ABSTRACT
A diagnosis of soft-tissue sarcoma (STS) poses a potential threat to life and psychological well-being. This article reviews the evidence about psychological adaptation, coping, and distress in cancer patients in general, and STS patients in particular. While the majority of cancer and STS patients cope reasonably well with their illness and treatment, many experience transient symptoms of depression, anxiety, and posttraumatic stress, and a minority develop clinical disorders. Risk and prevalence for depressive, anxiety, and posttraumatic symptoms and disorders in cancer and STS patients are reviewed, and the contribution of neuroticism, dispositional optimism, and monitoring/blunting to psychological adaptation in cancer patients is explored. The efficacy of various problem-focused and emotion-focused coping strategies is reviewed with special attention to denial and religious/spiritual coping. Issues specific to quality of life in patients with rare cancers and STS are addressed. The article concludes with a set of generalizations and recommendations for patients, providers, and researchers.

INTRODUCTION
Soft tissue sarcomas (STSs) are a diverse group of rare malignant mesenchymal tumors that account for approximately 1% of all cancers in an adult population (1,2). While STSs can occur at any age, the median age of patients at time of diagnosis is forty-eight years, with 40% of STSs occurring after the age of fifty-five. STSs can emerge anywhere in the body, but they most frequently occur in the extremities, viscera, trunk, and retroperitoneum (1). The primary treatment is wide surgical resection, often supplemented by adjuvant radiotherapy (3, 4). The role of adjuvant chemotherapy is less clearly established. The lungs are the most frequent site of metastases should they occur. If metastasis is limited, pulmonary metastectomy with curative intent is the primary treatment (2,5). If metastasis is extensive, prognosis is guarded (6), and treatment is primarily palliative. There are over seventy histologic subtypes of STS, and while the above generalizations are true for the majority of subtypes, they are not necessarily true for all. For example, gastrointestinal stromal tumors (GISTs) are unresponsive to chemotherapy but respond to other biological agents, and when GISTs metastasize, the liver is the most likely site.

An STS diagnosis is an alarming event that presents patients with a significant threat to life and well-being. Patients have to confront, perhaps for the first time, existential issues of personal vulnerability and mortality. Patients must find ways to master initial emotions of alarm and distress and to cope with potentially overwhelming amounts of novel, complex and confusing medical information. Some patients try to learn as much as they can about their illness and treatment, whereas others place all their faith in the hands of experts. Patients may have to learn how to cope with invasive and arduous therapies and manage interruptions in their roles as parents, workers, and community members. They may need to navigate issues concerning finance, career, and medical insurance. They may need to sort out issues related to body image, identity, dependency, and social stigma. Patients may struggle with fatigue, nausea, pain, mobility
limitations, hair loss, neuropathy, and other medical complications. The introduction to STS patienthood is a baptism by fire: It may take all of one's adaptive resources to cope with this unwanted and unexpected intrusion into one's life with its attendant disruption of one's life plans.

How well one adjusts to an STS diagnosis depends on a multitude of factors including: a) the complications encountered in establishing the diagnosis including diagnostic delays, misdiagnosis, and ineffective treatments based on misdiagnosis, b) the type, grade, stage, size, and site of the tumor, c) whether one is recently diagnosed or is experiencing a recurrence or metastasis, and one's d) age at time of diagnosis, e) understanding of diagnosis f) illness burden from comorbid conditions, g) degree of functional and role impairment due to illness and treatment, h) degree of physical disfigurement, i) burden of iatrogenic symptomatology and morbidity, j) relationship with the treatment team, k) coping strategies, l) personality structure, m) premorbid susceptibility to mental illness, n) expectancies and beliefs about cancer, and o) degree of support from family and friends. The experience of sarcoma patienthood varies depending on the unique constellation of these factors that each patient encounters and endures.

Imagine a best-case scenario: Patient A had a small, superficial, well-differentiated sarcoma located in an extremity. He is fortunate to have good health insurance and is diagnosed and treated at a sarcoma center. Treatment is completed after a single successful surgical resection with clear margins. This patient has no prior history (or family history) of psychosis, depression, or anxiety disorder. His personality is naturally outgoing and optimistic. He has no other medical illnesses. He understands that his prognosis is good and has supportive family and friends. He has a good relationship with his treatment team which takes the time to carefully explain the diagnosis, prognosis and treatment. His treatment turns out to be minimally disruptive to his physical, social and occupational functioning.

Compare this ideal scenario with a worst-case scenario: Patient B had a large undifferentiated retroperitoneal lesion that has recurred and metastasized. He has undergone multiple extensive surgeries, radiation therapy, and multiple courses of palliative chemotherapy marked by barely acceptable levels of toxicity. This patient has a past history of recurrent major depressive disorder and has several comorbid medical conditions including diabetes and coronary artery disease. He has strong psychological tendencies to ruminate and dwell on his problems and tends towards pessimism, defeatism and withdrawal. He is being treated by a local community oncologist who is not a sarcoma specialist and who is emotionally unavailable and only minimally communicative. The patient's sarcoma and the morbidity associated with illness and treatment have forced him into early retirement, and he barely gets by on social security disability. His Medicare eligibility has not yet kicked-in and he cannot afford COBRA benefits, so he is currently without health insurance. His wife has divorced him and he lives alone. His recurrent cancer, poor long-term prognosis, insecure financial status, and depressed demeanor have made him unattractive to others as either a friend or a potential romantic partner, and he feels isolated and abandoned.

It takes little imagination to predict that patients A and B are going to have vastly different psychological adjustments to their illness. Most patients will be neither as lucky as Patient A nor as unlucky as Patient B, and will experience conditions that lie somewhere between these two extremes.

The remainder of this article summarizes what psychologists know about psychological distress, coping, and adaptation in cancer patients in general, and STS patients in particular. Unfortunately, most research on psychological adaptation to cancer has been done with patients with frequently diagnosed cancers, especially breast cancer. Studies specific to patients with STSs are comparatively rare and tend to focus on comparing quality of life outcomes after different treatments. Quality of life measures provide useful information about STS patients' physical functioning, activities of daily living, and role functioning, but do not offer as much in-depth information about their psychological struggles and their adaptive and maladaptive coping strategies as one might wish.
The following sections combine what is known about psychological adaptation to cancer in general, supplemented by more limited information about what is known specifically about adaptation to adult-onset STS. Each section starts with what is known about cancer in general, and concludes with what is known about STS in specific. In each and every case in which comparisons between cancer patients in general and STS patients can be made, the data about psychological adaptation in STS patients does not look significantly different from the data from patients with other types of cancer. For the most part, the psychological issues that STS patients struggle with and the strategies they employ to cope with those issues are not all that different from the issues and strategies that all cancer patients struggle with. There are certain issues, however, which may be unique to patients with rare cancers in general, and STS patients in specific, which we discuss just prior to our conclusions and recommendations.

**Research on Psychological Distress in Cancer Patients and Survivors**

**Depression**

Depressive disorders comprise a group of clinical syndromes marked by a constellation of affective, cognitive, neurovegetative, and behavioral signs and symptoms. These signs and symptoms include a depressed mood, lack of energy, lack of motivation, diminished libido, insomnia or hypersomnia, poor appetite, anhedonia, and pessimistic assessments about one’s own worth, abilities and future. In severe cases, suicidal and/or delusional thinking may be present. The depressive disorders range from mild (e.g. Adjustment Disorder with Depressed Mood) to severe (e.g., Major Depression with Psychotic Features). One can have individual or multiple symptoms of depression without meeting the criteria for a formal diagnosis of a depressive disorder, so it is best to talk about a depressive spectrum ranging from transient single symptoms to severe and persistent pathology.

A minority of patients becomes clinically depressed after receiving a diagnosis of adult-onset cancer and during its active treatment, and a larger number of patients experience some depressive symptoms such as sadness, fatigue, or insomnia (7, 8, 9, 10). The risk for depressive symptoms decreases after the initial diagnosis and treatment phase and continues to decline over time for most long-term survivors, provided there is no recurrence or metastasis (11, 12, 13, 14, 15), although head and neck cancer long-term survivors show some decline in psychological function (16).

Estimates for the prevalence of depression in cancer patients vary depending on how depression is defined and measured, and the type of cancer or phase of illness studied. Published estimates range from 0% to 38% for major affective disorder and from 0% to 58% for more broadly defined depressive symptoms (9,10). The good news is that most patients either never suffer from depression or recover after an initial period of adjustment to the diagnosis and after the rigors of active treatment have subsided. Studies estimate that 75% of breast cancer patients adjust well by one-to-two years post-treatment. (11), that 43% of breast cancer patients never show any evidence of depression, and that the 45% who do show initial signs of depression improve over four-year follow-up (13). Another study found that during the first six months after completion of radiation therapy 61% of breast cancer patients never showed any signs of depression (14). There was a minority of 16% of patients, however with depression that either remained constant or worsened during the post-treatment period.

Risk for depression increases with advanced cancer stage (17) and upon metastasis, relapse, or disease progression (18). Survivors who are younger, unmarried, uninsured, less educated, and who have greater comorbidity and greater functional impairment are more at risk for depression than other survivors (15).

There is some evidence that cancer patients with depressive symptoms have a small increased risk of mortality (19). The mortality rate is 26% greater for cancer patients with depressive symptoms, and 39% higher for cancer patients who meet the criteria for major depressive
disorder. It is unclear whether this increased risk for mortality is related to biological factors such as the effects of depression-related hypothalamic-pituitary-adrenal axis dysregulation on cancer, or whether it is due to depressed patients being more likely to "give up," and fail to employ problem-focused coping strategies (see Coping Strategy section below). The evidence for elevated mortality rates in depressed patients underscores the importance of detection and referral by oncologists for treatment of depressive disorders.

The one study that specifically looked at psychiatric diagnoses in STS patients reported that 55% demonstrated good to excellent adjustment to their illness and surgery an average of two-and-a-half years past active treatment (20). Fifteen percent of STS patients, however, met the criteria for a concurrent psychiatric disorder, with depressive disorders and alcoholism being the most common (21).

**Anxiety**

Anxiety is a complex phenomenon with cognitive, somatic, arousal and behavioral aspects. Cognitive features (e.g., worry, rumination, distraction), somatic symptoms (e.g., rapid heartbeat, sweating, butterflies-in-the-stomach), central nervous system arousal (e.g., hypervigilence, insomnia) and anxiety-related behavioral aspects (e.g., fidgeting, muscle tension, avoidance) can be present singly or in combination. Anxiety is not merely or only a clinical phenomenon, however: It is a normal reaction to threat and uncertainty. As a cancer diagnosis may pose a significant threat to life, well-being and happiness, it would be abnormal not to feel some degree of anxiety in response to it!

Cancer diagnosis-related anxiety can be exacerbated when there is substantial uncertainty involved in diagnosis and treatment. There is reason to believe a sarcoma diagnosis may be more anxiety provoking than a diagnosis of one of the more common cancers, because rare cancers such as STS involve more uncertainty: There are fewer studies to read, fewer local experts to consult and fewer survivors to read about.

Some STS patients are fortunate, in that their sarcoma is diagnosed prior to surgical intervention, and their oncologist can recommend a definitive course of action with which most experts would concur. This is a set of circumstances that helps to minimize anxiety. Other patients, however, are less fortunate.

Some patients have their STS misdiagnosed, and a surgeon scoops out the misdiagnosed tumor without obtaining clear surgical margins. Survivors humorously refer to this as an "oops! procedure." When the identity of the tumor is finally established by post-surgical biopsy, the unfortunate patient has to undergo a second surgery to obtain clear margins. This type of treatment error underscores the importance of seeking an opinion from a major sarcoma center before undergoing surgery.

Some patients send biopsy slides to multiple pathologists and receive conflicting opinions about diagnostic subtype. Other patients get second and third opinions as to whether another round of surgery, chemotherapy, or radiotherapy is indicated and get conflicting treatment recommendations. Many patients seek information through Internet websites and online support groups and come across information that may conflict with what they have heard from their oncologist. The search for definitive information is a positive adaptive coping strategy, but under certain circumstances it can become a confusing process that feeds rumination and anxiety. STS patients may be more prone to this type of anxiety than patients with more common cancers due to the relative scarcity of available resources, information and support. None of this, by the way, should discourage patients from seeking second opinions or exploring online resources. The struggle to resolve discrepancies between sources of information can have positive outcomes: In some situations, discussing discrepancies with one’s oncologist can improve doctor-patient communication and lead to increased confidence in the oncologist’s approach. In other situations it can be the impetus to find an oncologist with more sarcoma experience.
Anxiety tends to be greatest during the initial period of diagnosis and treatment and tends to decline during periods when there is no evidence of illness and no active ongoing treatment (22, 23). During the diagnosis phase of a patient's illness, anxieties may focus on prognosis and treatment options; during the active treatment phase they shift onto the vagaries and rigors of the treatment regimen; during the post-treatment phase they shift to the risk of recurrence. If recurrence occurs, anxieties often focus on whether to stay the course with standard treatments, pursue clinical trials or seek out alternative and/or complementary treatments that may lack rigorous validation.

STS survivors are asked to return to their oncologists for periodic checks for local recurrences or distant metastases. It is natural for anxiety and intrusive rumination and worry to return during the time surrounding these periodic follow-ups. Studies find that from 36% to 46% of cancer survivors report anxiety around the time of periodic examinations (24, 25). The patient community has coined the term “scanxiety” to refer to the anxiety provoked by awaiting the diagnostic imaging results required by these periodic check-ups.

Cancer patients worry about disease recurrence (24, 26) or progression, increased risk for dependency (24) as well as developing new cancers (25). Fear of recurrence may continue even after a long illness-free period. In one study of testicular cancer patients who were diagnosed over a decade earlier, 31% had worried about recurrence "quite a bit" or "very much" in the week prior to the study (27). Studies of breast cancer patients show significant anxiety in anywhere from 31%-81% of patients and survivors (26). New anxiety is provoked whenever there is any evidence or suspicion of recurrence, metastasis or progression, either as a result of newly experienced symptoms, or of test or examination findings. Some patients, especially those with a "monitoring" personality style (see Personality Traits section below), are hyper-attentive to bodily sensations and can interpret any new sensations as possible signs of recurrence or progression, causing them significant worry and concern.

Medical information is sometimes presented in technical language that patients have difficulty comprehending. This can create questions and worries that unnecessarily add to patient anxiety. Medical personnel should present findings in language patients can understand and should allow sufficient time for their questions.

Anxiety can also be associated with sleep disturbance. In a recent study of insomnia in women with invasive ovarian cancer (28), anxiety was a major factor. While over half of the participants reported no sleep disturbance, 26.8% reported subclinical insomnia and 16.8% reported clinically significant insomnia. Predictors of insomnia included younger age, higher level of unmet needs in physical/daily living, and greater anxiety. The highest levels of unmet needs reported by the women were help in dealing with a) fear of recurrence, b) the worries of those around them, and c) living with uncertainty.

While anxiety in response to a cancer diagnosis is perfectly normal, some patients are more prone to anxiety than others. Younger patients (26, 29) and women (29) tend to experience greater anxiety. Patients with poor social support (29), past histories of psychiatric disorder (25, 29), or personalities characterized by dispositional pessimism (25) and/or neuroticism (30) are also at greater risk see Personality Traits section below).

Some patients suffer not only from normal anxiety but also from a clinically diagnosable anxiety disorder. Where does normal anxiety end and a clinically significant anxiety disorder begin? The answer lies in how disruptive the anxiety is to one's functioning and happiness. Anxiety becomes maladaptive when it interferes with cognitive processes and the ability to perform necessary activities, when it occurs under inappropriate circumstances, when it causes avoidance of situations that require involvement, and when it makes life miserable. While nearly half of all cancer patients report significant anxiety, far fewer meet the full diagnostic criteria for clinical anxiety disorders such as panic disorder, generalized anxiety disorder or specific phobia (29). How prevalent are these clinical syndromes? Prevalence estimates for
anxiety disorders have run from 0.9%-49% of cancer patients in the published literature (23), again depending on what methods and measures are being used to establish a diagnosis. Studies using stricter criteria tend to find a narrower range of prevalence somewhere between 10% and 20%. For example, more recent studies have shown prevalence rates of 11.7% (31), 13% (18), and 19.2% (12). Stark and colleagues (2002) found a rate of 18%: 9% of the patients met the criteria for panic disorder, 8% for generalized anxiety disorder, and 13% for specific phobia. (The diagnoses add up to more than 18% because some patients met the criteria for more than one anxiety disorder, e.g., panic disorder with phobia).

Patients with anxiety disorders also often suffer from comorbid depression (31). Thirty-eight percent of the anxiety disorder sufferers in a study conducted by Stark, et al. (29) met the criteria for a depressive disorder as well. Brintzenhofe-Szoc, et al. (32) found that mixed anxiety and depression occurred in 12.4% of a group of 8,265 cancer patients, whereas 11.7% of the patients had anxiety symptoms alone, and 6% had depressive symptoms alone. The study found the rates of symptom co-occurrence among sarcoma patients were similar to those in the total sample: mixed anxiety/depression symptoms in 15.7%, anxiety alone in 10.7% and pure depression alone in 5%.

The good news from Brintzenhofe-Szoc, et al. (32) is that 68% of sarcoma patients were free from anxiety and depressive symptoms at the time of the study. The bad news is that comorbid anxiety and depression was associated with a lower quality of life, slower recovery, poorer treatment compliance, and greater suicide risk than anxiety or depressive symptoms alone. Treaters need to be aware of comorbid anxiety and depression and treat it aggressively to improve treatment outcome and quality of life. Unfortunately, although there are guidelines for treating anxiety and depression among cancer patients and survivors (33) only about 10% of the cancer populations receive any psychosocial therapy (34).

**Posttraumatic Stress Disorder**

Post-Traumatic Stress Disorder (PTSD) is a subtype of anxiety disorder that can occur in people who have experienced or witnessed a traumatic event or series of events which involved either serious harm or risk of harm, and which caused intense fear, helplessness, or horror, such as the events encountered by combat soldiers, natural disaster survivors or rape victims.

In 1994 the American Psychiatric Association included life-threatening illness in the class of events that could cause PTSD (35). In order to be diagnosed with PTSD, a person has to experience multiple symptoms in each of three different domains: a) re-experiencing, b) avoidance, and c) hyperarousal. Re-experiencing can take the form of intrusive thoughts, flashbacks, and/or nightmares. Avoidance can include avoiding places, people, and things that can trigger remembrances of the trauma, trying not to think about the trauma, amnesia for aspects of the trauma, and a general numbing of emotions. Hyperarousal can take the form of hypervigilance, exaggerated startle response, insomnia, or irritability. In order to fully meet the criteria for a PTSD diagnosis, the symptoms of PTSD must last longer than one month, and must cause significant distress or impairment in an important area of functioning. We might note in passing that there has been some debate as to whether cancer is entirely similar to other PTSD precipitants. It has been argued by some, for example, that unlike other trauma victims, cancer patients can exert some degree of control over their cancer experience through collaborating in their treatment (36).

Cancer patients and survivors experiencing PTSD can re-experience aspects of being told of their diagnosis, of undergoing specific procedures, of experiencing certain side-effects or of being in the hospital. For example, survivors have noted that they feel as if they are physically back in the hospital when cued by a smell experienced while in the hospital. While rates of survivors meeting full PTSD criteria are relatively low, a great many survivors experience specific PTSD symptoms, either singly or in combination (37). For example, one study found that 36% of breast cancer survivors had at least one symptom of re-experiencing, 27% had at least two symptoms of
hyperarousal, and 8% experienced avoidance symptoms. Thirty-six percent of the survivors had more than one PTSD symptom (38).

PTSD has been frequently studied in cancer survivors who have received hematopoietic stem cell transplantation (HSCT). HSCT is an intensive medical intervention used in the treatment of hematological and lymphoid cancers, as well as other disorders (39). It was also previously used in the treatment of breast cancer. Although HSCT can be curative, it can also pose a threat to life (39, 40). Some research suggests that breast cancer patients who underwent autologous bone marrow transplantation may have higher rates of PTSD than patients who underwent less intensive forms of treatment. These findings are consistent with the view that the development of PTSD symptoms is correlated with the degree of perceived life threat (41).

The percent of cancer survivors who have undergone HSCT and who have probable PTSD ranges from 5% to 19% (40). The incidence of PTSD in cancer patients in general has been found to range from 0% to 32% (37). Why the wide variance in reported PTSD rates? Rates in different studies vary depending on the methods and measures used to establish the diagnosis. The more stringent and exact the diagnostic criteria used, the lower the diagnosis rate. Once again, there are many more patients who have one or more PTSD symptoms than there are patients who have full-blown PTSD. For example, while 67.7% of a breast cancer patient sample reported intrusive re-experiencing at some point during the course of their illness, only 3.9% met full PTSD diagnostic criteria (30).

PTSD symptoms are associated with poorer physical health, mental health and sleep quality (41). For cancer patients who have undergone HSCT, the disorder is more prevalent in patients who have lower degrees of social support, rely more on avoidance coping (see Coping Strategies section below), and have experienced more negative life events (42, 43, 44). Rates of PTSD-intrusion symptoms are also correlated with trait anxiety (45) (see section on Neuroticism below). Rates of PTSD are higher for patients who have experienced prior trauma, and repeated traumatic exposure can increase the likelihood of a pathological response to cancer and its treatment (e.g., PTSD). Past traumas may influence the creation of new trauma by depleting and overtaxing one’s adaptive coping resources. One study with breast cancer survivors found that loss of social support mediated the relation between PTSD symptoms and depressive mood (42). This is consistent with research findings that interpersonal relationships play a critical role in the psychosocial well-being of cancer patients.

Our review identified only one PTSD study that looked at soft-tissue sarcoma survivors (46). That research studied patients who had been treated with initial limb salvage procedures for locally advanced STS. Limb salvage was successful in 30 of the patients, but 9 patients had to undergo a subsequent amputation due to either complications of treatment or disease progression. PTSD symptom scores reached clinical significance in 20.5% of the STS patients. Interestingly, although amputees reported worse physical and social functioning and more role limitations, none of the amputees had clinically significant PTSD symptoms. There was no clearly evident reason why the amputees fared better than the patients with salvaged limbs in terms of their PTSD symptoms. Patients who felt that the surgeon had made the treatment choices rather than having made the treatment choices themselves, however, were more prone to intrusive PTSD re-experiencing symptoms. These results show the need for further studies on PTSD symptoms among STS survivors.

Given the similarity of PTSD symptoms in cancer survivors and survivors of other traumas, psychosocial and pharmacological treatments developed for other trauma populations (47, 48) may also reduce these symptoms in cancer survivors. PTSD treatments may need to be modified, however, for cancer patients (37). For example, treatment may be modified depending on where patients are in regard to their treatment trajectory and depending on their comorbid problems.
It may be helpful if doctors discuss the possibility of developing PTSD symptoms with patients. Imagine having survived cancer and its treatment and thinking that you can return to your "normal life," only to find yourself experiencing symptoms of PTSD! Many cancer survivors may not know that, like survivors of other traumas, they can develop these trauma-related symptoms. Patients and family members may be reassured to know that anxiety cued to reminders of cancer and cancer treatment is not uncommon, and that the experience of such trauma symptoms doesn't mean that one is "going crazy."

Lastly, we note that cancer patients who experience symptoms of Acute Stress Disorder (symptoms of dissociation, re-experiencing, avoidance, or hyperarousal in the initial month after trauma exposure) may be at greater risk to go on to develop full-blown PTSD. Acute Stress Disorder symptoms may well be a marker for a high-risk population who might benefit from psychological intervention (49, 50).

**Posttraumatic Growth**

Sometimes a traumatic crisis builds character. As Friedrich Nietzsche famously observed, "That which does not kill me makes me stronger." Some cancer survivors report that their battle with cancer has made them stronger by improving their character and their lives in specific ways. Some report an increase in their appreciation of life and revaluation of their relationships. Some report that their bout with cancer has helped them to reprioritize goals and taught them what is really most important in life. Some report a deepened sense of spirituality. Others come to the realization that they are stronger and more resilient than they had thought prior to their illness. This positive personality change has been called "posttraumatic growth" (51). Survivors who experience posttraumatic growth are more prone to rely on active coping (52), positive reframing (53), and humor (53) (see Coping Strategies section below). They are more likely to be dispositional optimists (54) (see Personality Traits section below), be younger at age of diagnosis (55), and have higher levels of social support (54, 56). They are also more likely to have had a more severe form of cancer (52), or perceive a higher degree of stress, threat of death or threat of recurrence (55).

**PSYCHOLOGICAL FACTORS AFFECTING ADAPTATION IN CANCER PATIENTS**

Certain personality traits and coping strategies help patients successfully adjust to cancer, while others impede successful adjustment. A personality trait is a broad disposition to react in a particular way across a wide range of situations. Personality traits often have a significant genetic component and are relatively stable over a person's lifetime, although they may be modifiable to a limited extent. Personality traits include factors like extroversion, conscientiousness and agreeableness. We explore three personality traits that have been shown to affect coping with cancer in this review: neuroticism, dispositional optimism, and monitoring/blunting.

Coping strategies, in contrast to personality traits, are more situation-specific, more deliberately chosen and more modifiable. Coping strategies include behaviors like seeking information, compulsive behaviors, or resorting to drinking and/or drug abuse. The dividing line between trait and strategy is not hard and fast, but more a matter of degree. For example, is maintaining a sense of humor a strategy or a personality trait? It's probably a little bit of both.

**Personality Traits**

**Neuroticism**

Neuroticism is a tendency to experience unpleasant emotions such as anxiety, anger, distress, and sadness. People with high levels of neuroticism feel negative emotions more easily and strongly, feel them more often, and tend to anticipate and dwell on the threat of loss or harm more intensely. Neuroticism is one of the major personality dimensions along which people tend to vary, and it has a strong biologically inherited component. There is considerable evidence that patients who are high in trait neuroticism have a harder time adjusting to and coping with cancer.
They are more prone to anxiety, depression and psychological distress (57, 58, 59, 60, 61, 62, 63); are more likely to experience fatigue (63, 64, 65, 66), have a lower quality of life (67,68) and a greater fear of cancer recurrence (27). They are less satisfied with their social support (69); are more likely to have reduced physical function, increased sexual problems and increased neurotoxic side effects from chemotherapy; and they are more likely to use alcohol and prescription drugs (63).

Patients with high levels of trait neuroticism are clearly at a biological disadvantage compared to patients with lower trait levels, but they are not necessarily doomed to poorer outcomes. If someone is a member of a high-risk group, there are strategies one can employ to modify and reduce risk. Patients with high levels of trait neuroticism may be able to modify their innate response pattern through cognitive-behavioral approaches that modify negative automatic thought patterns, as well as through meditation, relaxation, anxiolytic and antidepressant medication, and physical exercise protocols that positively impact affect and mood. They can also benefit from abstinence from alcohol and other addictive substances that can amplify emotional vulnerability.

**Dispositional Optimism**
Dispositional Optimism is a generalized tendency to expect positive outcomes from any given situation. Optimism is associated with a greater reliance on active, problem-focused coping strategies, improved psychological well-being and healthier lifestyles. Pessimism, on the other hand, is associated with avoidance coping strategies, procrastination in taking action, and giving up in difficult situations. There are studies that link optimism to faster recovery time after illness, reduced re-hospitalization rates after surgery (70), and positive physical health outcomes in general (71). Breast cancer survivors who have a pessimistic style report lower health-related quality of life than do non-pessimistic survivors (72). Breast cancer survivors who have received curative treatment are less worried about their health, womanhood, ability to perform their roles, and risk of death if they are more optimistic (26). Optimistic breast cancer patients report better emotional well-being (73), less psychological distress (74), and more fighting spirit (75), whereas pessimists report more helplessness and hopelessness (75). Optimistic prostate cancer patients are more satisfied with the treatment-decision making process (76). Optimistic head and neck cancer patients report less fear of recurrence (77). As of yet, there have been no studies examining dispositional optimism in STS patients.

**Monitoring vs. Blunting**
Monitoring is the tendency to scan for, focus on and amplify potentially threatening information, and blunting is the tendency to avoid, ignore, and distract from it (78). Monitors are more concerned and distressed about their cancer; experience more side effects such as depression (79), anxiety (79), pain (80), and nausea (79, 81); desire more information and ask more questions (82); request more tests and medications (83); are less satisfied with the amount of information they receive from their doctors (83, 84); and actually know more about their illness (84). Monitors do better when given more information; blunters do better with less (78, 80). Intervention strategies to reduce chemotherapy side-effects such as relaxation training, which are, in part, distraction strategies, work better for blunters than monitors because they are concordant with their predominant style (79).

**Coping Strategies**

**Types of Coping Strategies**
Lazarus and Folkman (85) identified two types of coping strategies: problem-focused strategies that are intended to ameliorate the causes of stress, and emotion-focused strategies that are intended to ameliorate stress-induced emotions. Choosing the right treatment team is an example of a problem-focused strategy, while using mental imagery to relax is an example of an emotion-focused strategy (see Table 1).
Table 1: Types of Coping Strategies

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<th>Problem-Focused</th>
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<td>Information Seeking</td>
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<td>Choosing One’s Treatment Team</td>
<td>Prayer/Meditation</td>
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<td>Advocating for Oneself</td>
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<td>Treatment Compliance</td>
<td>Present-Moment Focus</td>
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<td>Lifestyle Improvement</td>
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<td>Re-evaluating Priorities</td>
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<td>Using Complementary Medicine</td>
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<td>Maintaining Communication with Treaters</td>
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<td>Asking for Help from Friends/Family</td>
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Most patients will benefit from using a balanced combination of problem-focused and emotion-focused coping strategies in coping with sarcoma. Certain phases of the disease, however, may call for more reliance on one type of strategy. For example, during diagnosis and treatment, problem-focused strategies are critical in helping the patient find a specialist, work out a treatment plan with the medical team, and work with his or her support network to meet changing needs. Near the end of life, emotion-focused strategies may be prominent as the patient deals with more spiritual and relational issues and fewer treatment decisions.

Another way to categorize coping strategies is by dividing them into “approach” and “avoidance” strategies (86). Seeking information about one’s sarcoma and complying with treatment are examples of approach strategies, while denial of illness and resort to substance abuse are examples of avoidance strategies.

There is some overlap between the two categorization schemes. Problem-focused strategies, for the most part, tend to be approach strategies: both require active engagement. Emotion-focused strategies, however, can be either approach (e.g., seeking emotional support) or avoidance (e.g., denial of illness) strategies.

Which Strategies Work?
Research suggests that some coping strategies are more effective in promoting a positive psychological adjustment to cancer than others. Maintaining a fighting spirit (87, 88, 89, 90, 91), maintaining a positive focus and positive restructuring (58, 92), support-seeking (92), and information-seeking (93) are all associated with positive emotional adjustment to cancer. Rumination (88, 90), a fatalistic/resigned attitude (88, 90, 94), avoidance coping (67, 94, 95), and reliance on alcohol and drugs (12, 92, 96) are all associated with poorer emotional adjustment. Approach strategies may be more effective at reducing distress than avoidance strategies (58).

Some studies have looked at factors that contribute to maintaining a fighting spirit. Social support is one factor that seems to enable cancer patients to have more “fight.” Men who are married are
more likely to display fighting spirit (97), and perceived physician support has been shown to facilitate fighting spirit in women (98).

Being able to express one's emotions rather than denying them or holding them all in has been shown to be helpful in multiple studies (45, 58, 89, 91, 99), but uncontrolled and unmodulated emotional ventilation is associated with increased distress rather than less distress (100). Emotional expression, like most things in life, may be best when used in moderation. On the other hand, it may just be that very distressed patients tend to ventilate more.

Some researchers have suggested that different coping skills and strategies may be more helpful at different illness and treatment stages (74, 101, 102, 103, 104). For example, factors like information seeking and fighting spirit may be most useful when a diagnosis is first made, whereas stoicism, acceptance, and seeking religious solace may be most useful during the terminal stage of illness (101).

**Humor**

Studies looking at the role of humor in cancer patients have yielded mixed results. While some studies have pointed to a positive benefit of humor in reducing cancer-related distress (74) and promoting posttraumatic growth (53), one recent study associated coping through humor with a poorer quality of life (67). One possible reason for the lack of uniformity in these outcomes may be that these studies do not consider that there are different types of humor and different uses to which it can be put. After all, while humor can be joyous, self-effacing, and good-natured, it can also be mordant, demeaning, and cruel; it can enhance social attachments, but can also be used to keep others at a distance. Some styles may be healthier than others.

Despite the popular belief that "laughter is the best medicine," research on the effects of humor on general medical outcomes has also yielded mixed results. Martin (105, 106) reviewed the research on humor's ability to affect endorphins, immunity, pain tolerance, stress-reduction, self-reported symptoms, social support, and longevity. Methodological problems and mixed patterns of findings made it difficult to draw any firm conclusions. Martin emphasized the need for more research "before one can have any confidence that humor or laughter affects physical health in a positive way."

None of this is meant to deny the momentary release, pleasure, and sense of well being that can come from a deeply felt laugh. In the grim battle with illness, moments of laughter and release should be welcomed and enjoyed, even if their long-term clinical significance is in need of further clarification. Until proven otherwise, we recommend keeping one's sense of humor.

**Denial**

The scientific literature has been divided over whether the avoidance strategy of "denial" is helpful (88, 99, 107, 108) or harmful (74). Scientists are philosophically inclined to think that believing and accepting the truth is better than hiding from it, and are therefore inclined to think that denial is both "wrong" and "bad". A good deal of research evidence, however contradicts this belief. Vos, et al. (109) recently found, for example, that lung cancer patients who displayed more denial complained less about fatigue, nausea, vomiting, appetite loss, and pain, whereas Lehto, et al. (99) found that denial/minimization predicted longer survival times for melanoma patients.

The problem with the concept of "denial" is that it is an overly amorphous concept whose meaning has changed over time. The term originated as a psychoanalytic construct referring to an unconscious mechanism of defense (110), but that specific meaning has broadened and shifted as psychoanalysis’s influence has diminished within the scientific community. The term "denial," at least as it is used in the contemporary research literature, now refers to diverse group of processes, not necessarily unconscious, that range all the way from denial of one's diagnosis to minimization of the impact of disease, denial of negative emotions, or distraction from and avoidance of illness-related thoughts (111).
These are all quite different processes. There is, after all, a world of difference between the statement "I don't really have cancer," and a kind of tough-minded approach to life that doesn't allow much to get under one's skin. Some of the processes included under the "denial" umbrella may be helpful to psychological adjustment by minimizing distress over both the short and long-term, whereas others may be helpful in the short-term but harmful over the longer-term. For example, outright denial of diagnosis may make one psychologically comfortable but may prevent one from getting the treatment one needs to extend life or put one's affairs in order at the end of life. On the other hand, not dwelling on one's cancer all of the time is probably always helpful, and most patients benefit from having some degree of skill in distracting from and avoiding illness-related thoughts at least part of the time. Including all of these processes under the same label is like adding apples and oranges and only confuses things. One possible route to clarity would be to restrict the use of "denial" to its initial psychoanalytic denotation and refer to the other processes now included under its umbrella by other names (e.g., "distraction," "isolation," "minimization," "intellectualization," etc.).

Finally, let us note that a patient's outright denial of the realities of illness can have an effect on significant others. Patient denial may create perplexity for loved ones who are left unsure as to whether to forcefully strip the patient of his or her only tenuous coping mechanism, or continue to allow the patient to make suboptimal denial-based treatment decisions. How can they get the patient to go to a sarcoma center if the patient is in denial? How can they help the patient to seek a second opinion? How can they help the patient transition from "fight" to "acceptance" mode at the end of life? How can loved-ones say "goodbye" when the patient doesn't believe he or she is actually dying? While denial may help a patient maintain his or her own equanimity, it may also create emotional quandaries for significant others.

**Religious/Spiritual Coping**

The value of religious and spiritual coping in cancer patients and survivors is just beginning to be explored. Religious and spiritual strategies such as prayer (112) are used by the majority of cancer patients, and many feel that their faith gives them the strength to cope with cancer and helps them find meaning in their cancer experience (113). In addition, strong ties to a religious community can provide an important source of social support. Patients often ask friends and family to pray for them and experience this as an important supportive intervention.

The issue of religious and spiritual coping is multidimensional, however, because religion and spirituality are complex phenomena. Religion and spirituality can provide a broad variety of potential benefits including a sense of meaning and purpose to life, a sense of harmony and inner peace, and faith that one is being cared for and looked after by a higher power. They also contain elements that can be potentially harmful to patient well-being, including the belief than one's illness is a punishment or a sign of abandonment by God. Illness can provoke a sense of spiritual crisis by creating doubt about God's fairness, beneficence or existence. Religious beliefs can also delay or impede diagnosis and treatment when patients refuse tests or procedures and place all of their trust in God. Additionally, patients who are not particularly religious prior to diagnosis can experience a negative process of spiritual conflict and doubt when they try to utilize religious coping after their diagnosis (114).

Given the complexity, and the different definitions of what comprises religion and spirituality, it is not surprising that a recent review (115) of seventeen studies of religious/spiritual coping and cancer found mixed results. While seven studies found benefit in religious coping, three found it to be harmful, and seven found non-significant results.

One recent study (116) found that while 76% of breast cancer patients relied on God or partnered with God as a coping strategy, 15% felt abandoned by or angry with God. Reliance on/partnering with God didn't seem to have any beneficial effect on emotional well-being, but feeling abandoned by or angry with God was associated with depressive symptoms, poorer mental health, and poorer life satisfaction. Does this mean that these negative religious beliefs caused these negative outcomes? Possibly, but not necessarily. The direction of causality is hard to
establish in a correlational study, and it is just as possible that these patients were having negative religious beliefs as a consequence of being depressed and having poorer mental health.

Another recent study (117) looked at two components of spirituality in cancer patients: a) finding meaning and inner peace in life, and b) having faith. It found that having a greater sense of meaning and peace protected against depressive symptoms and cancer-related distress. Those patients who reported greater faith also reported greater personal growth as a consequence of their cancer experience. [Only one of the 23 items used to measure these factors referred to belief in a deity, so these findings can apply to both theistic and non-theistic spiritualities.]

There is a considerable body of evidence from outside the realm of cancer research that correlates religious belief and practice with longevity in the general population. For example, Hummer, et al. (118) found that the average church-going twenty-year old has a life expectancy that is 7 years longer than a non-church-attending peer. The reasons for this are probably complex and may be related to increased social support, better health-related behaviors, and other factors. Given the potential power of religious and spiritual beliefs and practices for good or ill, there is a great need for further research on how religious and spiritual factors impact on cancer patients' well-being and longevity. Patient-provider communication about religion/spirituality can also help facilitate an understanding of patients' context for their disease and treatment. When negative religious beliefs appear to be interfering with either treatment or quality of life, referral to chaplaincy may be beneficial.

Should Patients Be Encouraged To Adopt Healthier Strategies?
One might be tempted to guess from all this that patients who exhibit traits and coping strategies that are associated with poorer outcome ought to be taught how to change their predominant coping style. This might be true to some extent, but we would like to introduce one caution here. Patients are sometimes pressured by well-intentioned others to internalize and exhibit positive feelings and attitudes that do not genuinely reflect their own inner experience. These pressures can serve to intensify feelings of failure, isolation and being misunderstood, and are not likely to be helpful. Every patient is bound to experience negative emotions from time to time as they face the possibilities of mortality, disability, role impairment, financial stress, treatment induced symptoms and pain. Empathic acknowledgement of negative emotions helps patients feel supported and understood, allows them to accept their own inner experience, and frees them to move on toward increased acceptance.

In addition, patients and survivors may be better off learning how to identify the strategies that are most useful to them given their personality types rather than trying to emulate someone else who may have a different psychological structure and needs. The most successful professional interventions are often ones that provide a good match with a patient's native coping style and not some idealized style (78, 79).

### Coping Resources

This is a list of on-line resources with information about helpful coping strategies.
- [Coping Skills and Checklists](#) from the American Cancer Society
- [Coping](#) from the American Society of Clinical Oncology
- [Coping with Cancer](#) from the National Cancer Institute
- [Resilience: Build Skills to Endure Hardship](#) from the Mayo Clinic
- [Cancer Diagnosis: 11 Tips for Coping](#) from the Mayo Clinic
- [Coping Skills](#) from the BBC
- [The Cancer Survival Toolbox](#) from the NCCS
FACTORS SPECIFIC TO PATIENTS WITH ADULT-ONSET STS

STS patients share certain problems in common with other patients who have rare cancers. STS patients have probably never heard of the diagnosis before and face the anxiety of coping with an unknown foe. Family, friends, and employers are equally unfamiliar with the diagnosis, and are unsure how to respond appropriately. It is harder to find factual information, find a support group or locate mentoring peers. Patients often don't know, and haven't even heard of, anyone else who has the disease. Research dollars are scarce, and researcher interest is confined to a smaller circle of experts. Since sarcoma research is sparse compared to other cancer research, so is knowledge about the illness, and treatment strategies are not as advanced. Patients often struggle with whether to have their sarcoma treated locally by an oncologist with limited sarcoma-related experience, or to travel to a sarcoma center, with all the attendant expense and life-disruption that it entails.

STS survivors also face specific physical challenges. Approximately 50% of STS patients and survivors suffer some degree of post-treatment physical impairment including pain, soft-tissue fibrosis, loss of range of motion, and decreased muscle strength (119). STS patients who undergo amputation have to cope with issues related to stump maintenance and prosthesis use. Patients with extremity STS who undergo limb-salvage surgery (with or without adjuvant radiotherapy) often have significant difficulty in physical functioning due to the excision of muscle tissue, the disturbance of neurovascular and lymph structures in surgery, radiotherapy-related fibrosis and edema, and the dependent nature of the limb (120). STS patients undergoing chemotherapy may have the additional burden of experiencing iatrogenic symptoms associated with various chemotherapy agents such as hair loss, fatigue, nausea and vomiting, loss of appetite, and peripheral neuropathy (121).

There is very little written in the medical literature about chronic pain in STS survivors as an unintended result of surgery, radiation, and chemotherapy. One study (122) reported that 36% of limb-salvage patients and 30% of amputees reported some degree of pain over a year after treatment had concluded. We know from studies of patients with other types of cancers that some of the procedures used to treat sarcoma can result in significant rates of chronic pain. For example, studies of patients with other types of cancer report post-thoracotomy pain in 22%-70% of patients, and post-amputation pain (phantom limb and/or stump pain) in 30%-80% of patients (123). A recent review noted that we lack even the most basic data on the incidence, prevalence, and epidemiology of chronic pain syndromes in cancer survivors (123). This is even truer for STS survivors, and is clearly an area where more research is needed.

Survivors with chronic pain often resort to a variety of treatment approaches to try to cope with their condition. Common approaches include pharmacotherapy (e.g., opiates, anti-inflammatories, GABA analogues [gabapentin, pregabalin], and antidepressants [tricyclics, duloxetine]), cognitive-behavioral therapy, mindfulness-based stress reduction, hypnosis, acupuncture, biofeedback, transcutaneous electrical stimulation, exercise regimens, and physical therapy. Different treatments may work better for different types of pain, and for different personality types. It probably matters a great deal, for example, whether pain is due to nerve injury, soft-tissue damage, or lymphatic system disruption. As another example, hypnosis may be a treatment of choice for pain sufferers who are highly or moderately hypnotizable, whereas other treatments may be more effective for low hypnotizables. Only future research can help sort these matters out.

There was some evidence in earlier studies that patients who underwent limb-salvage treatment were more dissatisfied with their sexual functioning (124, 125) than amputees. A more recent study (122) found, however, that although limb-salvage patients experience more physical complications related to treatment, their functional outcome is better, they do not differ from amputees in their quality of life or subjective well-being, and they are equally satisfied with their marital life. A recent study of long-term survivors of pediatric-onset osteosarcoma found no differences in functionality, quality of life, self-esteem, or romantic relationships between limb-

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A Resource from The Liddy Shriver Sarcoma Initiative
salvage patients and amputees (126). The difference between the earlier studies and the more recent study may reflect improvements in surgical and radiological techniques since the 1980s. Most studies concur that, in most respects, patients who undergo amputation and patients who undergo limb-salvage surgery do not differ significantly in their quality of life (20, 122, 124, 125, 126). The one exception to this is a study by Thijssens, et al. (46) which showed greater physical, social, and role limitations for amputees. The amputees in this study may be different from the amputees in the other studies, however, in that they had initially undergone limb-salvage treatment that had failed due to subsequent necrosis, ischemia, or local recurrence. They may have a different set of psychological expectations and reactions than patients who underwent an initial planned amputation. This interpretation is supported by the finding that osteosarcoma limb-salvage patients who underwent subsequent amputation had a greater degree of body image disturbance than osteosarcoma patients who underwent either successful limb salvage or initial planned amputation (126). These studies point to the importance of prior expectations in determining post-treatment satisfaction.

Treatment-related physical impairments can sometimes lead to being unable to perform certain activities of daily living. They can also lead to limitations in role functioning, e.g., functioning as a parent, spouse, or employee. For example, some STS patients are unable to return to work after treatment, especially if the work requires hard physical labor or extensive use of an affected limb (127). Older STS patients may end up seeking early retirement. Fortunately, research shows that activity and role limitations are less frequent than physical impairment in STS patients (119). This is good news because role limitations have been shown to contribute more to lowering the quality of life of STS patients than physical impairment or activity limitations by themselves (128).

There is some evidence that patient involvement in making treatment decisions affects STS patients’ perception of outcome. Patients who feel they have more involvement and control in the treatment decision-making process report increased physical functioning, fewer role limitations, and fewer PTSD symptoms (46).

Lastly, we might note that the problems and concerns of STS patients can often be invisible to others. Friends and family may not observe overt signs of disability or morbidity, but the patient lives daily with the knowledge of ongoing risk of recurrence and metastasis. As a result, patients can sometimes feel unsupported by friends and family who fail to appreciate their ongoing risk and anxiety (1).

CONCLUSIONS AND RECOMMENDATIONS

One can draw a number of broad conclusions and recommendations from this review concerning the incidence of distress and disorder and the personality traits and coping strategies that impact on psychological well-being in cancer patients in general, and STS patients in particular:

1) Most patients cope reasonably successfully with cancer and its treatment. While many patients do experience difficult symptoms of anxiety, depression, and posttraumatic distress, most of the symptoms abate over time given successful progress in cancer treatment, and most patients do not develop clinically significant syndromes or disorders.

2) Continuing fears of recurrence are normal even years after successful treatment. Many patients also experience transient intrusive recollections of aspects of their diagnosis and treatment years after treatment is completed. Anxiety that has abated over time is often re-evoked by follow-up appointments, and by possible symptoms (or actual diagnoses) of disease progression, recurrence or metastasis.
3) Cancer patients who develop clinical psychiatric disorders often have risk factors associated with these disorders. Major risk factors include prior histories of depression, anxiety, or substance abuse, past exposure to trauma, high levels of trait neuroticism, low levels of dispositional optimism, and inadequate support networks. Patients with these risk factors may benefit from early referral for psychological support.

4) Clinically significant levels of depression, anxiety and PTSD need to be actively treated to preserve quality of life and improve clinical outcome. Oncologists need to detect these disorders and refer to appropriate psychiatric and/or psychological resources. Patients need to recognize the signs and symptoms of these disorders and ask for referral.

5) Certain coping strategies are clearly identified with superior psychological outcomes. These include maintaining a fighting spirit and positive focus, a moderate degree of emotional expression, and seeking information and support. Patients do best when they balance problem-focused and emotion-focused coping strategies, rather than relying on only one type of strategy. If a patient’s coping strategies are not sufficient for the challenge, the patient can seek to learn new ones.

6) More research is needed to clarify when humor, denial, and religious/spiritual coping strategies may be of value and when they may be counterproductive. It is likely that these strategies can be either useful or harmful depending on an individual’s personality and situation, and according to how, when, and to what use they are employed.

7) There is a need for more research on the etiology, incidence, prevalence, and effective treatment of chronic pain conditions in STS survivors.

8) There is considerably more research on psychological vulnerability and morbidity in cancer survivors than there are studies of post-diagnosis growth, resilience and thriving. What character strengths and virtues help patients to not only adapt but also to grow and thrive following a cancer diagnosis? We look forward to the increasing influence of positive psychology (129, 130) on research and an increased focus on a diversity of outcomes beyond distress and dysfunction.

We would like to end with the following recommendation to patients: Well-intentioned family, friends, and acquaintances do not always know how to be of help. We wish they did, but they do not. You need to directly ask for what you want or need: a hug, a trip to the grocery store or pharmacy, assistance with finances or paperwork, accompaniment to an appointment, or a sympathetic, non-judgmental ear. It’s okay to ask for help. In fact, family and friends often want to help and receive gratification from knowing they are providing appreciated assistance.

NCCN Clinical Practice Guidelines in Oncology: Distress Management
The National Comprehensive Cancer Network recommends that "Distress should be recognized, monitored, documented and treated promptly at all stages of disease and in all settings." To access these guidelines, register for a free account at NCCN, and then login.

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs
The National Institutes of Health asked the Institute of Medicine to study the delivery of psychosocial services to cancer patients and their families and identify ways to improve it. This report recommends ten actions that oncology providers, health policy makers, educators, health insurers, health plans, quality oversight organizations, researchers and research sponsors, and consumer advocates should undertake to ensure that this standard is met. There are two versions of this report: a report for patients and a report for providers.
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