



The Caregiver's Manual

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Notice:

This book is intended as a reference volume only, not as a medical manual. The information given here is designed to help you make informed decisions about your health. It is not intended as a substitute for any treatment that may have been prescribed by your doctor. If you suspect that you have a medical problem, we urge you seek competent medical help.

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Introduction

If you are a caregiver for a chronic disease patient, more likely than not, it will be by conscious choice. Those who are forced into this role by circumstance, accident or obligation, eventually find a way to relieve themselves of this responsibility.

The caregiver is usually the person closest to the patient. The person most motivated to try and alleviate the patient's mental and physical suffering. To this end, you will probably be willing to stretch your own mental, physical and spiritual resources to the maximum.

Occasionally, the caregiver's duties could overlap the functions of the attendant, nurse or even the doctor. However, the thrust of your purpose is different. It is not limited to the obvious, menial tasks or chores that a patient may require assistance with.

The caregiver helps the patient form a competent team of people, who work together, towards the improvement of the patient's health and well-being. The patient is at the core of this group. The doctors, nursing staff, attendants, support groups, medical social worker, helpful family and friends make up the rest. You play the important part of linking together all these people, in a cohesive and advantageous fashion. You help improve the rapport and communication, amongst the patient and others.

As a caregiver, your lending moral, spiritual and philosophical strength will be of equal importance to the physical support that you provide. You become the one responsible for reminding the patient of all the reasons to live well. The caregiver's attitude and bearing can significantly influence the patient. It can encourage him to fight his disease, to the best of his abilities. Conversely, a resigned, depressed caregiver can increase the patient's guilt and despondency.

Hence, this is a role which requires conscious effort and understanding.

Based upon my personal experience of 13 years, as also that of the other patients, caregivers and medical workers that I interacted with during this time, I first wrote "It's Your Life – A Practical Handbook for Chronic Ailments", which is available as a free download at www.serenereflection.com I suggest that the caregiver read that book as well. To avoid repetition, I have omitted material already covered there. However, it is likely to be useful and relevant for the caregiver too.

In addition, the following is what I found worked best, for the caregiver herself.

Manual

✓ Remember You Chose This

We tend to forget, that there is always a choice.

There may be some of you, who think that they had no choice. There was no-one else, the finances did not permit it, etc.. However difficult or improbable it may sound, the fact of the matter is that you have chosen to be the primary caregiver.

You could have left the patient in a hospital, institution, by themselves, with hired help, or even worse case scenario, to deteriorate without adequate care. You have chosen a difficult job, because you cannot tolerate these unwelcome options. Therefore, you have not been constrained into this role, but finally, have made the only apparent choice. The only one your heart and conscience allowed you to see.

Reminding yourself that you have chosen this situation, helps increase tolerance and patience, substantially. It also decreases the frustration.

✓ Understand Your Role

- It is crucial to realize that you are the caregiver and not the patient. This means that you may have to watch your loved one suffer much misery, pain and suffering. If you identify with all this, you yourself

will be emotionally drained. In turn, this causes immense depression and physical exhaustion. If you are unable to control your own responses, you will not be in a position to offer strength and support.

- Consciously avoid imagining “how much it hurts”, “how scared you must feel”, “how depressed you must be”, etc.. This type of empathizing has no constructive result.
- Similarly, if your patient happens to be a loving and considerate person, he/she may often feel concerned, guilty or depressed about all that you have to undergo, because of their illness. It would be appropriate to remind them of their role too.
- Instead of both experiencing the agonies of both roles, by deed or imagination, it is far more strengthening to understand clearly, the role each has to play. There is no way for you to take on the patient’s miseries and nor can the patient spare you from whatever you have to face. So at least try and keep the sum of both challenges down.

✓ Take Care of Yourself First

The initial reaction of every involved caregiver, is to stretch one’s own mental and physical abilities, to breaking point.

- There is a hidden irony in this. The primary aim of any caregiver-patient team, would be to maximize well being and longevity of the patient. If you are expecting to succeed in this endeavor, it automatically implies a long span as a caregiver. No person can go for very long periods of time, by neglecting their own welfare. The irony lies in choosing short-term exhaustion over long-term goals.
- Pace yourself out. Chronic disease is a long haul. Feeling guilty about caring about yourself, or being emotionally wrought, will only weaken your own physical status.
- Ensure that you are eating quality, nutritious food, at regular times. Without fuel, you cannot possibly stand up to all the extra work. Do not confuse the patient's diet restrictions, with what would be good for you. Many caregivers try and switch over to the patient's diet, because of feeling bad or guilty, that the patient has certain restrictions. This may be harmful to your well being. Besides, if you have clarified the roles, you will understand that your abstinence is not helping the patient. It is only making both of you feel sorry about giving up something you may have enjoyed before.
- Try and work some exercise into your schedule. Physical activity is a good way to burn stress and rest the "worry muscles" as well. It also improves stamina.
- Fortify your mind. Seek assistance in faith, religion, spirituality, family or community. The stronger you become, the more support

you can lend to your loved one. Tough times are a frequent part of chronic illness. The patient is physically sapped and may often lose will and hope. You have to be well prepared for such occasions. Only if you are inherently composed and capable, can you offer strength, support and determination to fight the disease.

- Try to take a regular break. You can choose a creative hobby, reading, music, meditation or simply a soak in a hot bath. Whatever relaxes and rejuvenates you. This may only be fifteen minutes in a day, but you need to make some time for yourself too. If you are able to take a few hours out for yourself, in a week or month, do it. Do not hesitate. It is imperative to give yourself time to heal and process your own emotions.
- Even one of you maintaining some touch with “normal life”, makes it possible to imagine achieving it again.

Very often, both patient and caregiver, are pulled into a vortex of disease related activity. The actual treatment and medicine regime, information seeking, interaction with medical workers, fund planning, physical exhaustion, all are to be dealt with, over and above the symptoms themselves. This all leaves very little time, energy and enthusiasm for anything outside of this realm. However, if you make a conscious effort to retain normalcy, you will continue to be hopeful of returning your patient to this normalcy too. If you lose all hope and aspiration yourself, how are you going to motivate your patient?

✓ Be Compassionate With Yourself

- There will be times when you are completely exhausted and frustrated. A caregiver ends up doing the work for three people. You have to shoulder your own, the patient's and the caregiver's responsibilities.
- There are also many changes and constraints that may affect your lifestyle adversely. Social activity, leisure, fun, work of your own choice, all these can become limited.
- Finances may become a major concern, automatically forcing you into giving up many things for yourself as well.
- Society in general, may not notice the more subtle sacrifices that you have to make. By default, the concern and sympathy goes to the patient. This can be disturbing to the caregiver. A burden of guilt may also be introduced, for even having considered one's own emotions and difficulties.
- Be kind to yourself. It is natural to experience anger, depression and yearning for another kind of life, a better life.

The patient may have had to give up most things, because he is now unable to do them, or because they are now detrimental to his well being. You, on the other hand, have to compromise, simply because you are the caregiver. Despite the health, inclination and ability, you

are making changes in your lifestyle. How can this possibly be easy? Even if your family, friends and sometimes the patient, do not see or understand this, you must be fair and understanding to yourself.

- Join a support group, where others in similar situations, are far more likely to empathize and counsel you, than your own relations.
- Vent your tears, fears, frustrations and other such emotions. Confide in a trusted friend or support group. Consider writing a diary.

Bottling up your frustration and emotions can make you tired, angry, intolerant, unhappy and physically unwell. It also makes your breaking down in front of the patient, a distinct possibility. This is something you will want to avoid. It would add to the patient's guilt and misery and can undo all your efforts, at maintaining a positive attitude.

✓ **Educate Yourself and Your Patient**

- Just as the patient needs to educate himself about his disease, the caregiver too, needs to be well informed. Very often, you may be participating in the diet and treatment implementation. If you are ignorant about these, you may end up making serious errors.
- Sometimes, acts of omission are as decisive, as preventive or corrective measures.

- Encourage your patient to learn more with you. Ask questions, read books, visit web-sites. Do everything that is within your means, to be prepared for whatever your patient's disease entails.

✓ **Prepare Yourself**

- Find out what possible scenarios you may have to witness. If necessary, visit the hospital unit beforehand, without your patient. That way, you can steel yourself, without showing your distress to the patient.
- Some diseases involve painful or difficult treatment, examples: chemotherapy or dialysis.

For the new patient and his family, these can be frightening and shocking. You are both thrust into an alien situation, without really knowing what to expect. You may need to have the strength and stomach to witness injections, oozing blood, vomit, etc. . The routine, apparently impassive behavior of the staff is further disconcerting. Obviously, all this can be quite hard to deal with. Especially if you have never been exposed to the medical field beforehand. If you have received no counseling, all this can be overwhelming.

- Disease symptoms themselves can be very hard. Watching a loved one in acute distress is never going to be easy.

- Further, many chronic diseases are degenerative. You require to prepare yourself for all the possible pitfalls.

Only when you are prepared, can you start helping the patient prepare. You will have to learn to be matter-of-fact and emotionally restrained, if you want to provide any assistance to your patient.

✓ Encourage the Patient to be Independent

- The protective instincts of a caregiver have to be contained consciously. The more active and independent that a patient can be, the better are his chances of successfully battling his disease.
- Allow the patient freedom to do everything that he can manage by himself. The patient is already fighting helplessness and depression. Often, the overwhelming frustration is due to having become “dependent” to any extent, on another person. The more that he can manage by himself, the more the hope of recovery. Rather than succumbing to your nurturing instincts, it is better to keep hope and enthusiasm alive in the patient.
- If necessary, provide discreet support in the background. But avoid being overbearing. Strict controls only provoke the patient to rebel in frustration and you end up having to combat non-compliance.
- Allow the patient to take his own medication, make his own appointments, discuss with his physician, etc.. You will provide

maximum benefit, by simply being available if needed. Taking charge of all activities can lead to the patient completely losing self-confidence.

- What starts out as your well-intentioned, caring and comforting attitude, can fast lead into dangerous territory. The patient can lose all interest, stop being responsible for his own well-being and instead turn complaining and petulant, when you can't keep up the same level of support.

If your objective is to help the patient lead as normal a life as possible, then the basic thing to do, is treat him as normally as possible.

✓ Food

Food plays an incredibly important part in chronic disease. Chronic diseases generally have prescribed diets and restrictions. As we normally eat three meals a day, this restriction becomes a constant reminder of the condition. Even if the patient is feeling relatively well, he is not allowed to forget that he has a serious ailment.

Added to this, is the frustration of giving up items that have been thoroughly enjoyed before. To top it all, several medicines may have to be ingested after meals. All these factors make meals a highly stressful affair.

- Strive to improve the enjoyment. Improve the ambience as much as possible, to distract from the compromises made in the food itself.
- Use a favorite and allowed food as a treat or incentive, to persuade the patient to eat a required, disliked item.
- Become well versed in allowed substitutes. For example, when salt is cut down, herbs or lime can add to the flavor.
- Find different recipes which are tailored to the diet, but are yet interesting. The internet is a wonderful source of all kinds of special recipes and allowed substitutes. You may have to try food from a different nation, but eventually, some of the abundant varieties in the world, will meet both diet and appeal.
- Attractive presentation will make the food more appealing. Color, arrangement and any possible aroma (allowed herbs or condiments) will enhance interest.
- Have enjoyable company over. It can be a potluck, so as to minimize your workload.

This may all seem like a lot of work and fuss. There is a reason. If your patient loses interest in food, constantly complains, gets bitter and unhappy and reduces intake, there will be a heavy price to pay.

Without adequate nourishment, immunity, health, well being and will to live, all decline rapidly.

Extra efforts are worthwhile, to avoid the possible complications of reduced intake.

✓ **Being Honest With Your Patient**

Often, doctors and staff choose to inform the caregiver of the present status and proposed measures, instead of the patient. You may be required to convey this information to your patient. In such situations, sometimes the caregiver is tempted to withhold disturbing information. Instead, they try and cover up, saying all is well. However, I would suggest that the patient is always as well informed as possible.

You can be gentle and supportive. But withholding the truth has little benefit. Keep in mind, that even sedated or unconscious patients have been known to absorb conversation around them. The chances of the patient hearing part or mistaken information, from one of the many people surrounding him, are quite high.

Besides, you would be depriving the patient of preparing himself mentally, as also of informed decision making. He will be the one bearing all the consequences. Would it not be more fair to ensure that you, the caregiver, maintain an honest and trusted role in his life?

✓ Clarify the Patient's Choice

- Be sensible and honest with each other.
- Discuss honestly, the possible course the disease may take. Understand your patient's views clearly. Encourage him to make an oral or written "living will". This way, you will have a clear understanding of which treatment and extent of medical support the patient desires. Convey this information to the primary physician too. Doing all this when the patient is in relatively stable or good health, is always better.
- Ultimately, the patient is the one who endures all the physical trauma. Your emotions may cloud your judgement, if you are called upon to make these choices. If your patient is not in a position to convey his own options, your choices will be hard and difficult. It is far better to be armed with clear knowledge of the patient's will and intent, to execute such decisions.
- Prepare yourself mentally to the possibility of having to actually execute such wishes. Insisting upon "Do Not Revive" may be the hardest thing you ever have to do. But if your patient has insisted upon this, like any other "will", his wishes should be honored. As also, any eye or organ donations that he may have willed.

✓ Be Practical

- To cope efficiently with chronic disease, one has to learn to be practical and objective.
- Encourage the patient to put his affairs in order and make a proper will. Allowing yourself to be superstitious or overly emotional, implies not taking sensible steps. You will be dealing with a lot during the patient's lifetime. In the unfortunate event of his being incapacitated or passing away, you will be left with more troubles and confusion, if you do not minimize these when it is possible.
- Some patients require gentle persuasion and tactful handling. There may be a danger of your actions being misinterpreted. But you should use all the resolve and diplomacy necessary, to convey the importance of these matters to your patient.

✓ Emergencies

Material covered in a similar section in "It's Your Life – A Practical Handbook for Chronic Ailments" , would make relevant reading for the caregiver as well.

- The caregiver plays a crucial role, during emergencies. The patient will take his cues from you. If you panic or exhibit distress, it is likely to make the patient even more fearful. It is imperative that you be calm and composed.

- Many disease symptoms tend to aggravate at night. When your patient is keeping unwell, it is wise to remain dressed in your street clothes, even at night. This way, any time loss or hesitancy in taking immediate action, is minimized.
- Ask your patient to keep bathroom doors unlocked. This is a place where many incidents can occur. Accidents, like slipping, are commonplace here. Further, is the added risk that comes about due to the physiological changes associated with passing of urine/stools, vomiting or bathing.

A locked door may stand between life and death, if a patient requiring aid, cannot be reached in time.

✓ **Constantly Express Affection**

- The caregiver is sometimes forced into the role of the disciplinarian, as you have to help the patient follow his diet, medication and treatment plan.
- Perhaps, you may assume the role of a teacher or guide, in trying to motivate the patient to live actively and positively.
- Concurrently, you are restraining your own emotions and trying to act objective and level-headed.

- Unfortunately, there may be occasions when you are forced to see your patient physically changed, hooked to all kinds of devices, with different needles and tubes attached. At such times, even the nature of the patient may be different. He may be tired, uncommunicative, depressed or irritable. Disbelief and consequently, detachment can set into your approach.

You may have to remind yourself about how that person truly is, under normal circumstances. That he is still hidden there, below all this trauma. Help him remember this as well. Together, you must bring him back to normalcy.

- Hospital units may leave little privacy, to both, the patient and caregiver. Expressing affection in front of others, does not come easily to everyone, especially in reserved societies. Public displays are frowned upon.

Due to all the above factors, routine display of love and affection may become limited. Consciously avoid this. It is a well accepted fact, that demonstration of love and affection, play a huge role in healing. The human touch, especially of a near and dear one, has been known to lower anxiety, mental trauma and even physical pain.

Don't allow yourself to be intimidated or embarrassed by the situation. Your patient will benefit immensely, by you verbalizing your love and offering your reassuring touch. Tender Loving Care, or TLC, can prove to be one of your patient's most potent remedial therapy.

✓ Guide Family and Friends

- An astonishing number of peers have difficulty in dealing with chronic disease patients. Many may even avoid meeting or interacting with your patient and yourself, confessing helplessness and fear.
- Support and acceptance from your social network can be a boon. However, this is unfortunately rare. You may need to evaluate the people surrounding you and educate them in how best to deal with your patient. If necessary, speak to them privately and prepare them for whatever the present state and forthcoming condition is likely to be.
- Encourage them to behave as normally as possible with the patient. Most patients prefer to have their disease referred to in a matter-of-fact way. Excessive emotion or obvious disregard, can both be equally disturbing. Such reactions can imply a whole host of negatives for the patient. It may increase the patient's own fears and depression. Or it can be interpreted to imply fear, horror, "death sentence" or even revulsion, in case of visible symptoms or disease consequences.
- Even if it sounds rude, it is better to warn your visitors not to discuss their favorite "medical horror story" with your patient. Learning about another's miserable experience is hardly going to be a comfort to you both.

- Others may not realize the huge efforts made by the patient and caregiver, to boost their optimism and confidence. Disturbing visits can undo weeks of intensive effort.
- Instead of exposing your dear one to such negative influences, try and increase his interaction with the strong, positive and cheerful people in your community. Surround him with those who show acknowledgment and support, instead of fear, pity or sympathy. Caring for a chronic patient, need not be conveyed by a display of sorrow and grief. Solidarity, enthusiasm, humor and thoughtfulness are far better means. Show him all the beauty in living, so that he is motivated to return to a state of well being.

If all that he sees is despair and despondence, there will be nothing worth fighting for.

- Continue all possible social activity. If you can't take him for a hike, but a walk in the park is still feasible, do that instead. If you can't go out dining at restaurants, go over to family, who discreetly prepare the menu relevant to your patient's diet. If you can't go bowling, have friends over for a round of board games instead. Try and keep your patient and yourself, as connected as possible, to a normal social circle.

This alone can increase his well being and optimism, well beyond measure.

✓ Delegate

The initial protective instincts for a loved one, may prompt you into trying to do everything yourself. If assistance is offered, do not hesitate to accept it. This will help you conserve energy, as also give yourself and your patient, a change.

Most things, you will have to do yourself. But help can always be taken for housekeeping, grocery and medicine shopping, baby-sitting, dog walking, driving, etc.. At least the burden of ordinary chores can be relieved.

Many of the people surrounding you may want to help and cannot imagine how to do this. Tell them yourself. Pride and ego have no place in such situations.

If it becomes necessary and you can afford it, consider day care facilities or nursing assistance at home. Choose pragmatic options over emotional ones. Help of this kind will allow you to enhance your productivity and income. This can provide change as well as financial relief.

✓ Keep Trying New Support Options

Finding the energy, inclination and initiative to try something new, may feel next to impossible, on most days.

There are countless safe alternative therapies. For most of us, there is much to be learned about different coping skills, psychological tools, new mindsets, deeper and clearer understanding of faith, religion or spirituality.

When one is struggling to achieve even a minimal quality of life, the idea of diverting resources towards such ambiguous activities, is very likely to seem impractical, if not wasteful.

However, any one of these may prove to be your lifeline.

Energy Psychology tools such as [EFT](#), [TAT](#) and [Dynamind](#) all hold the potential of significant relief for emotional and physical challenges.

Do not underestimate the strength and support waiting to be derived from such means. The learning process in itself, instills hope. It diverts your attention away from worries and fears. Actively attempting to improve the situation, lessens the sense of helplessness and takes away the notion of being the powerless victims.

It is easier to accept what one cannot change, provided you are confident, that you have exhausted every means possible, to try and change it.

Epilogue

Your role is a decisive one, in deciding how long and more importantly, how well, your loved one lives. I hope that this material helps you accomplish a substantial quality of life, for yourself as well as your patient.

However, there is one harsh possibility that you have to face. It is likely that you will be witness to the death of your near one.

A caregiver is generally highly emotionally attached to the patient. Over and above that, the duties of caregiving become such an integral and time consuming part of one's life, that very often, the caregiver's entire life revolves around the patient. Practically all daily activities, energies, resources and attention are devoted to maximizing the welfare of the patient. Hence, the void left by the departure of your patient, can be all consuming and staggering.

This, therefore, necessitates some practical readiness. Keep yourself engaged in other people and interests, even if you cannot devote much time to them. You may need to fall back on these, for support. Plan your finances and career. If you do not have an independent source of income, start learning some skills or preparing for a vocation, which will provide you with occupation and livelihood.

Keep in touch with your own inner guidance, understanding what your individual goals are. Do not give up on what you personally want to achieve, from your own life.

Discuss these issues with your patient. You will feel better to have learned this person's inputs, as he is so important in your life.

In the course of supporting a chronic patient, one discovers all the beauty in life. You must, in order to motivate the patient - to fight all the oppressive odds. Both of you would have cultivated greater appreciation for other people, relationships, interests and good health. All the factors that make a life well lived, so worthwhile. Forgetting all these painfully gained insights, in the grief of your loss, would be such a waste.

The fundamental reality of life is that everyone dies. And those who remain behind, must go on to make the best of their own lives. Having focused so much of your love and resources in maximizing your patient's welfare, it would be unfair, to do anything less for yourself.

I hope that you and your patient find the strength to convert this challenging situation into one of the most educating and rewarding experiences of your lifetime.

All my good wishes.