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Is Independent Advocacy Right for Me?

Transcript of Podcast 1: What does a patient advocate do?

You've identified yourself as someone who thinks that JUST MAYBE advocacy IS right for you! And because INDEPENDENT patient advocacy is a career for those with passion and compassion, meaning you'll likely invest your blood, sweat, and tears.... we want YOU to be sure that it's a good fit before you begin to invest your time, money, and efforts into carving your niche in our advocacy world...

By the time this podcast series is complete, we hope you'll say "yes yes yes! Independent advocacy DOES sound right for me!!

So let's get started! We'll begin by answering the first question asked by many advocate wannabes:

What does a health or patient advocate do?

If I look up the word "advocate" in the dictionary, the definition will include references to the legal system and sometimes it will even reference the healthcare system... and often it will make it sound as if advocates are somehow at odds with the people who get dragged through those systems, as if – wow – things aren't being done right here – this person needs an "advocate" to help. It almost sounds contentious ...

And – you know – none of those pieces of the definition are wrong.... But there are definitely important nuances to consider...



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Specifically, when it comes to the healthcare system, advocates play many roles. You may know, or may even have met, or maybe you have BEEN a hospital patient advocate. Sometimes the customer service people who work for insurance companies are called patient advocates. Pharmaceutical companies sometimes call their marketing and customer service people advocates... And then there are other names for all those folks like “patient representatives” or “ombudsmen” – you’ll also hear “navigators” or “Liaisons” – or care or case managers... they are all titles for the same thing – and that is:

Someone who helps patients find better outcomes from the system.

Now that all sounds well and good, but what do we mean by “find better outcomes?”

Well there are basically two patient outcomes we want to improve: care outcomes – anything having to do with the actual care received, whether that’s a doctor appointment or lab tests or surgery or the outcome from any sort of treatment. You have probably also seen or heard us use the term “care manager” – because we use that interchangeably with advocates who work on the care side.

The other side is cost outcomes – meaning – making sure that patients finances are being dealt with fairly, whether that is the cost of insurance premiums, or getting a claim approved or processed, or recognizing that so many hospital bills are just wrong – and then reconfiguring them and negotiating them.

You can see that those two SIDes of advocacy are both HUGE! And anything we can do as advocates or care managers to improve that journey for a patient will fall on one side or the other.

There’s also a very important point to call out here – that is – patient advocacy as a profession is NOT medical. Let me repeat that – it is NOT medical. So all the



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assistance provided to patients is about all the aspects to the journey that support medical, but not medical services themselves.

So – how does one get involved in the profession of patient or health advocacy or care management?

There are advocates who work for employers – those mentioned previously – who work for hospitals, pharmaceutical companies, health insurance companies and other businesses that profit from healthcare services.

And then there are INDEPENDENT advocates also called private advocates – like the difference between a lawyer who works in her own firm, or instead, for a large legal corporation.

The Alliance of Professional Health Advocates – APHA - focuses on helping those who wish to be independent advocates -independent of the constraints put on them by those larger profit-making corporations which too often value those profits over the patients they are supposed to be helping.

So what kinds of things might you help a patient with when you are independent of those large corporations?

Here are some examples:

A patient isn't sure he has been diagnosed properly... but he's afraid to ask his doctor more questions. So he hires a private advocate because – who on the inside of the system will question the doctor?

A patient has been told what sort of treatment she will need, but she has actually read about some other sort of treatment and wants to learn more about it – but isn't sure how to do that. You might be able to help her figure that out.

A patient has just been discharged from the hospital and was given a long list of instructions, but is just too exhausted, or still in too much pain to be able to



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process them. Who but someone like you, can help that patient get what he needs?

A patient was approved for her surgery, followed all the recommendations, and the entire process seemed to go great – until she gets home and a few weeks later gets a bill from the anesthesiologist – because the one who had been approved didn't show up that day, and the one who helped with her surgery wasn't part of her plan. Who is going to get that payment to the anesthesiologist approved for payment by insurance? You might be that person!

An adult daughter realizes her mother can no longer live by herself in her big house, and needs help determining where to move Mom – assisted living? Or a nursing home? And oh by the way – brother, who lives clear across the country – refuses to cooperate or help out. If you have experience with mediation or negotiations, that liaison can be you.

These examples – and hundreds more – are representative of what a patient advocate does. Now – this is important! – not every advocate does all these things! In fact, the smartest and best advocates figure out which parts they are good at, and which parts they LIKE to do – and those are the services they actually offer themselves. They also learn how to find other advocates to partner with who do the parts they don't do themselves – and that is how they best serve their clients.

Aha – did you hear that word – “clients”?? Once you are working in your own independent business, that's who they are – those patients because your clients... which, of course, takes us back to that word advocate. Just like in the legal system, we call those people we work with – through our own, independent and private practices – clients.



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Finally, a little story for you that provides a great picture of who we are as independent advocates:

About 10 years ago, I was trying to determine whether or not the clients who hired and paid for a private patient advocate could take a deduction on their taxes for that. You know – the IRS maintains a list of allowable deductions and items that can be charged to a Flexible or Health Spending account... but what we didn't know was whether patient advocates could be a deduction, too. Since that could mean huge deductions for clients, and might make a difference in whether they could afford to hire an advocate, it was an important question that needed an answer.

After about two hours on the phone, and a thorough discussion of how such a deduction would ever get approved, the IRS rep and I started going through the existing list of deductions.

"You can deduct for nursing services," he told me.

"But we aren't nurses, I told him – in fact, it is against our code of ethics and we can't get liability insurance to perform medical services.

"Home health – home health is deductible" he replied, working his way down the list."

"But we aren't home health, I explained. Again, we aren't doing anything medical like tracking blood pressure or assisting with ADLs (activities of daily living) – so that's not really a good parallel.

As he was working his way down the list, I was, too... and came upon (get this!) guide dogs and therapy animals.

That's it! I told him... that's where we are – we are like guide dogs for patients who have been blinded by the healthcare system. We are the ones getting them



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from point A to point B safely, securely, and looking out for THEM and ONLY THEM!

And so – I submit to you that patient advocates – also called health advocates, navigators, care managers and, as you’ve heard, a long variety of names... we are GUIDES – with vast knowledge of a system that is capable of delivering good services to its patients, but too often misses the mark – bringing that knowledge to our work with our clients – the patients who deserve so much better than the system usually delivers.

And THAT is what a patient advocate does.

Find additional resources on the page where you found the podcast and transcript:

<https://myapha.org/advocacy-right-for-me-podcast-1/>