

*a helping*  
HAND  
BOOK

WHEN A LOVED ONE IS CRITICALLY ILL

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WHEN A LOVED ONE IS CRITICALLY ILL

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with writings by  
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USC SCHOOL OF MEDICINE - UNIVERSITY OF SOUTHERN CALIFORNIA

# *Stanley J. Waxman*



*1914-1998*

Stanley J. Waxman was an actor, teacher, poet and devoted family man. The loving way he lived his life was an inspiration. His legacy includes countless poems and musings. We are grateful for the comfort and insight they bring. In this text, beneath his words are his initials, SJW.

Where there is honesty there is endurance.

SJW

# Introduction

My 84 year-old father, Stanley J. Waxman, was an ICU patient in the fall of 1998. Over a period of two weeks, his condition worsened, then improved, then worsened. Meanwhile, our family sat in the waiting room trying to distract ourselves with nervous conversation and the outdated magazines that littered the tables. The air conditioner was up too high, the coffee was stale and there weren't enough chairs. We were upset with a doctor because of the condescending way he spoke to us, we were annoyed that we had to pay for parking, we were irritable with each other. Mainly, we were worried that Stanley would die.

In the end, he did die. While we were grieving the loss of such a beloved man, we talked about our hospital experience and wished we had had some way to use those countless hours, some way to sort out all the painful and confusing feelings. It was out of such musings and subsequent meetings with several experts, that this workbook was born.

Whether the patient is a parent, a spouse, a child, a lover, another relative or a friend, if you spend time with the thoughts and the difficult feelings which flood you during a crisis, you can ease the pain. At first it might seem like exploring all these feelings – your worry, confusion, frustration, anger, guilt, sadness – will be overwhelming. But, it takes tremendous energy to control all these feelings and when you release them, energy returns.

At the end of this book, there are suggestions for taking action. Even a small action can make you feel like you are in control.

Besides easing the emotional pain, this workbook has been designed to cause reflection, promote understanding, foster endurance and inspire hope. The examples reflect a variety of responses to a health crisis. Some of them will mean something to you and others won't. We each go through these experiences in our own unique way.

While this workbook is meant as a private experience, doing the exercises might eventually improve communication with your family, your doctor and other hospital personnel.

You don't have to follow this book in the order it is presented. Flip to the section which will be most helpful. You could date your entries and then go back and look at them later. Though there are additional blank pages at the end of this book, you might want a larger notebook. Or you might write only one word, or doodle or sketch. Perhaps you'll find that by simply reading this book your own experience will be a more bearable one.

I owe a debt of gratitude to Dr. Rex Yung, humanitarian extraordinaire, whose idea it was to put Stanley's poetry to such healing use. I also thank Elina Harper, RN, Clinical Case Manager at USC University Hospital, and Katherine Brown-Saltzman, Clinical Nurse Specialist at UCLA Medical Center, for their invaluable input. Rabbi William Cutter, Stanley's colleague

and a longtime friend of the family, encouraged this project from its inception. A heartfelt thanks to others who generously lent their expertise: Jo Sadalla, MSW, Candace DePuy, Ph.D., Tandy Parks, RN, MPH, and Mary Schmitz, RN, Ph.D. Also much appreciation to Susan Dworski for her design and for her support in the final stages of this project.

I wrote this book with the love and support of my family: my mother and Stanley's wife, Rena; my husband, Dennis Hicks, and our daughters, Tessa Hicks and Jessica Williams; my brother, Mark Waxman, his wife, Paula, and their sons, Taylor and David Waxman.



In verbal wars the warriors gird  
Themselves and with keenest skill  
Sally forth with cutting s-words  
That slash and cut and wound and kill.

SJW

Hate fastens its fangs on those who fear.  
SJW

# Anger

An orderly snaps at us, a custodian doesn't clean up properly, a nurse is too hurried to answer our questions, a doctor keeps us waiting. We may even be angry at the patient whose lifestyle caused his – and our – suffering. We may be angry at God. We cast about, looking for a target for our anger. Our rage may or may not be justified. Nevertheless, it is there along with the worry and fear. It can be a relief to have a private place to pour out the anger and blame which has built up. It doesn't have to be logical or rational; emotions aren't necessarily reasonable.

Write freely; these entries are not meant to be read by anyone but you.

## Examples . . .

*I'm furious that the doctor didn't return my call for three days.*

*I'm angry that you were too weak to give up smoking.*

*It makes me furious that all our money is going to this hospital and you still might die.*

*I hate that doctor for making jokes at a time like this.*

*I hate the dim lighting in this waiting room and that the chairs are welded together so we can't move them.*

*All this could have been prevented if that idiot doctor had been paying attention.*

*I'm furious that our kids aren't getting along at a time when we should all be pulling together.*

*How could you criticize my mother at a time like this?*

*I hate that tube down your throat; I can't stand to see you so helpless.*

*I'm angry with God for letting you suffer like this.*



Smile at the world,  
It's not unfriendly -  
Just shy and full of fear.  
It has a willingness to laugh  
But over the will is the mist of a tear.

SJW

Put on the garments of bravery, and courage will internalize itself.  
SJW

# FEAR

Our fears keep us awake at night and tug at us during the day. We worry that if we say them out loud, they might come true. But naming fears doesn't make them happen. In fact, bringing them out into the open makes them lose some of their power. By looking at the fear, we might even find an important insight.

Once our fears are written down, we might decide to share them with others. This can be difficult because other people are walking around with their own fears. It might be better to share these feelings with someone who is outside this crisis.

At least in this workbook, you can let all the fears come out.

## Examples . . .

*I'm afraid your condition will get worse.*

*When you yelled at me yesterday it hurt my feelings and made me feel afraid and alone. This is hard on me, too, you know.*

*I'm afraid the doctor doesn't know what he's doing.*

*It scares me to see the look of panic in your eyes.*

*I'm afraid I won't know what to do about all the legal and financial things.*

*I'm afraid that I won't know how to go on without you.*

*It frightens me when you keep trying to tell me something and I can't understand what you're trying to say.*

*I am afraid of the gap that you will leave in my life if you die.*





I hate for a day to slip away  
And leave not a trace behind.  
I hate for a thought  
To miss being caught  
And leave a space in my mind.

SJW

Strength is weeping, and then moving forwards more firmly  
because you have wept.

SJW

# Regret

We all have regrets. During an illness, these regrets jump into our consciousness. We wish we had done things differently. We wish other people had acted differently. We regret that we didn't say more. We regret that we said too much. We regret that we may not have another chance.

Feel free to express yourself about your regrets.

## Examples . . .

*I wish we hadn't argued this morning; I didn't know you'd be lying here tonight.*

*I wish I had called the doctor right away instead of waiting.*

*I regret being such a wimp when you were so demanding. Even though you are the patient, I hurt too.*

*I'm sorry it's so hard for me to see this experience from your point of view.*

*I wish our relationship was stronger; I don't think I can go through this with all the bad feelings between us.*

*I wish we could talk about what's going on with this illness instead of making small talk.*

*I'm sorry I got angry at you; it's because I'm so worried.*

*It breaks my heart to see you like this; I'm so sorry I can't take away your pain.*



In the winter of my years  
My legs have lost their spring  
I'm wary of the fall  
But summer birds still sing

Arise my love, and cling  
With me to hope - and never fear;  
We'll stride with strength together  
Across the seasons of the year.

SJW

Whether there's hope or not, we have to hope.  
Negativism simply breeds negativism. It is downhill and  
hastens destruction. Positivism (even if illusionary) infuses  
a life-giving serum of its own. It sustains and nourishes.  
SJW

Hope

We hope for a cure. We hope this hospital experience will be over soon.  
We hope for communication at the end of life, even if it's only a meeting  
of the eyes, a squeeze of the hand. We hope for a "good death," one  
without suffering.

This is an opportunity to write about anything you would like to see  
happen. Don't hold back. Hope conquers fear.

## Examples . . .

*I hope the treatment will make you well.*

*I hope our children will forgive me for not calling them before the situation became so serious.*

*I hope you won't get worse while you're in the hospital.*

*I hope the ICU nurses will keep track of the medication.*

*I hope I can let my tears flow freely; I don't want to hide my true feelings.*

*I hope you don't suffer in the end.*

*I hope I can tell you I love you before you go.*

*I hope you will forgive me for all the times I let you down.*

*I hope we can have a little more time; I'm not ready to let you go.*

*I hope I can believe this is for the best.*





There, in the carousel of my mind,  
I see them, moving up and down,  
Revolving to the sound  
Of music, loud and soft;  
There, my close ones, family, friends,  
Up and down and round they go,  
Passing with smiles, with waves and fears  
Across my vision, now seen,  
Now out of sight,  
Then seen again...  
And so they go  
'Round and round...  
Until the music stops  
And, for a moment, silent turning...  
Then - all the motion ceases.

Now nothing seen - nothing heard...  
Yet all are there -  
Quiet turning, soundless song  
In the carousel of my mind.

SJW

The measure of a person is his capacity to “take it,” — his tolerance for pain — his will to rise above it. But he whose capacity to bear weight is lessened, who has a low threshold and whose strength cannot command his will, must be measured by different standards. With the healthy we can be stern in judgment, but with the ill, only compassion will serve.

SJW

# Compassion

True compassion means walking in someone else's shoes. When we try to imagine how someone else is feeling, a bridge is built.

Sometimes it's difficult to fully empathize because we are so filled with our own suffering and worry. Also, if we really put ourselves in the position of someone who is sick, we ourselves may experience physical symptoms. There are people who can help with this – social workers, chaplains, nurses, physicians. Use their help! That's what they're there for.

Try to imagine what your loved one is thinking and feeling.

## Examples . . .

*I know that you can't wait to get out of this damned hospital.*

*I bet you hate it when everyone tries to cheer you up.*

*I know you're afraid that you'll never fully recover.*

*I know that you worry about being a burden.*

*I realize that the medicine is making you all foggy.*

*I think you're afraid that you will cry and that I'll think you're a coward.*

*I know you love it when you open your eyes and I'm here, just squeezing your hand.*

*I know how frustrating it is that you can't communicate.*

*I know you're scared that it will hurt when the end comes.*

*I know that even with so many people visiting you, you feel very alone.*

*I won't give up on you; even though you can't communicate, I think I'm still getting through.*



Oh, Miracle-making, creative Power,  
I beseech you, press another hour  
Into the day.  
Hold back the sun, hold back the moon,  
Let it be eleven when it's really noon.  
Oh, I pray,  
Use your temporal power  
And grant us, please, that extra hour.  
Please say  
You will give us an expanded day  
To stretch our time for study and for play.  
Oh, yes,  
Employ your mighty lever  
And let us go beyond forever!

SJW

It is important to know when to get off, when to let go. The picture is never finished. The book is never ended. But the time comes to hang the one on the wall and put the other to bed.

SJW

# Acceptance

It's so difficult to accept our own helplessness in the face of this awful situation. We want to erase this illness which is causing so much suffering. But, we can't. It's painful to realize that our loved one may end up physically scarred or mentally altered. We may have to face the fact that there's nothing more the doctors can do, that our loved one may die.

Yet, until we accept those things that we can't control, we can't move forward. And, if we are to have any positive affect on the future, we must accept our own limitations in the present.

Take some time to write about what you can accept.

## Examples . . .

*I accept that my worst fears have happened; now I need to focus on what lies ahead.*

*I have to accept that this illness will leave you weakened and vulnerable.*

*I accept that there are limits to what doctors and medicine can do.*

*I accept that this illness and recovery will take as long as it will take.*

*I have to accept the fact that your body will be different after this illness.*

*I must learn to accept that your mind won't ever be the same.*

*I have to face the fact that there is nothing more to be done.*

*I think you're ready to die but it's so hard to let you go. This is your time and I must learn to accept it.*

*I have to accept that we did the best we could, we treated this the best way we knew how.*

*I know that the person who is dying is not the vital person I loved; it's okay for this body that is so ill to end its suffering.*





Is it the clock's round face, swept by a moving hand,  
Or the digital count of temporal phenomenon?  
Is it the shapely hourglass with spilling sand,  
Or the dial that marks the changing shadow of the sun?  
Is it the slow pendulum's swing, the charming chime,  
The frozen figures that revolve on towers?  
Are these the ways to calculate the time,  
Are these the means that will define the hours?  
No! Hours are molded by the work that's done,  
The day is sculpted by creative souls,  
A week is fashioned by the love of one  
Who shapes the clay-like years to ideal goals.  
    Thus, work's the sustenance on which one feeds  
    And Time is measured not by clocks, but deeds.

SJW

Acting involves a constant search for reason in a world where reason is not always apparent or discoverable or even present. So... act out of your gut.

SJW

# Action

While there are some things we can't change, there are others we can. We can't change the doctor's busy schedule, but we can make sure she answers all of our questions. We can't change a discouraging prognosis, but we can be active in our caring. We can't avoid sleepless nights, but we can take breaks during the day.

Taking action — even small acts — can make us feel powerful in the face of such an overwhelming experience.

What are some resolutions for action you could take?

## Examples . . .

*I'll ask the doctor to go into a private room to talk instead of standing in the hall.*

*I'm going to decorate your room with photographs so the nurses can see what you really look like.*

*I'll try not to get irritated when you keep asking the same questions.*

*I'm going to write a letter to our granddaughter about the memories I have of our life together.*

*I'm going to bring in a tape player and play your favorite music.*

*I'll try to control my anxiety when I'm around you.*

*I'll tape what the doctor says so I don't have to remember everything.*

*I will forgive you for the pain you've caused me over the years.*

*I will forgive myself for wounding you back.*

*I'm going to take a break, walk outside and feel the sun on my skin.*



What are the things that we should count?  
Might they be coins or jewels, houses or cars?  
Do these add up to an amount  
Significant among the stars?

What are the things that we should count?  
Might they be hours or days, months or years?  
Do these add up to an amount  
That all desire and each reveres?

Or - should we calculate with care  
The loving thoughts that come our way?  
For they're of worth beyond compare,  
Adding joyous sum to every day.

SJW

Look at “heart” and see the “ear” in it. It means: “Listen to your heart and listen with your heart.”

SJW

# Self-Appreciation

It is empowering to make resolutions about what we are going to do. It is equally empowering – and comforting – to recognize that, sometimes without even knowing it, we have already done a lot. It is important to focus on what we have given and what we continue to give.

Concentrate on all the positive things you've done and write them down.

## Examples . . .

*I made sure you had a cool cloth on your brow.*

*I brought in a basket of bagels for the nurses to show my appreciation.*

*I called all the family and now everyone is praying for you.*

*I have been a devoted daughter all my adult life.*

*I told the doctor that you seemed anxious and he gave you anti-anxiety medication.*

*Over the years, I cooked your favorite meals.*

*I moved your arms and legs to give you a feeling of movement.*

*When you finally opened your eyes, I was right there.*

*I told the nurse to wait outside when he intruded on a private moment.*

*I loved you the best way that I knew how.*





So many things there are to share:  
A glance, a game, some bread, the air,  
A moment's joy and, yes, despair:  
So many things there are to share:  
A sight, a sound, a silence rare  
Or speech revealing that we care.

SJW

Life is not just blood pulsing in your veins. It is thought racing in your mind. It is hope and dream and burst of plan.

SJW

# *Notes*

Beyond your feelings, resolutions for action, and appreciation for what you have already done, there may be other things you'd like to write about. Perhaps you need to make a list of things to bring to the hospital, write down what the doctor said or keep a log of which medications are being given. Or maybe you need more space to continue exploring your thoughts and feelings.

The following pages may be used any way you wish.















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