is also true. But it really just irritates me because that's all we hear."

The same holds for generic offers of help. One respondent singled out the phrase "if there is anything I can do, just let me know." They continued "there are SO many better alternatives — besides, I can't even think straight right now - much less tell you what I need. BUT — if you say, 'I'm running to the grocery store. How about I bring you a rotisserie chicken?' I would say 'yes' in a heartbeat." Another respondent reinforced this point by noting "the worst is 'if you need anything just let me know'……..don't say that. DO something! Anything … cancer patient needs are endless. Food, money, errands, childcare, cleaning."

"Suspicious Causes and Treatments"

The elusive nature of the causes of cancer and the inconsistency of its treatments is like an open invitation for phrases and expressions that many people with cancer find objectionable. Among dubious causes, one respondent reported hearing "did you know abortions can cause breast cancer?" while another was counseled "make sure to not eat any sugar." On the treatment side, respondents reported unhelpful advice like "I have a friend who was cured by with Dandelion tea"

and “have you looked into coffee enema cures?” Another respondent generalized the point by simply reporting “have you tried (any fringe treatment)?”

“Justifications”

Apart from suspicious causes, several respondents identified more metaphysical justifications or rationalizations for why someone might be diagnosed with cancer. Among these comments, “everything happens for a reason” was cited by several respondents. A more religiously tinged version of this rationalization was reported as “God never gives you anything you can’t handle.” While these expressions may have been well-intended, it’s harder to find good intentions in a final example that “you must have needed to learn a lesson.”

“Denials”

Among the most commonly reported expressions were remarks that expressed denial or disbelief that the respondent was actually ill with cancer. These widespread comments may reflect the fact that many cancers and its effects are often not visible, but respondents who knew better found these remarks unhelpful. Many respondents reported being told “your voice sounds good”; “you sound strong”; “you don’t look like you have cancer”; and “I just don’t believe that YOU have cancer.” Yet others were told “but you look so good” or “but you’re so young” as if these conditions somehow precluded having cancer. Some respondents were more directly challenged when people said things like “are you sure you even have cancer?” and “is that even a real thing?” (in response to a rare cancer). While it is easy to envision these spontaneous reactions upon hearing that someone has cancer, it is also easy to imagine that such remarks are particularly awkward for a patient seeking support in difficult times.

“Dubious Comparisons and Rationalizations”

Another family of comments were presumably intended to provide comfort through comparisons to people or situations that were worse than the status of the person with cancer. A variation on this theme was some kind of rationalization that was meant to help the patient see their situation in a better light. Given the prevalence of stories about heroic recoveries in the cancer community, I was especially struck by the observation that “I don’t need to know about the guy who ran a marathon every day on his treadmill as part of his recovery.” While such recoveries may be inspiring to some, they are not the norm for most patients dealing with wicked side effects and it’s easy to see why such stories could demoralize rather than inspire people with cancer.

There were many responses along the lines of “you have the good kind of cancer”; “I’m glad they caught it early”; “at least it’s not …”; and “if you had to get cancer, thyroid cancer is the one to have.” Some comments spoke to supposedly less arduous treatments when people were told “be grateful you have the good cancer that’s easy to treat, unlike others” and “good thing you only

need surgery and not chemotherapy." While some may find comfort in these remarks, for others they can easily be heard as minimizing the treatment challenges that awaited these patients. Other comments were meant to be inspiring or uplifting but they were not heard that way by two respondents. One called out "you're so lucky that insurance is paying for your post-cancer breast reconstruction, because it's like getting a free boob job." Another person invoked a high standard for recovery when they said "Well my aunt Betty had it and they did just fine! They still worked and never missed a day!"

One respondent thoughtfully addressed the problems with these comparisons. They said "I think inadvertent or intended 'compete and compare' comments are also tricky to handle. Any cancer diagnosis is tough. Telling the mom who's lost her son because of lymphoma when there's 'only' a 6% chance of this happening that this is 'bad luck' won't stop her grieving. Or being told by someone with pancreatic cancer 'at least you've got a chance of being cured' doesn't really hit the mark in terms of a supportive comment."

"Questionable Praise or Encouragement"

Quite a few respondents identified phrases or comments that were meant to encourage or praise them, but they didn't hear them that way. One example is the rather tepid observation that "with what you're going through, it looks you're doing as well as could be hoped." Yet another dubious comment sparked a defensive reaction from the patient as noted in this comment: "I don't like it when people tell me that the chemo I received killed everything, even my good cells. Why do people say crap like that? I just reply, 'it saved my life.'" Others identified comments that simply didn't resonate with how they were actually feeling. "You're an inspiration"; "You look beautiful'; "You're strong"; "You can do this" were examples. The recipient of the last comment clarified that they "didn't appreciate pep talks as much as empathy." Further examples of questionable pep talks included messages to "kick cancer's ass"; "save the boobies"; and "don't think like that. Be positive." One respondent questioned whether people were sincere when they promised to pray, noting "Did you pray for us for real? Like sit down and actually say a prayer specifically for us? If not, don't say it."

Yet another pep talk phrase triggered this response: "I also hate 'you got this!' I find it dismissive and lazy. A) it's invariably said by a person who has no clue what I've 'got' (other than cancer); B) it's frequently used as a way to shut down further communication and segue to a different subject; and C) it's grammatically incorrect." A final example involved a slogan in a hospital room that listed "What Cancer Cannot Take From You." The patient begged to differ, noting that they "covered this framed saying in my hospital room with a towel as most of the sayings were obviously written by someone who never took the journey. Cancer will take every last thing from you it can."

“Awkward Questions or Statements”

This closely related category of expressions included questions about whether a patient smoked or was a smoker, presumably in the context of a lung cancer diagnosis. But this is only the most explicit type of comment that seeks to link lifestyle choices and behaviors to the emergence of cancer and can easily be heard as blaming the victim. Other questions cited by respondents could have been reasonable in some contexts but were heard by these respondents as intrusive in some instances. Examples included “how long will you be on this treatment?”; “what stage are you?”; “so what’s the prognosis?” Some comments came across as rather harsh regardless of the context in which they were voiced. Examples here included “I had a friend with that … they died”; “At least you got cancer as an elderly person since your life will be over soon anyway”; and “Well at least you know what you’re going to die of.” A final respondent cited a hypothetical example that they would not welcome by noting “no one’s said it to me, but I’ve heard cancer described as a ‘gift,’ which I find totally objectionable (at least if the person so describing has never had it).”

“Premature Closure”

Additional responses suggested that others sometimes thought it was time to get over cancer even if that was not the subjective experience of the person with the illness. Examples here included “but you’re all done with this now” and “just move on.” Several other remarks asserted that a positive outcome was pending even if the patient didn’t feel it by claiming “oh, you’ll be fine” and “you’ll beat it again; you did before” (in reference to stage 4 breast cancer). Still other comments claimed an end point that patients did not see in the same light. Examples included “this is your new normal” and “‘you are in remission’ (meaning to them you are cured).”

“Inattentive Listeners”

One might think that speaking with other people who have had cancer would be more likely to elicit empathy. But in at least some cases, respondents said that when conversing with people who had experienced cancer, those others inappropriately shifted the conversation’s focus to their own cancer story rather than actively listening and providing support to the initial speaker.

“Empathy for Others”

The difficulty people experience in talking about someone’s cancer was acknowledged by several respondents. One simply said they had no objections or problems with whatever words people used “as long as the terms are not intended to belittle other people about how they deal with their lives as survivors.” Another acknowledged that “I also think people really don’t know what to say. Cancer is very awkward!!” Yet another respondent recognized that well-intended friends often just have no experience in how to speak about cancer with a patient. A final respondent said, “I’m also

aware that every comment given has been with genuine good intention and not aimed at upsetting me.”

Final Thoughts

Building on these insights, my own interpretation is that many of these comments reflect the discomfort that family members, friends, and others feel when someone they care about is seriously ill. They often don’t know what to say or how to say it. Saying things that deny or downplay the seriousness of a cancer diagnosis may be their way of coping with a reality they don’t want to face. They may genuinely wish us well, but their motivation may also be that then they don’t have to deal with an uncomfortable situation. They may want everything to be back to normal long before such an outcome may be feasible or even possible because it will make them feel better. More broadly speaking, these data suggest that different words and expressions strike people with cancer in widely varying ways. Nobody objects to all the phrases identified herein and some people liked some of them in particular contexts. But every respondent identified one or more idioms they found problematic.

Above and beyond specific words or phrases, the broader reality is that talking about cancer is unavoidably “awkward” (to use one respondent’s characterization). This inherent awkwardness is exacerbated by two additional factors. First, U. S. culture is not particularly adept at addressing matters of illness and mortality. We medicalize illness, sequester the ill, and deny the inevitable as long as possible. Many traditional cultures had supernatural beliefs, myths, and cosmologies that recognized death and dying in ways that have been largely lost in secular, postmodern societies. Second, that leaves us groping for ways to talk about these issues at precisely the same time that our culture has a heightened sensitivity around language itself. The culture wars, critiques of “wokeness,” accusations of political correctness, and myriad disputes over identity claims all exemplify the intensified weight and impact of the words we use and the significances they convey.

Given all this, it’s not surprising that I could easily elicit a long list of words, phrases and expressions around cancer that are often not heard in the way they were intended. But there is a further risk in this exhaustive compilation of objectionable language. Some readers may be left feeling that there is nothing they can say that would be appropriate and withdraw the support that people with cancer need.

So how might people offer support to a person with cancer in the face of all these potential language hazards? A good starting point is to remember the admitted cliché that “everyone is different.” In this context, that means that how language is heard is a highly subjective experience that varies greatly from person to person. The same word, phrase, or expression can be heard very differently depending on the speaker’s tone, their relationship to the patient, the context in which something is said, the patient’s worldview and temperament, and even the mood of the moment. One example is the phrase “everything happens for a reason.” It’s meant to be reassuring and some will hear it that way. But it can also imply that an illness is somehow justified

or deserved, and that the person with cancer may bear some responsibility for their disease. References to cancer as an opportunity or a growth experience and admonitions to “stay positive” may also be well-intentioned but can be heard in very different ways by people with cancer.

In addition to considering individual differences among people with cancer, a second guideline would be recognizing that there is a crucial difference between people finding their own meaning in this deeply personal experience and other people prescribing for them what meanings they should derive. The former is a healthy process; the latter can be an unwanted imposition. Moreover, when “advice” is offered, it is the person with cancer who is the final arbiter of what is genuinely helpful. So there can be no “approved list” of things to say to a cancer patient that is generally applicable to such a diverse population.

I’ll conclude with this example. Some people with cancer are also people of faith for whom religious expressions of support can be profoundly helpful. An example is the expression “God never gives us more than we can handle.” But if a patient is not currently feeling as if they can handle their disease, it can imply that they are somehow at fault for not being strong enough to cope with these challenges. And if they don’t share a religious worldview, they will likely be put off by this approach.

A final respondent delved deeply into these complexities. They objected to “religious language of all kinds” and any expectation that a cancer experience is something to be grateful for. They broadened their objection to encompass “any kind of expressions that frame cancer as some kind of spiritual enlightenment program: meaning non-cancer people who only choose to see or value cancer experiences where diagnosed folks suddenly gain a new outlook or renewed purpose in life, usually leaning towards an ‘improvement’ from their pre-cancer life with words like ‘more meaning,’ ‘positive,’ ‘gratitude,’ ‘closer to God/heaven,’ etc.” They continued by saying “this is unacceptable because it elevates only one kind of cancer experience while simultaneously erasing and silencing the wide diversity of cancer experiences. Such language reflects an interpretation of cancer that enforces and dangerously spreads a narrative of toxic positivity where no other emotions are allowed or acknowledged or validated, especially not any difficult ones like grief/loss, anger/rage, sadness, pain, betrayal or distrust in one’s own body, dread, fear, anxiety, uncertainty, and more.”

To generalize from this point, the broadest lesson to be derived from this survey is to avoid language that imposes untoward meaning on another person’s experience. Each patient has their own distinctive values and world view. Language that recognizes their standpoint will be the most effective way to provide meaningful support to those facing the myriad challenges of a cancer diagnosis and treatment.

This article was originally published January 30, 2023, by the Leukemia & Lymphoma Society. It is republished with permission.
