

FORUM

Beyond Denial and Despair: ALS and Our Heroic Potential for Hope

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Abstract / Because the patient with amyotrophic lateral sclerosis (ALS) knows at the outset that he or she is facing an incurable and always fatal illness, the experience of hope may be different in the ALS community from that in the general palliative care community. Although the word "hope" is frequently and passionately used by both patients and professionals in the ALS community, to date there has been little published on the subject. Hopelessness and despair are a very real part of the ALS experience. But true hope, of a kind more powerful than mere physical survival, can also be part of the ALS journey. What is this "hope" the professional is expected to engender and the patient is encouraged not to lose? How can professionals help the ALS patient find hope and meaning? This article is an exploration of hope by someone who has experienced ALS, first as an occupational therapist, then as the daughter and caregiver of an ALS patient. Based on literature review and personal experience, factors leading to both hope and hopelessness are explored. Finally, the author offers several strategies that palliative care professionals can use to help ALS patients find hope.

Résumé / Le patient atteint de sclérose latérale amyotrophique (SLA) sait dès l'annonce de sa maladie que la SLA est incurable et fatale. Ainsi, l'expérience de l'espoir pourra être vécue différemment chez ces patients que chez ceux qui sont soignés dans des programmes de soins palliatifs. Même si on remarque que le mot « espoir » est utilisé fréquemment et avec passion tant par les personnes atteintes de SLA que par les professionnels qui les soignent, à ce jour on note peu d'écrits sur le sujet. Les sentiments d'impuissance et de désespoir font vraiment partie de la maladie. Mais le véritable espoir, d'une nature plus profonde que la simple survie, peut également faire partie du processus de la maladie de la SLA. Quel est cet « espoir » que les professionnels doivent susciter chez les malades et que les malades doivent conserver? Comment les professionnels peuvent-ils aider les malades atteints de SLA à trouver un sens à la vie et à cultiver l'espoir? Cet article se veut une réflexion sur cette notion d'espoir, l'auteure ayant vécu l'expérience de la maladie d'abord en tant qu'ergothérapeute et par la suite en tant que fille et soignante de sa mère atteinte de SLA. En se fondant sur une revue de la littérature et sur son expérience personnelle, l'auteure explore les facteurs qui conduisent tant à l'espoir qu'au désespoir. En conclusion elle propose des stratégies pouvant être utilisées pour aider les malades atteints de SLA à retrouver l'espoir.

In the depth of your hopes and desires lies your silent knowledge of the beyond; and like seeds dreaming beneath the snow your heart dreams of spring. Trust the dreams, for in them is hidden the gate to eternity.

Kahlil Gibran (1)

INTRODUCTION

As an occupational therapist and a former amyotrophic lateral sclerosis (ALS) caregiver, I have frequently heard and used the word "hope". During my personal crisis with ALS—my mother had the disease for approximately two years—I became very interested in exploring the meanings of this word, used so frequently and passionately in the ALS community. It became apparent to me that this word is often tossed about, or dropped for effect, but is seldom elucidated. It seems to be a word with a meaning that is only intuited, or discussed merely in terms of assessments and measurements. What is this "hope" that the ALS patient and family are encouraged not to lose? What is this "hope" that the ALS professional is expected to engender or, at the very least, not to diminish?

Hope is occasionally mentioned in the ALS literature and, indeed, in the general medical literature as being both appropriate and necessary for the patient's well-being. The ALS Association currently has the phrase "A Reason for Hope" at the top of its letterhead. Yet hope, its definition and meanings to the ALS patient, family, and professional, and ways of fostering hope have not been thoroughly explored. In fact, in searching the existing literature, I could find only one article devoted exclusively to ALS and hope (2), and one article recently submitted for publication (3).

ALS is a disease currently without a cure, but with a tremendous potential for profound healing of patients and professionals alike. Unfortunately, our technologically advanced, death-denying society tends to equate hope with physical survival, thus robbing many ALS patients of the

chance to experience hope as a truer, spiritually empowering part of life's close.

Siegel, in his well-known book *Love, Medicine, and Miracles*, has this to say about our current climate in health care:

Our power to heal people and their lives seems to have diminished as dramatically as our power to cure diseases has increased. This is because the knowledge of human nature, which used to be the doctor's principal resource, has been abandoned as irrelevant in an age of science (4, p.121).

The purpose of this article is to explore our "power to heal people and their lives", whether those people are the patient, the family, or the professional. To do this, it is necessary to provide professionals and patients with an increased understanding of the ALS experience as it relates to the powerful and mysterious human experience of hope. A look at our human nature would be incomplete, however, without an exploration of the very real lessons of denial and despair that are also part of the ALS journey.

DENIAL, DESPAIR, AND HOPE

Denial, as I experienced it during my mother's illness, is a rather convenient and tidy way to control the amount of reality to be dealt with at any one time. Denial can be healthy. It is a defence mechanism that is commonly used by ALS patients and their families, and sometimes even by the professionals working with them. Denial often serves the purpose of maintaining hope, as it prevents the patient from being completely overwhelmed by the gravity of the situation. Because ALS involves so many losses, it is typical to be in denial over some aspects of the disease, while having complete or near-complete acceptance of other aspects. Like so much of life, acceptance is a process. It is not all or nothing, and it certainly does not happen overnight. ALS patient Morrie Schwartz explained this well:

I don't know if one ever arrives at complete acceptance. I do know I have reached a comfortable level of acceptance. When we talk about acceptance, we have to think about the developmental aspect of it over time. Acceptance becomes stronger and stronger until finally it's all there. (5, p.44)

Denial, if held onto too tightly or for too long, can become a form of false hope. It becomes a form of lying. Real hope cannot thrive in a climate of deception or where truth is being withheld. Our faith in medical technology often facilitates this unhealthy denial. False hopes can be generated by the patient, by friends and family who struggle with their own mortality issues, or even by the professional. Bruhn states:

Indeed, the physician is a symbol of hope, and failure to offer hope undermines the image the physician often feels he must command to remain in control of the relationship....False hope may be intentionally or unintentionally given to preserve the caregiver's (physician's) image. (6, p.217).

Patients may be sensitive to the professional's need to feel in control and, fearing abandonment, may actually engage in denial to mask their own despair.

Not surprisingly, however, many ALS patients do suffer from hopelessness, depression, and despair (7-12). Despair comes from the Latin root "speare" and means, literally, to be without hope. In the lives of patients and families struggling with ALS, this despair can be conceptualized as the experience of hopelessness arising from many sources—fear, pain, anxiety, depression, isolation, frustration, humiliation, failure, guilt, regret, false hopes, abandonment, loss, disillusionment. These are but some of the issues that patients with ALS must face, often on a daily or even moment-to-moment basis. It is easy to understand why, under such conditions, one would be almost overwhelmingly tempted by despair.

In spite of formidable challenges, however, many individuals with ALS are able to pass through denial and despair to reach a level of deep-seated and authentic hope. This is not hope for survival, but for something richer and more meaningful—a peaceful acceptance of life, and its inexplicable beginnings and endings. Some patients seem to reach this level of awareness on their own, some with outside help, but all as a result of enormous emotional and spiritual work. The fact that many patients report a good quality of life, are able to maintain true hope and peace up to the moment of death, and become teachers for us all is proof of the heroic human potential that lies within us. Perhaps professionals have more to learn from patients than immediately meets the eye.

There is no universally agreed-upon definition of hope. Indeed, it is not even universally agreed that hope and hoping are ultimately or always beneficial. (For further exploration of this, the reader is encouraged to explore the Buddhist literature.) Nevertheless, it seems that hoping is a common and universal activity for humans, and that all of us have an innate sense of what hope and hopelessness are.

Hope also seems intimately and essentially tied to the ability to find meaning in one's life. It is commonly believed that hope requires meaningful connections to others. Indeed, for hope to thrive, it appears necessary to have an emotional

investment in meaningful loving relationships. Not only is hope connected to our relationships with others, it is tied to our relationship with God. No matter what our beliefs or understanding of God or a higher power, hope is dependent on our belief in something larger than ourselves and more important than our own egos.

Unfortunately, our society often views hope as being dependent on human survival, thus minimizing the profound hope to which ALS patients are spiritually entitled. This erroneous and defeating belief is often encountered by ALS patients when they are told, simply, to get their affairs in order, or that there is nothing to be done for them. "But the resiliency of hope is not linked to continuing life," Christopher says (13, p.5). In an article on the link between honesty and hope, Christopher identifies what she sees as a major barrier in the palliative care movement—the myth that telling the truth will rob terminally ill patients of hope. She says we distort hope's true meaning when we make it depend on human survival, and she concludes that being truthful with patients will actually enhance hope, because it gives patients the necessary information, control, and freedom to choose who they will be in life and in death (13). It is possible to be candid and hopeful at the same time. Candour is, in fact, necessary for true hope.

In the face of certain death, what would one hope for? Certainly people hope, quite reasonably, not to be abandoned, and to die peacefully and without pain. With proper palliative care, there is no longer any reason, nor excuse, for any ALS patient to die in pain or in great distress. But beyond these basic hopes, there are infinite hopes of a more mysterious and transcendent nature. One can hope to die at home, in the loving presence of family and friends. One can hope to conclude one's life in a way that provides an offering of love: to be an example to others, to mend any broken relationships, to say what needs to be said, to treasure every remaining moment. ALS patient Morrie Schwartz captured this sentiment well when he said:

I still might be able to accomplish one of my purposes by being an inspiration to other people who want to be able to die with some kind of inner peace (5, p.65).

Hope for what might follow death, surely the greatest mystery shared by us all, can also be profoundly healing. One can hope for survival of the spirit on some other realm. Perhaps one hopes for eternal life in Heaven, or for enlightenment and liberation, or for reincarnation, for another go at learning the lessons of life. But even in the absence of firm beliefs or strong faith

in an afterlife, hope can remain spiritual. One can hope to live on in the hearts and minds of others—the hope that one has lived one's life in a way that is somehow ultimately beneficial to those who live on.

These hopes, and more, are available to and deserved by the ALS patient, even in the absence of hope for a cure. There are several ways that professionals can care for their patients and themselves, in the service of hope.

FOSTERING HOPE: STRATEGIES

Hopelessness is a reality for many ALS patients and their loved ones. There is evidence that psychological distress may shorten the ALS patient's survival time (11). The competent professional will, therefore, intentionally work toward becoming comfortable with discussing emotional and spiritual issues, and will be straightforward and active in these aspects of care. Although hope is an intimate and personal experience, there are many ways that the ALS or palliative care professional can help patients maintain or enhance their capacity for authentic hope. Although many of these recommendations have been made by others and some have found empirical support in the literature (in diseases other than ALS), I offer these suggestions based primarily on my intimate experience with the hope and despair of ALS and, secondarily, on my experience as an occupational therapist.

Focus on here and now: It is important first to recognize our limitations. We cannot currently cure ALS. Although it is entirely appropriate to hope for an eventual cure, we do not have this option today, and our hopes should not rest solely, or even primarily, on this. We can remind our patients (and, indeed, ourselves) that the only life we have is right here, right now, in this present moment.

Watch for "hope traps": It is important to remember that, sometimes, a patient's hopes rest on very shaky ground. They may be completely tied to a cure or "beating this thing", or to a particular expert or institution. Hopes that are based on something completely external to ourselves or to an outcome that we cannot control are precarious at best. They are not reliable. Professionals should be aware that patients whose hopes are pinned to such tenuous things are in great danger of having a serious "hope crisis" if or when reality finally calls.

Recognize warning signs: Recognizing the warning signs of despair improves the quality of care we provide. Be aware that patients may

underreport their feelings of despair and their need for support. It is, therefore, imperative that professionals develop comfort in discussing painful feelings and that they do this consistently, not only with patients who appear distressed and not only when the patient raises the issue. Monitor vigilantly for signs of despair, not just at pivotal times of loss—diagnosis, loss of function, loss of speech, decrease in respiratory status—but as a general rule throughout the entire course of the illness.

With that caveat, there are some trends to bear in mind. Patients with respiratory distress tend to experience high levels of anxiety (14). Patients with dysarthria may be more anxious, while those with primarily physical impairment may be more depressed (8). Older patients may have higher levels of depression and hopelessness than younger ones, and patients with a rapidly progressive course experience more anxiety than those with slower progression (11). Patients with primarily upper extremity involvement tend to experience higher levels of distress than patients with primarily lower extremity involvement (14). Impaired function in mobility and eating may be predictive of lower self-esteem (8). Importantly, caregivers may experience more depression than do patients (7).

Monitor the family: Remember to monitor the family carefully as well. The family's strength, and sense of courage and peace will directly affect the patient's quality of life and quality of death, perhaps more than any medical intervention. Caregivers typically feel overwhelmed when caring for a person with ALS. Family members may feel more hopeless and impotent than does the patient. Feelings of guilt about not doing enough, while feeling overwhelmed and resentful about having to do so much, are common. These feelings of resentment often lead to further feelings of guilt. Family members should be allowed to express these feelings and should be assured that these reactions are entirely normal. Professionals should be well-educated on the support and services—such as respite care, hospice, support groups, counselling services—that are available to the family. Helping the family is often the most direct and beneficial way of helping the ALS patient.

Encourage socialization and interaction: Fine states that, "Acquiring a sense of belonging to a social group or, for that matter, to all of life, is a powerful way to sustain oneself in the face of death or other extremes" (15, p.497). Recognize the importance to the patient, not just of family support and assistance, but of loving relation-

ships and a sense of involvement with life. Loving relationships can in themselves be expressions of hope. Patients can sense hope in the concern that others feel for them.

Value communication: The expression of hope through involvement in loving relationships is very much dependent on consistent, truthful, and heartfelt communication. This can present an enormous practical and emotional challenge to the ALS patient and loved ones. The loss of my mother's ability to communicate was by far the most heartbreaking loss of the ALS experience. It is difficult enough to grieve, to express fears and pain, and to share one's heartfelt sentiments when one can communicate easily. How much more traumatic it is when communication is impaired, as is often the case with ALS. Repressed emotion is unhealthy to our bodies and to our spirits. Assisting the ALS patient in finding and obtaining the appropriate means of communication should be a top priority in the plan of treatment, perhaps above any other intervention, if one is to instil or preserve the patient's hope, as well as her or his sense of dignity, control, and autonomy.

Foster control and power: Bruhn says: A key factor in giving or removing hope from the patient-caregiver (professional) relationship is the patient's sense of control over his environment (6, p.217). Seligman (16) emphasized that patients' belief in control over their environment can prolong life, but that loss of this control can further weaken them. The ALS patient should always have control regarding treatment options. We can, and should, do our best to fully educate patients on the possible pros and cons of different treatment options. But we must leave the final decision to them, for only they know their own hearts, and how they would like to live and die.

Provide a team: Another way to help patients maintain as much control over their environment as possible is to consistently involve the assistance of various other health professionals, who can help patients remain as independent and autonomous as possible. This, in itself, is hope-inspiring, as the focus is on what the patient "can do" and not on what has been lost. The physical, occupational, and speech therapist, as well as the psychologist, social worker, and chaplain, each have a role in helping the patient to maintain a sense of control. In addition, the physician's routine referral to other disciplines will help assure the patient that she or he is not being abandoned, that everything possible is being done, and that a team of concerned individuals on his or her side.

Educate truthfully, sensitively: Closely related to a patient's need for control is the need for truthful education and information about the disease process, treatment options and, importantly, the mode of death. Properly presenting this information can be a difficult task. The physician should not withhold the truth, but must somehow discern the patient's readiness to receive potentially distressing information. There is no formula or technique for accomplishing this. It involves intuition and perception more than training or knowledge. However, active listening, genuineness, and a compassionate and not-too-busy presence are essential. Patients should understand early on that every symptom is manageable and that death is almost universally peaceful. Determine the patient's knowledge of the death process and quickly dispel the myth that the patient will smother or choke to death. This terrifying and erroneous belief is held by many ALS patients and their loved ones, and must be corrected at the outset.

Teach and encourage coping: In addition to education about these ALS basics, the patient should be guided in learning coping strategies, and ways not only to reduce stress but perhaps to find genuine peace. This could include socializing with family and friends, increasing intrinsically meaningful leisure pursuits—watching television does not qualify!—or participating in an appropriate exercise program. Prayer, meditation, music, writing, massage, yoga (which can be adapted to most any ability level), touch therapies, and counselling with either spiritual advisors or psychotherapists are some of the techniques people find nourishing to their spirits. These practices can typically be explored or deepened by anyone, regardless of physical ability.

Support in the ALS community: The emotional and spiritual value of being with others who "have been there" cannot be overestimated. This is the great value of support group involvement. If no support groups are available, or if the patient does not wish to attend, perhaps he or she can be put into contact with others via the telephone or the Internet. The professional should maintain a list of support groups, of individuals willing to share their personal experiences and insight, and of appropriate and reputable websites for the ALS community. By experiencing moments of honesty and candour from professionals and from others in the ALS community, the patient has the opportunity to experience increased trust, which helps inspire authentic hope.

Celebrate humour: A comedian once said, "After we cure all diseases, we're all going to be pretty

embarrassed dying of nothing!" In addition to the techniques discussed above, the value of humour as a hope-inspiring strategy is perhaps the most underestimated. Valliant said, "Like hope, humor permits one to bear and yet to focus on what may be too terrible to be borne" (17, p.386). Singer and writer Jimmy Buffett said it more simply: "Humor is the antitoxin of terror" (18, p.276). It is neither inappropriate nor disrespectful to laugh and play with someone who is dying. Humour binds us to one another, reminds us that we are participating together in this great mystery. Indeed, we should not be afraid to laugh with our patients, and to help them (and ourselves) see the humorous side of our shared human experience.

Sharing ourselves: The willingness to share of ourselves with our patients is the bedrock of the true therapeutic relationship. From the moment of diagnosis until the time of death, the ALS patient needs to know we are both concerned and available. We can provide hope with our consistent and hopeful presence in their lives. We provide genuine hope through love and compassion when we say, in effect, "I care about you and I will not abandon you. No matter how sick or despairing you may become, I will not forsake you." Being present for our patients means we do not hide. We do not hide behind our technology, our status, or our credentials. We do not deny our patients the chance to truly know us. In issues of mortality especially, we are all equals.

CLOSING THOUGHTS

Facing one's own mortality is no simple task. ALS is a wake-up call to everyone it touches—a call to examine our own souls, our hopes, desires, regrets, and fears. It provides us with or forces upon us the opportunity to look beyond the preconceived definitions of a successful life. It provides us the opportunity to determine for ourselves what is truly important and lasting. Because ALS is currently incurable, yet not immediately terminal, we have time to settle our affairs without being distracted by false hopes created by technology.

Until a cure for ALS is found, perhaps we can at least keep the "gifts" of ALS close to our hearts. We have the chance to say our goodbyes, the chance to learn what love is, and the realization that hope does not depend on survival of our bodies, even less on survival of our egos. ALS has long been considered a completely hopeless disease in a society that views death as the ultimate failure. Those of us who have learned the lessons of ALS, whether by professional choice or by personal chance, know otherwise.

I would like to dedicate the following poem, by John Milton, to my mother Elaine Cottrell, who died on August 19, 1998, having had ALS for approximately two years.

ON TIME

*Fly, envious Time, till thou run out thy race,
Call on the lazy leaden-stepping hours,
Whose speed is but the heavy plummet's pace;
And glut thy self with what thy womb devours,
Which is no more than what is false and vain,
And merely mortal dross;
So little is our loss,
So little is thy gain.
For when as each thing bad thou hast entombed,
And last of all, thy greedy self consumed,
Then long Eternity shall greet our bliss
With an individual kiss;
And Joy shall overtake us as a flood,
When every thing that is sincerely good
And perfectly divine,
With Truth, and Peace, and Love shall ever shine
About the supreme Throne
Of him, t'whose happy-making sight alone,
When once our heav'nly guided soul shall climb,
Then all this earthy grossness quit,
Attired with the stars, we shall for ever sit,
Triumphing over Death, and Chance, and thee, O Time.*

Date received, October 27, 2000; date accepted, July 5, 2000.

ACKNOWLEDGEMENTS

I would like to thank Dr. Edward Kasarskis, Dr. Robert Sufit, Dr. Glenn Telling, Mr. Thom Fisher, and Mr.

Adrian Centers for their encouragement, support, and editorial assistance.

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