Healthcare **Communication** Review

On Building Health Partnerships: Food-for-Thought, Practical Tips, Resources

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Understanding and Managing

CHRONIC CONDITIONS

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Chronic Conditions: What Do They Mean For Patients?

Chronic: *Marked by long duration or frequent recurrence; Not acute.*
Merriam-Webster Online Dictionary

In addition to being long lasting, chronic conditions or illnesses generally begin and progress slowly – often getting more severe over time, especially if they are not managed well. Chronic conditions differ from acute illnesses, which often begin with sudden, sharp symptoms and are relatively short lived. Patients are generally expected to fully recover from acute conditions – broken bones and appendicitis, for example. Any lifestyle changes that may result from acute conditions are often a matter of choice, rather than need. Chronic conditions and illnesses, on the other hand, generally last a long time – often for a lifetime – and require lifestyle changes.

This Means It Is Important For Patients…

If there is ever a time when patients should be active partners in their care, this would be it. Remembering that there are no guarantees in life or medicine, there are at least two good reasons why patients with chronic conditions should become active partners in their care. First, and foremost, they can help themselves…

To Maintain their Best Possible State of Health

Patients' conditions and circumstances differ, so the best possible state of health may be different for each patient. But it has been shown that being an active patient is a good way to maintain the best possible state of health, whatever that may be. That is, the call for patients to be involved in making health decisions and manage their care is largely based on the results of more than 30 years of studies, which have found, over and over again, that patients who take control of their care are more likely to have better health outcomes. Being active partners in care can also help patients…

To Maintain their Best Possible Quality of Life

Another important difference between chronic and acute illnesses has to do with patients' quality of life, which is generally not affected, in the long run, by acute conditions, as is often the case with chronic illnesses. So, what is quality of life? Why is it important to maintain it? And how can being an active partner in care help maintain it at the best possible level for each individual patient?

What is 'Quality of Life?'

WebMD describes quality of life as patients' general wellbeing. Other sources, such as anemia.org, often describe it as an overall *sense* of wellbeing. An important part of this sense of wellbeing is what may be called a sense of self. That is, we each think of ourselves in certain ways. In addition to how we see our bodies and what they can do, our sense of selves may include the way we see ourselves within the family and at work. Chronic illnesses often change all that. Certainly our physical states change. This, in turn, may change our ability to do the things we've done before.

See **Chronic conditions** *Pg. 2*

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From the Editor

Some chronic conditions can have very little effect on the way people go about their daily routine (for example, the highly irritating post-nasal drip). Then, again, some conditions can be quite serious and greatly effect people's lives (blindness, deafness, asthma, arthritis, cancer, diabetes, and heart disease, to name just a few). If not managed properly, some chronic conditions may even be life-threatening. Happily, however, not only are many such conditions preventable, but when they occur, many are also manageable.

In this issue, then, we look at the role of active patients, and their family caregivers, in managing chronic conditions. We begin on page 1, with an article on why it is especially important for patients with chronic ailments to take an active role in their care. This is followed by the article, on page 3, which addresses steps patients can take in managing their care once a diagnosis has been made. Because doctors sometimes have difficulty making diagnoses, on page 4 we explore some of the reasons why the cause of symptoms may sometimes be hard to find and suggest steps patients might take when that is the case. Along these lines, one of the two books reviewed in this issue, *How Doctors Think*, looks at the process of diagnosing ailments and offers suggestions for patients. The second reviewed book, *Living a Healthy Life with Chronic Conditions*, offers practical suggestions for active partners in care. As always, we hope you find the articles in these pages useful and extend our best wishes for all to…
Be well. *Judith Greenfield*

Chronic Conditions *continued from Pg. 1*

These changes can, at least at the onset of conditions, shatter the images we have of ourselves. Our sense of who we are, in our own minds at least, is lost. This can be a great sense of loss and, perhaps, explains why the Clinical Center of the National Institutes of Health (NIH) describes the emotional reactions of patients who learn they have chronic conditions in the same terms used to describe the emotional reactions of patients who learn they are dying: shock, denial, confusion, fear, avoidance, anger, and grief.[1]

Why Is It Important to Maintain Quality of Life?

Maintaining a sense of wellbeing is important not only because feeling "good" is preferable to feeling "bad," but also because how we feel mentally can (and often does) affect how we feel physically. There are, in fact, well-established, proven links between mental functioning and physical functioning. We now know that changes which occur in one, leads to changes in the other. This has been reported in many places, including in the 1999 U.S. Surgeon General's Mental Health Report.[2]

How we cope with a condition, therefore, can help shape the course of an illness. This partly explains why two people with the same disease can have very different illnesses. It stands to reason, then, that a person who can manage to regain some sense of self – even if it is a somewhat different sense of self than before the condition – may be more likely to regain an overall sense of wellbeing, or quality of life.

How Being Active Partners in Care Can Help?

Being an active partner in care does double duty. By being part of the decisionmaking process and taking actions that control their physical conditions, patients are also re-taking some level of control of their lives. This control, even if it is limited control, also goes a long way to helping them regain a sense of self and, with it, a sense of wellbeing, or quality of life.□

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[1] www.cc.nih.gov/ccc/patient_education/pepubs/copechron.pdf

[2] www.surgeongeneral.gov/library/mentalhealth/chapter1/sec1.html.

Managing Chronic Conditions: Following Patient 'Jane Doe'

Picture Jane Doe, an imaginary patient. She has just learned that she has XYZ, a life-changing chronic condition. She knows something about this condition and knows that it can get worse over time. She knows that it can change the way she lives her life – maybe even to the point of not being able to work and do the other things she needs to do and wants to do.

Dr. April Showers (her imaginary doctor) is giving her information. Dr. Showers is talking about next steps and telling Jane that things are not hopeless – that this condition can be successfully managed and that she can continue to live a good life. Jane is hearing her doctor's words, but not taking it in. Like many patients who get this sort of news, she is stunned.

After the Diagnosis

After leaving the doctor's office, she finds that she doesn't really recall much of what the doctor told her. At home, she realizes that she should start learning about her condition and figure out her next steps, but she can't bring herself to do much of anything. She is on an emotional roller coaster – going back and forth between believing it is all a mistake, being afraid, angry, or depressed or simply pushing it aside and just not thinking about it.

Family and Friends Trying to Help

Jane is not helped by the encouragement she gets from family and friends. Even though she realizes that they are probably right, it doesn't help her when they tell her things will be OK; that she will feel better once she gets down to doing what has to be done. She just keeps on 'stewing' until, one day, she is ready to do what needs to be done.

Taking Charge

Jane begins by looking for more information about her condition. She goes to the website of the 'National XYZ Association.' She also goes back to Dr. Showers to talk more about her illness and what can be done about it. She brings her sister with her to help her remember what the doctor says. Because she had already started to do some research, she is now able to ask questions that she might not have thought of before.

Making Decisions

Dr. Showers explains Jane's different treatment options and what they would mean for Jane on a daily basis – what Jane would have to do, or not do, each day. She also explains the risks and benefits of each option – how they are expected to help but also how they might harm Jane. After the doctor recommends one of the treatments, Jane asks her why she prefers that one. Jane is not sure she wants to try the recommended treatment and explains why. The two talk more and after a bit decide on a plan of action that both agree to try.

Managing Her Condition

Jane goes home and, before long, realizes she needs to keep track of her medical records (such as lab work and other tests), her medications (times and doses and reactions), and paperwork (health insurance approvals, disapprovals, co-pays, appointments with specialists, with other practitioners, and more). This means she needs to get organized so that she can easily find something when needed. She also realizes that she can no longer handle all her daily chores, (for now, at least) – that she will need to give up some and get help with others.

Then Jane decides to get another form of help – emotional and practical support – from people who understand what she is going through because they have XYZ, too. Not being a 'joiner' she first tries an online support group (at the National XYZ website), knowing that she doesn't have to 'chat' if she doesn't want to. After a while, she joins a local group, too. From both, she sees that even though members differ in many respects, they also have many similar experiences. She is helped by the emotional support she gets and also by the practical tips she learns from them, such as how to make needed lifestyle changes by setting specific, do-able goals – for instance, not just deciding to exercise by walking, but by first deciding how far, and how often, she will be able to walk.

Being able to make changes in her lifestyle helps her take control of her life and, although she has her ups and downs, she is able to maintain a quality of life that works for her. Over the years, she has had to give up some of the things she did before she got sick, but has also been able to add some new things that give her life purpose and a sense of satisfaction. Jane continues to see Dr. Showers and other helpful practitioners on a regular basis to review her progress and, where necessary, make adjustments.

What 'Jane Doe' Learns Over the Years

Jane has also learned some things about herself that she never knew, namely that she could learn enough about her medical condition to make important decisions; that she could actually make those decisions, even though they were not always easy to make; and that she was much stronger than she had ever imagined. In the end, she realizes that all is as good as it can be, given her condition, and that is not bad!

Some Important Points to Make

After The Diagnosis

Every patient is different. And while Jane's reaction to her diagnosis was typical, other patients may not experience the same range of emotions that she did. Even if they do, there may be differences in how strongly, or for how long, they feel those emotions. Some patients may even feel relieved when they are diagnosed. (See article on page 5.)

See **Jane Doe** *on Pg. 4*

Jane Doe *continued from Pg. 3*

Family and Friends Trying to Help

When patients like Jane voice their concerns, family and friends often try to help by offering advice. This is such a natural reaction, that many people have given or gotten such advice. Chances are, then, that they have seen first hand how this usually doesn't help. Unasked for advice, for instance, is often met with resistance and sometimes, perhaps, annoyance. Why? Possibly because they are not yet ready to act. For many people, patients included, talking about what's bothering them helps them come to grips with their situation and brings them to the point of figuring out what to do and then doing it. In other words, talking can be a form of thinking out loud.

Think of the comedy act where one person is going on and on about a problem and the listener is barely able to get in a word. But the process of talking helps the talker figure out what to do, so he thanks the listener for helping when all she actually did was listen. Family and friends might take this to heart. Instead of trying to help 'fix' the problem by giving advice, they might help by simply listening – listening and validating. That is, letting ill loved ones know that they are being heard and that their feelings are valid can be so helpful to them.

> *"That is hard."* OR, "*I can understand why you feel that way.*"

On the other hand, those who want to talk about their concerns might help themselves by first telling the listener what they want.

> *"I really need to talk about something that's bothering me, but I just need you to listen, not give advice."* OR,
> *"I would love to know what you think about what I should do and why."*

Taking Charge

Getting information about one's chronic condition is an important first step for patients who want to take charge. Getting that information from the national association devoted to that particular condition is a great place to start. Other sources of information can also be very helpful. These include online websites that cover a range of medical topics, such as: **www.healthfinder.gov**, **www.medlineplus.gov**, **www.mayoclinic.com**, and **www.kidshealth.org**. The key is to find reliable online sources. The Medical Library Association (MLA), at **www.mlanet.org**, offers guidelines for evaluating other online sources. (Click on 'For Health Consumers')

Taking charge means more than getting medical information, however. It means doing a number of other things as well. Links to information about how else to cope with and manage chronic illnesses can be found by doing a Google search at **www.google.com**. Enter "Coping With Chronic Illness" in the search box, then click on the MedlinePlus link for excellent articles. There are also other useful links on the Google page but be sure to use the MLA guidelines for determining the reliability of the other sites.

Making Decisions

Making decisions is a major part of taking control. This calls for more than just getting information, however. It calls for discussing that information with doctors: making sure it is relevant for individual patients, what it means if it is, and how it might affect their lives. This is a time when patients should not only ask questions, but also tell their doctors where they are coming from – what is important to them, including personal preferences – and discuss that as well. This may help both doctors and patients decide which treatment options to try. When there is no agreement between the two, negotiations can be helpful. It's not as hard as one might think. If both patient and doctor ask and discuss 'what' and 'why' questions, they are on a good path. For a more detailed description of negotiation tips, see "Doctor-Patient Negotiation: A Problem Solving Exercise," by scrolling down to Volume 1 Number 2, at **www.healthcp.org/articles.html**.

Managing Conditions

Having made a treatment decision, the next step is to manage the treatment. As Jane learned, managing chronic conditions usually means getting organized and getting help. A number of books can provide guidance here as well. Some address chronic issues in general (see review on page 8). Others offer suggestions for people with specific diseases. Even when that is the case, however, many of these books can be quite helpful for patients regardless of the conditions they have. Two examples are: *Aftershock: From Cancer Diagnosis to Healing A step-by-step guide to help you navigate your way* (visit (**www.aftershockfromcancer.com**) and *Otherwise Healthy: A Planner to Focus Your Thoughts on Organizing Life After Being Diagnosed with Breast Cancer* (visit **www.otherwisehealthy.com**). Reviews of these books can be found at **www.healthcp.org/cancer.html**.

If selected treatments don't work, the process of rethinking next steps should include a repeat discussion of 'what' and 'why' questions. With the passing of time, new medical developments may have occurred and patients' personal preferences may have changed. Once again, the hope is that doctors and their patients will agree on a treatment, although patients will have the final say when there's no agreement.

Lessons

As with other aspects of an illness, the lessons learned by individual patients will differ from one another. If, however, the often harsh realities of a chronic illness and the need to take charge of one's care results in the discovery of strengths patients never knew they had; and if they result in a new-found appreciation of friends, families and life; then perhaps we can understand why some patients express gratitude for their changed life.□

Chronic Symptoms: When Their Cause Is Hard to Find

Strange as it may seem, patients sometimes feel relieved when given a diagnosis that other patients often find upsetting. Why? It's generally NOT because they are happy to have a serious, life-changing illness. More likely, it's because they have been suffering from symptoms for a long time and the reasons for those symptoms had not been easy to find. When the cause of their symptoms is finally found, even if it means they have a serous condition, there are at least two reasons why these patients might feel relieved. First, it not only tells them, but tells their doctors that they had not been "crazy" – that their symptoms were not "just in their heads." Second, giving a name to their symptoms now allows both patients and their doctors to make plans – to figure out how to deal with their conditions – to start doing something about them. It now allows patients to regain some sense of control over their lives and that, as had been stated earlier in this publication, is no small thing. This brings us, of course, to the question of why the cause of symptoms is sometimes hard to diagnose and what patients can do when that happens.

Why Is It So Hard To Figure Out What's Wrong?

"Medicine's ground state is uncertainty. And Wisdom – for both patients and doctors – is defined by how one copes with it."

Atul Gawande, in *Complications: A Surgeon's Notes on an Imperfect Science*

In 2003, the Human Genome Project reached its goal of identifying all of the genes in human DNA (20-25 thousand in all). With the amazing advances in medical knowledge made by this and other research projects, it's easy for us to believe that doctors can easily find, and be sure of, the causes of symptoms experienced by their patients. Sadly, however, that is not always the case. Why? Because even though medical practitioners often benefit from new knowledge gained through research, there are many reasons why uncertainty in medicine still exists.

Take, for example, the achievement of the Human Genome Project. How much more certain can a statement be when it claims that ***all*** the genes have been identified? Yet the exact number has not been determined! The reason, we are told, is that the genes are still being analyzed and different ways of doing so lead to different counts. This, however, may point to one reason why certainty can be so hard to achieve: even if experts agree on the facts, they often disagree on what those facts mean.

Then consider that even though particular conditions have well-known symptoms that point to them, they can also cause symptoms that are unusual for them. Sometimes they even cause no symptoms at all. Gallstones are one example of this. Normally, gallstones make themselves known when they block bile ducts, causing great pain. But different symptoms may occur instead or, in many cases, not occur at all, in which case no treatment is needed.

So even though research may show doctors that certain symptoms point to disease ABC, for instance, clinical experience (time with patients) also shows them that other, unexpected symptoms may also lead to that disease. Furthermore, some symptoms, like stomach pain, can occur for a number of reasons. This, of course, can make diagnosing the problem more difficult. What can make it even harder still, though, is how doctors are taught to reach a diagnosis. According to Dr. Jerome Groopman, in *How Doctors Think* (See Review page 6), doctors-in-training are taught to follow set procedures and, as well, 'practice guidelines' that form 'decision trees.' By following the different 'branches' of a decision tree, doctors are expected to find the correct diagnosis and treatment. (Examples of 'decision trees' can be found at **www.familydoctor.org**. Click on 'search by symptom' and then select a symptom.)

While these methods can be quite effective for uncomplicated conditions, Groopman states that they can fall far short of expectations when many symptoms occur at the same time and when symptoms, or test results, are unclear. Decision trees and set procedures, he says, often discourage doctors from keeping open minds about other possible causes – they are discouraged from "thinking independently and creatively." In other words, doctors are encouraged to place greater importance on knowledge gained from the laboratory than on knowledge gained from patients' actual experiences.

What Can Patients Do?

Trust has always been an important part of the healthcare process. For many, this has usually meant that patients should trust their doctors. But other forms of trust are equally important. First, patients should trust themselves. It may not be easy at first, but patients should work to accept that their own views of how they are feeling and what is and isn't working, should be told to, and heard by, their doctors. When diagnoses are not easily found or treatments are not working, it is especially important for patients to speak up, to make themselves heard and to try to get their doctors, as Groopman puts it, to "think outside the box."

An example given by Groopman relates to a situation where the doctor assumes that her patient's symptoms are related to a previously diagnosed condition. The patient, however, senses that this is something different. Groopman suggests that, by asking the very simple question: "*what body parts are near where I am having my symptoms*," the patient might help his doctor to take another look at other possibilities. Also important, Groopman reminds us, is that: "*What we say to a physician, and how we say it, sculpts his thinking. That includes not only our answers but our questions.*"

See **Hard to Find** *on Pg. 6*

Hard to Find, continued from Pg. 5

This suggests that patients should assess the feelings they have towards their doctors because those feelings will likely come through when they speak. Patients who think of their doctors as foes, might tend to speak harshly or in a hostile tone. Those who think of their doctors as partners in care might tend to speak in firm, yet respectful tones.

Those who say that patients shouldn't have to 'point' doctors in the right direction and also shouldn't have to 'coddle' doctors when doing so, might consider the following. If patients no longer think of doctors as 'gods,' then that means they are human. To err is human and, if Groopman is right that the way doctors think can lead to errors in diagnoses, then it is certainly in patients' own interests to try to help their doctors get on track.

Another aspect of being human is that we generally react negatively when someone irritates us. Even though doctors make every effort to be objective and to not let their emotions guide them when irritated by their patients, like other humans, they can, often unknowingly, let their feelings cloud their thinking. Since the goal is to help doctors keep open minds, therefore, patients might help themselves by speaking in ways that will not shut their doctors down tight!

Trust – doctors trusting their patients – will go a long way toward helping patients be heard by their doctors. What has been called an 'open secret' in medical practice, however, is that patients often lie about what they are, or are not, doing. So when patients are failing to respond to their treatments, some doctors think their patients are lying about following that treatment. If patients sense that this might be the case, raising the matter may help. They might say, for instance, *Doctor, it sounds as if you do not believe that I am doing what you told me to do, but I am, and I'm still not getting better. Let me ask you, if you believed me, what would you do next?* If their doctors respond well to this, then some progress will have been made. If the doctor doesn't respond well, then patients might consider finding another doctor.

A lack of trust, however, may follow patients to their new doctors. As Groopman reports, doctors often note their lack of trust in their patients' charts and new doctors who see this note may accept this judgment at face value. When meeting with new doctors, therefore, patients might, in their own words, say something like: *I have not responded to treatment and I think Dr. X doesn't believe me when I say I've been doing what she told me to do. I hope you will at least consider that I may be telling the truth and that you will be open to figuring out what to do next.*

It's important to remember, however, that not only do doctors need to earn their patients' trust, but patients also need to earn their doctors' trust. A key to this is how we talk and act. Perhaps it will help us to think of how we want doctors to respond to us, and then do likewise with them.□

BOOK REVIEW

How Doctors Think

By Jerome Groopman, MD Publisher: Houghton Mifflin Co.
Reviewed by: Alvin S. Konigsberg

Good doctor-patient communication is necessary for effective diagnosis and treatment of illness. Knowing "how doctors think" can help patients feel safe enough to fully describe their situation and fully explain their symptoms. In Chapter 1, Groopman writes:

> *"A growing body of research shows technical errors account for only a small part of our incorrect diagnoses and treatments. Most errors are mistakes in thinking. And part of what causes these cognitive errors is our inner feelings, feelings we do not readily admit to and often don't even recognize*."

Using many case studies and examples, Dr. Groopman illustrates his personal struggles with the practice of medicine: his prejudices, his errors and his vulnerabilities. As such, he tears down the barrier that very often separates physician and patient. In the chapter entitled "The Uncertainty of the Expert," Groopman addresses the claim that uncertainty undermines a patient's sense of hope and confidence in his physician and the proposed therapy. He says:

> *"... taking uncertainty into account can enhance a physician's therapeutic effectiveness, because it demonstrates his honesty, his willingness to be more engaged with his patients, his commitment to the reality of the situation rather than resorting to evasion, half-truth and even lies. And it makes it easier for the doctor to change course if the first strategy fails, to keep trying. Uncertainty sometimes is essential for success."*

By drawing on other doctors' experiences, as well as his own, Groopman shows that errors of thinking are not uncommon. He also shares his thoughts about dealing with abrupt and inconsiderate doctors, as well as those with great sensitivity and concern, but poor clinical skills.

An excellent book for the reader who enjoys medical analysis, there are chapters on heart disease and cancer and discussions of many other illnesses. In the surgery chapter, Dr. Groopman shares his own story as a patient whose problem with his right hand and wrist was misdiagnosed by five surgeons. Although his medical expertise and experience helped him achieve a favorable outcome, he also offers suggestions to help the average patient without extensive medical knowledge and support and without abundant financial resources.

I highly recommend this book. While it may support fears about how prone to human error medicine can be, I found its truthfulness, authenticity, humility, and humanity very reassuring.□

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BOOK REVIEW

Living a Healthy Life with Chronic Conditions
Self-Management of Heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema and others

Written by Kate Lorig, RN, DrPh, et al. Bull Publishing Company
Reviewed by Marge Gagnon RN, MS, CNS

Hope… Being in Charge… Action Plans… Acquiring Skills… Finding Resources… These are the ingredients that come together to make this book a must read for anyone with a chronic health condition. So often, people become their disease. With this as the focus of life, they forget about living. This book helps people find a new prescription for a healthier life. While certain symptoms that individuals experience are caused by the disease itself, others are caused by stress/anxiety, pain, difficult emotions, depressions, fatigue, etc. Using a simple table, the author connects the skills that one needs to manage specific chronic diseases. With entire chapters to each disease, the authors provide basic information about the disease, getting a diagnosis, monitoring and controlling the disease, treatments that are commonly used, a list of community resources and suggested readings.

Because the main focus of the book is to help patients actively manage their health, it carries the reader through a process that includes goal setting and creating do-able action plans. Setting **do-able** goals helps individuals gain confidence that, with planning, active engagement, and reordering how the task at hand is approached, they can do what needs to be done. Filled with practical tips on types of exercise, one quickly realizes that the suggestions begin with do-able exercises even for the "couch potatoes" of the world. Start small and build upon the gains you make each week is the basic formula. Chapters on healthy eating, sex and intimacy, using your mind to manage symptoms, acquiring communication skills, managing medications, and making treatment decisions are all topics covered in this same straightforward way.

According to the authors, *Living a Healthy Life with Chronic Conditi*ons has "helped thousands of people with chronic illness fulfill their greatest possible physical potential and to once gain derive pleasures from life. Originally based on a 5-year study conducted at Stanford University, this work has grown to include the feedback of medical professional and people with chronic conditions all over the world."□