

Second
Edition



So You Want to Be a Patient Advocate ?

Choosing a Career in Health or Patient Advocacy

Updated to Include Advocate Certification

Find answers to your questions about becoming a health or patient advocate, including:

- Where can you find a patient advocacy job?
- What education and experience do you need?
- How much money can you make?
- Is private advocacy an option for you?
- And many more.



Trisha Torrey

Every Patient's Advocate

So You Want to Be a Patient Advocate?

Choosing a Career in Health or Patient Advocacy

Second Edition



by
Trisha Torrey,
Every Patient's Advocate



Choosing a Career in Health or Patient Advocacy Second Edition

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Chapter One

The World Needs Patient Advocates

Channeling Forest Gump here: health care is like a box of chocolates. We never know what we're going to get.

Patients enter the healthcare system with difficult symptoms or to prevent health problems from cropping up later.

Sometimes they get exactly what they need with no hiccups whatsoever.

But too often:

- Problems crop up – some of which can be solved in the short term, and some which require far more effort to overcome.
- They get what they need in the short term, but wish for additional support to weather future storms.
- Solutions are offered by providers but payers stand in the way.
- Their safety and well-being are jeopardized, leading to medical mistakes which cause injury, extended illness, or even create new medical problems for them.
- They unnecessarily die or go into bankruptcy.

Not unlike that box of chocolates, we never know what our outcomes are going to be, not all of them are to our liking (does anyone else think the chocolate covered cherry tastes like cough syrup?), and some are unpalatable all together.

Further, even for those who think they've gotten what they need, sans hiccups, they may be fooled without realizing it. Undisclosed errors, medical bills which arrive months, or even a year later. (You know – like when you grab that yummy vanilla crème only to find out it's full of nuts?)

Guide Dogs and Watch Dogs

I won't go into the details or all the reasons the healthcare system has become so dysfunctional, or the many ways it creates hurdles big and small for patients. Those problems are outlined in other books.¹

Instead, this book is an overview of the people who offer solutions; patient advocates. The more hurdles put in the way of patients, the more confusing the system, the more onerous or dangerous it becomes, the more we need advocacy professionals to help them navigate the system successfully.

Enter health and patient advocates and navigators, who, like guide dogs and watch dogs, protect patients and keep them safe. They prevent problems or fix problems, hold providers' toes to the fire, coordinate care, and make sure the care patients do receive doesn't create a financial tailspin for them.

Please note the contrast with healthcare personnel that work within the system, mostly in clinical positions. In fairness, the great majority of providers, including doctors, nurses, advanced practice nurses, physician assistants, the many nursing roles and others – they are all advocates of a sort. They are direct medical advocates.

But they have some real constraints imposed on them through that same system – services they can't or won't provide because of the money implications (see Chapter Four: The Allegiance Factor.)

The advocate role is intended to balance those constraints. When problems crop up, advocates are there to fix them. And if problems are likely to crop up, advocates can be there to prevent them.

Important! Notice that an advocacy role is not a medical role.

For example, if you want to drive to Denver, you need someone who knows the route, someone who can and will pack your suitcase, someone else to drive the car, and someone who is willing, and can afford to do so, to pay for the gas. Those are all very different aspects of a road trip to Denver. They may or may not be performed by the same person.

Advocates fulfill the role of knowing the route from beginning to end, and safely navigating patients along it. They won't necessarily pack the suitcase or fill the gas tank. Doctors may prescribe the route, but they certainly don't drive the patient there; nor do any other providers fulfill that role.

Needed: More Advocates to Fill the Gaps

In recent years, there has been more recognition of the problems the healthcare system creates for patients. The media regularly reports on obstacles and insults delivered to patients. We talk to friends and family and learn about their difficult experiences. Or we

1 *You Bet Your Life! The 10 Mistakes Every Patient Makes (How to Fix Them to Get the Healthcare You Deserve)* <http://bit.ly/YouBet>

suffer at the hands of the system ourselves, and experience firsthand how extremely difficult it is (if not impossible) for patients to get what they need.

Of course, healthcare is big business. The goals of all providers, facilities and suppliers, are to either suck as much money as possible out of the patients who need their products and services, or to save as much money as it can in the delivery of those products and services. Even outside the United States, in countries where the government pays for all care, the goals remain the same. They may not be trying to profit in the same ways, but their budgets must always be stretched.

Those profitability and efficiency goals are at the very core of most problems imposed on patients.² They want either the most expensive route to Denver (so they can make more money) or the cheapest route to Denver (so they can save more money) – but no one is guiding the patient, to choose the right route for her, on her terms. That’s where advocates come in.

Lately we have seen the introduction of new technology solutions that are intended to keep patients safer, and sometimes to make the actual delivery of care more efficient. Some are effective, such as systems set up to prevent the prescribing of the wrong drug, or a wrong or dangerous dose of a drug. Another example of a positive technology: Patients living in more rural areas may be “seen” through telemedicine by specialists in larger cities.

Unfortunately, though, there is no technology solution for some of the major problems patients experience.

- A hospital patient, confined to a bed after surgery, is hours past when he was supposed to receive his next pain meds, and can’t get anyone to answer him even after pushing his call button over and over again.
- A lifesaving but expensive drug, approved by the FDA, is prescribed by the doctor, but not covered by a patient’s health insurance.
- A patient about to begin chemo hasn’t been able to find a doctor for a second opinion.
- Another patient, upon discharge from the hospital, has no one to help her into her home, bring in groceries, or make sure her prescriptions have been filled.
- Still another one has just received a medical bill for thousands of dollars – after only two treatments – and can’t understand how that bill can possibly be right.

Of course, I could fill this entire book with similar examples.

Who is supposed to help these folks get what they want and need from the system?

2 Those goals notwithstanding, yes, I recognize that no provider, facility or supplier specifically intends to harm patients – their customers. But too many prove by the way they behave and operate that they are willing to sacrifice some patients to achieve what they consider to be their more important goals: profitability, efficiency and bigger paychecks.

These problems require PEOPLE SOLUTIONS.

Enter Health and patient advocates, navigators, and care managers.

Choosing Advocacy as a Career

There are thousands of patients who navigate the system every day, and not nearly enough advocates available to prevent problems or fix them afterward.

Are you considering becoming one of those people who can be there to help these patients? I hope so. I expect that's why you have purchased this book.

I want to support your choice, but – this is important – you need a realistic view of what the career entails and whether or not you can be successful (by your own definition of successful.)

To help you decide if patient advocacy is the right career for you, I have outlined the basics in this book. It is not an exhaustive discussion of the profession, but it is certainly enough to help you decide whether it's a direction you'd like to take and then, if it is, how to make the best choices for your career path.

In this book you'll find:

- The basic tenets of health and patient advocacy.
- The best personality and ethical traits needed to be a good advocate.
- The different types of advocates, including job availability, pros, cons and resources.

Bottom line: the information you will need to determine if patient advocacy is the best career choice for you.

One more point to make here – a confession, of sorts....

As you will be able to tell from reading this book – I love patient advocates! Their devotion and passion for their work, helping people who so desperately need that help, is often so strong that it's physically visible – seen in the time and effort they put into their work. They are so dedicated to helping the patients who need help that many would prefer to do it for free – their compensation is about the satisfaction of a job well done.

I make this statement regardless of the patient advocate's situation: employed, volunteer, self-employed, other-employed – whatever.

But I do have a bias, and that will be apparent here, too. While I will give you the straight dope on the profession of advocacy, as objectively as possible, you will see me lean at times toward the independent, private advocate – the advocate who works for his or her

patient-client directly with no hospital or insurer or anyone else getting in the way of that relationship.

My bias comes from ten years of observation and understanding, and the eventual founding, in 2009, of the Alliance of Professional Health Advocates – an organization that supports private advocacy. See? I just can't help it.

But none of my bias is a reflection on how much I appreciate every advocate – all advocates who work on behalf of patients no matter in what capacity, no matter how they are compensated, if they are compensated at all. They all play an important role, and I have love in my heart for them all.

So let's get started. There's no time to dally. Patients need you!

Chapter Two

A Patient Advocacy Career at a Glance

What Patient Advocates Do

As long as patients have had problems with their health and needed help with their care, there have been patient or health advocates. From family members or loved ones, to large non-profit organizations, to advocates in hospitals or insurance companies to individual, private advocates – or anyone in between – when someone is sick and needs help, there has often been someone who will step up to help. That’s what a patient advocate does.

But in the past decade or two, health care and its payment systems have evolved, or devolved, into a system that is now unrecognizable by most patients or their homegrown advocates. Marcus Welby no longer exists, and trying to get the right care by the old rules just doesn’t work.

Here are some comparisons that might sound familiar:

You get arrested for something you didn’t do and are thrown into jail. You don’t know anything about the penal system, and have no idea what you need to do get out. You don’t even know the right questions to ask.	So what do you do?	You call a lawyer.
You receive notice that the IRS (or CRA) is auditing your tax return. As far as you know you only deducted what was allowed, but you’re not the expert.	So what do you do?	You call an accountant.
You decide it’s time to buy your first house. You look around and find one you just love! But, now what? How do you get a mortgage? How can you be sure there are no termites? Who is in charge of paying your taxes? What if the plumbing leaks or the heater blows up?	So what do you do?	You call a real estate agent.

In these all-important aspects of life, there is a professional who can step in to fill the needs of someone who feels as if his physical, mental or financial health is in jeopardy. And now, for healthcare challenges, that includes patient advocates.

<p>You are diagnosed with something dire, or your medical bills are far too high and may have errors, or you're afraid to spend the night in the hospital because you've heard about medical errors, or you need advice because you've got a chronic disease to manage, or your pain is out of control and doctors won't help you any more, or, or, or, etc.</p>	<p>So what do you do? #</p> <p>You call a patient advocate.</p>
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Patient Advocates – Titles and Descriptions

Patient advocates go by a variety of names. In some cases what they choose to call themselves depends on a job title, or the work they do. In other cases they choose what they will be called based on personal preference. Here are some of the monikers you might see, all of whom are advocates:

- Patient advocate (or health advocate)
- Patient navigator (or health navigator)
- Consumer health advocate
- Care and case manager or coordinator
- Care and case partner
- Care and case advocate
- Ombudsman
- Eldercare professional
- Family mediator
- Health coach
- Health insurance advisors or disability advisor
- Medical bill reviewer or claims reviewer
- And many more.

For purposes of this book, we will use the title “patient advocate” to represent all these titles and others that may be found in use by the general public.

Services Provided by Patient Advocates

In general, there are categories of services provided by advocates. They range from medical/navigation type advocacy such as that performed by cancer nurse navigators, to hospital bedside advocacy, to handling details like tracking down the right hospital personnel to help an inpatient, to ombudsman-type services that include holding insurance company toes to the claims fire, or accepting complaints about providers.

For an employed advocate, the services are about customer service, assisting the organization's customers, resolving complaints, and defending and enhancing the

reputation of the organization she works for. Learn more about those services in Chapter Five: Getting a Job as a Patient Advocate (Section: What Job Responsibilities Do Employed Patient Advocates Have?)

The list of advocacy services provided by private advocates is long. Certainly not all advocates provide all these services, but this will give you an idea of some of the tasks you might perform if you choose to be an advocate.²

- Background Research: Diagnosis, Treatment Options and more
- Dental Advocacy (from dental decisions to billing problems)
- Geriatric / Eldercare or Home Health Services
- Guardianship / Conservatorship / Fiduciary Care
- Hospital Bedside, or Travel / Accompaniment to Appointments
- Integrative, Holistic, Complementary and Alternative Therapies
- Legal Assistance including SSDI (Medical / Healthcare Related)
- Mediation (Helping families manage health-related disagreements)
- Medical / Navigational Assistance (Helping you work with your medical providers.)
- Medical Bill Reviewing / Health Insurance / Payer Assistance
- Mental Health and Substance Abuse Assistance
- Pain Management
- Pregnancy, Birth and Pediatric Assistance
- Prevention (Prescription Drug Review, Health/Wellness Coaching, Weight Loss, Immunity, Others)
- Shared Decision Making
- Health Insurance Consulting

Patient Advocacy Certification: An Important Step Forward

One question asked frequently by those considering advocacy as a career regards certification. They want to know how to become certified, or whether they need a license to practice advocacy, or whether a specific course they have found online offers certification, or whether that certification is 'real' – and more.

Why is that important to them? Because they recognize that being certified means they will be held to a standard of professionalism. That standard is important for not just the status of advocacy, but it also helps patients understand there is a standard of practice they should be able to expect when tapping into the services of an advocate.

3 <https://advoconnection.com/advocacy-services/>

In 2018 certification became available for advocates.

Developed by the Patient Advocate Certification Board, the new credential demands deep knowledge of the profession's ethical principles, its standards, best practices, the law, health care system basics, and more. Those who pass the PACB's rigorous exam earn their BCPA designation, Board Certified Patient Advocate.

You can stay up-to-date on advocacy certification, and register to take the next exam, at the PACB's website: www.PACBoard.org

Licensure is something else all together. Licenses are generally issued by governments (state or local) and only give permission for someone to practice their craft, and are often unrelated to whether that person has the skills required.

As of 2018, no state or local governments license advocates.

The Patient Advocacy General Employment Landscape

If you decided to be a lawyer, or a real estate agent, or an accountant, or any other personal service provider, you would have a small handful of general choices of employment in that profession. The same is true for this very personal profession of patient advocacy.

Employers

If you are looking for a regular paycheck, or generally prefer not to be self-employed, then finding an employer who will hire you as an advocate is your goal.

Find more information about patient advocate employment in Chapter Five: Getting a Job as a Patient Advocate.

Self-Employment:

Being self-employed, developing one's own advocacy practice, is a great approach to combining advocacy work with the independence of choosing which patients you might want to work with.

Learn more about starting and growing a private advocacy practice in Chapter Six: Patient Advocates in Private Practice.

Chapter Three

Do You Have the Personality and Skills to Be a Good Patient Advocate?

I promise, this overview isn't going to sound like the mean girls in high school assessing whether or not you are cool. By my measure, the fact that you are considering entering into such a worthwhile helping profession by itself makes you one of the cool kids.

But the nature of patient advocacy most definitely requires certain skills and traits, some in more abundance than others. As we go through them⁴, you'll see why this is important.

The lists in this chapter are very general, applying to all advocates, regardless of employment prospects. Those which are specific to your choice of employment are included in the appropriate chapters later in this book.

Your Advocacy Personality

» **You must be a people person.**

Patient advocacy isn't really about medicine or science or insurance or billing. It's about people who have problems with those aspects of their healthcare. Genuinely liking people – even people who may be upset, frustrated, cranky, angry, sick or hurt, or any other

⁴ These traits have been borrowed and edited from *The Health Advocate's Start and Grow Your Own Practice Handbook*, Chapters One and Two.

emotion – and being able to work with them under those circumstances, is paramount. If you don't like to work with people, you won't like being a patient advocate.

Do you get along with people even when they are difficult or at their worst?

» **You must be a good listener.**

One of the most important people skills you'll need is the ability to listen. When a patient or caregiver comes to you for help, they are not coming to hear YOUR stories, or YOUR experiences. They are hiring you to listen to them. Active listening, which sometimes includes the ability to "hear between the lines" is one of the most important skills you need to bring to your advocacy work.

Do you listen to others well?

» **You must be empathetic.**

Studies show that most patients feel as if they don't get nearly the amount of compassion or empathy they wish to get (and used to get) from their providers. It's a big reason private advocacy is growing so quickly – it's filling that empathy void.

No matter how you deliver your advocacy services, whether through an employer, or through your own private practice, or even as volunteer, empathy and compassion need to rule every step you take, every conversation you have, the decisions and recommendations you make, and most importantly, the way you deliver those messages. Empathy rules.

Would others identify you as an empathetic and compassionate person?

» **You must be ethical and trustworthy.**

People will come to you with their most intimate problems – problems that regard their health and their money. They must be instantly able to trust that you can help them.

Further, you must know what you stand for, being sure you do your work guided clearly by what is right and what is wrong. Too many other healthcare professions have yielded their ethics to money, or to marching to the tune of the money-holders requirements. (Learn more about this in Chapter Four: Standards, Ethics and the Allegiance Factor.)

Do you have an honest face, voice and demeanor? Do other people trust you quickly?

» **You must have patience.**

When patients and caregivers are hurting, or upset, or frustrated, or angry – or even when they are happy and grateful – they are still people who will share all those emotions verbally and physically.

» **You must be a creative problem solver and decision-maker.**

There are two kinds of people in any workplace: those who wait around for someone to tell them what to do, and those who just get the job done, taking initiative, making decisions, trying new approaches, pulling out the stops to solve every sort of problem, and trusting their intuition that they are making good choices.

As a patient or health advocate, your creative problem solving and decision making chops will be tested on a constant basis.

Are you confident and creative enough to face challenges, develop creative solutions and make good decisions?

» **You must be a confident communicator.**

When people are sick or frightened or unsure, they want to know that someone who isn't those things is looking out for them - that the caregiving someone, the advocate, has confidence in the information and recommendations being made. Their advocate's confidence gives them a bit more confidence of their own. That's a real gift in a healthcare world of uncertainty.

Now, I don't mean false confidence. I mean accurate, confidence-inducing communication.

Here are some examples of the differences:

Challenge	Over-confident	Under-confident	Just right
Mrs. Jones is upset because her hospital bill is far higher than she expected.	Sure Mrs. Jones - I can easily cut your hospital bill in half!	Gee I don't know Mrs. Jones. I hate asking those folks in the billing department for help. They give me the evil eye.	Sure Mrs. Jones. I'll work with the billing department to be sure these charges are accurate. If they aren't, we'll work to correct them.
Mr. Brown is upset because his wife has been diagnosed with breast cancer.	Oh Mr. Brown, I'm sure she'll survive this just fine. We'll find a second opinion doctor who will reverse this diagnosis and then you won't have to worry about it any more.	Gee Mr. Brown, I am so sorry to hear about your wife's diagnosis. I'm not sure if there is anything I can do to help you or her. Chemo and radiation are just horrible experiences.	Well Mr. Brown. I can imagine you and your wife are probably quite anxious over all this. Let's confirm her diagnosis with a second opinion doctor, then once it's confirmed, talk about which treatment option is her preference once she has all the facts in front of her.

I hope the ideas of confidence and expectation management are clear to you.

Are you a good, confident communicator?

» **You must have a thick skin.**

No doubt you've heard the truism that you can't please everyone all the time, and there is no place that is truer than in advocacy. Further, for all the reasons cited in this chapter—when people are sick, and cranky, and their very life and financial stability are being threatened, they are bound to be times that even the simplest of problems seem overwhelming. And when your patient “ain't happy – ain't nobody happy.”

You need the ability to understand that in most cases, their dissatisfaction isn't personal – it's how they are coping. Because you represent all the steps and emotions that they must cope with, you will be the target of their discontent more often than you can imagine.

It may take a while to develop those emotional calluses, and even better, develop that balance between being calloused and being empathetic. But a true professional knows how to balance those two successfully for both her own benefit and her patient's.

How thick is your skin?

» **You must understand which side of your bread your butter is on – and proceed accordingly.**

I know – this one seems a bit cryptic. It will remain so until Chapter Four: Standards, Ethics and the Allegiance Factor. It's so important, it requires its own chapter.

Your Advocacy Skills and Knowledge

In some ways, skills and knowledge are easier to quantify. They are most certainly easier to develop even if they haven't been a part of who you are to this point in your life.

Advocacy skills are, basically, customer service skills, health and health system knowledge, and people and communication skills.

- Knowledge of how the healthcare system works
- Knowledge of how patients and caregivers think, and the ability to put oneself in their shoes (empathy and point of view)
- Knowledge of doctors' offices, hospitals, other facilities and healthcare organizations function

- Knowledge of how insurance works, both for and against patients
- Health system navigation knowledge
- Knowledge of HIPAA basics
- Shared decision making skills
- Billing, insurance claims and reimbursement systems knowledge
- Creative problem solving
- Research skills and good resources- for learning about diagnoses or treatment options, finding good professionals to work with and more
- Professionalism
- A solid commitment to, and understanding of customer service tenets
- Good telephone manners
- Well-spoken
- Strong handshake (an air of confidence)
- Facilitation / negotiation / bargaining/mediation skills for working with patients and their loved ones, or encouraging medical personal to see things your way

Notice this list of skills is not medical. I am often asked whether it is necessary to have a clinical background and experience. Doctors, nurses, nurse practitioners, physician assistants, and other clinical roles can provide good medical knowledge for advocacy, but since you won't be doing medical work, those skills won't be called upon in the ways you might expect.

In other words (loud and clear!) No! You do not have to be a physician or nurse to be an effective and successful patient advocate!⁵

In fact, as of 2018, if you listed the top 25 successful independent advocates in the United States, more than half had no clinical background before they chose their advocacy career.

In many cases, the skills or knowledge you need must have been developed in other jobs or experiences you've had before now. Many are skills you can learn by taking classes or working with a mentor.⁶

5 There may be times medical knowledge will be useful to a patient you will help. If you don't have the medical background needed, you will have developed a resource bank of people who do have that medical knowledge and can be called upon to help your patient.

6 www.HealthAdvocatePrograms.com

If you identify an employer you'd like to work with (find more about this in Chapter Five: Getting a Job as a Patient Advocate) there may be additional skills and experience they seek.

For Independent Advocates – Business Skills

The skills listed to this point have been about advocacy itself. They are needed no matter what flavor of advocacy you might choose for your career.

One of the fastest growing delivery systems for patient advocacy is independent, professional, private advocacy – advocates who are self-employed, work with patients and their caregivers directly and are paid by them directly.

In order to succeed as an independent advocate, your business skills must be developed and honed just as your advocacy skills are. You will most likely be self-employed, and will need to be able to start and grow a private practice.

Find that additional list of business skills in Chapter Six: Patient Advocates in Private Practice where they are covered in depth.

Filling the Gaps

If you find you have most of the knowledge and skills from this list, you'll be ready to continue with your decision-making about advocacy as a career.

If you haven't had a chance to learn the skills you'll need, you'll find more than three dozen universities, colleges and organizations that teach advocacy courses. Find them listed at www.HealthAdvocatePrograms.com.

You'll also find linked from there an extended article on filling your education gaps.

There are links to additional information throughout this book. To make them easier to access, I've put them all together, online, so you can just click on them rather than typing them out.

Find access information on page 46 of this book.

**We hope you enjoyed this sample of
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