

***PEN's Insurance Pulse 2017***

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## **Murky Waters: Dealing with Uncertainty in Healthcare**

Michael Bradley

### **Uncharted Waters**

Uncertainty is a normal daily event for most of us. We wake up every morning not knowing what mood we'll be in, how bad the traffic will be, what the weather will be like, what work will have in store for us. Now, every day we also wonder what changes in healthcare will be in the news. We can be certain that the changing healthcare market will have some impact on our lives. Staying current with all the changes can be a full-time job, especially for people affected by a bleeding disorder.

It's vitally important that you stay on top of key healthcare issues, even if you find them confusing at times. But remember, you don't need to be an expert. You just need to stay informed, create a network of people and experts to talk with, and believe that you have a voice and can make a difference in your own healthcare.

To make sure there's no uncertainty about *this* article, it will focus on the changing face of healthcare in the US, and on the importance of understanding your current healthcare situation, creating a plan of action, and then taking action to become a more informed healthcare consumer. Let's put this into a real-life situation, and see how staying informed can have a dramatic impact on your life by creating more certainty.

### **Adjusting Your Sails: Craig's Story**

In the late fall of 2009, Craig, who has hemophilia, was looking forward to attending graduate school. What he was *not* looking forward to was the financial transition that this move would involve—not just paying for college, but finding affordable healthcare.

Craig was nearing his lifetime cap on his mother's insurance. When he'd hit that cap—the maximum amount his insurance would cover—he would no longer be covered. Craig remembers sitting with his mother at the kitchen table, insurance papers in one hand and a large calendar in the other, planning out exactly how much cap space he had left, how much medicine it would cover, and how long that medicine would last.

Craig knew he would need a new insurance plan that summer; insurance laws (rather than graduate program selection) would be one of the primary motivators in choosing a graduate school. He eventually chose a school in New York because he was guaranteed not to be disqualified for insurance due to his preexisting condition. Even then, Craig faced the painful truth that his student insurance would not cover his factor. He needed another plan. So he ended up buying additional private insurance that was part of a high-risk pool—to the tune of

over \$1,200 a month. Craig's monthly income was just over \$1,300 a month. Luckily, he was able to get some financial assistance to help pay his monthly premiums.

In 2010, the Affordable Care Act (ACA) was passed. Craig was able to adjust his plan again, and he enrolled in one of the Health Insurance Marketplace plans. He was able to work with his insurance company to cut his premiums almost in half, to under \$700, with no meaningful change in coverage—an incredible boost for a struggling graduate student. Then, with the expanded Medicaid eligibility in 2014 in his state, Craig adjusted his plan once more, and was able to qualify for Medicaid. For the first time, his family was freed from the financial healthcare burden that had become a normal part of his life.

### **Becoming a Champion**

Craig took advantage of these healthcare changes because he stayed informed. He was an advocate. Advocacy needs to be a basic part of life, especially when you're in the bleeding disorder community. But there are many different definitions and types of advocacy: grassroots, legislative, healthcare, insurance, self, family, professional, and legal advocacy. To simplify, instead of using the word "advocacy," I'll use the term *healthcare champion*. So, let's talk about what becoming your own healthcare champion means.

One definition of champion is "a person who fights or argues for a cause or on behalf of someone else." First, it's essential to become a champion for yourself, actively managing your own health. Second, you need to become a champion for your family, your friends, and your community. But you don't have to do it alone! There's nothing better than finding someone to walk beside you on your journey down the road of healthcare understanding.

We have all seen what's happening in the retail industry. Some of our favorite stores are closing, while others are cutting staff and making the shopping experience feel more like pumping gas at a self-serve station. It's so easy to shop online in the comfort of our homes, to cash checks by taking a cell-phone picture, and to talk to a gadget that will order stuff for us! We're becoming a self-serve society, and healthcare is rapidly moving in the same direction.

Self-directed, high deductible, health savings account (HSA), managed care, Health Insurance Marketplaces—these are all types of insurance plans that force us to make our own choices about healthcare. What should my deductible be? Is my doctor covered? Can I go to my hemophilia treatment center (HTC)? How do I choose the deductible that fits my current financial situation? How best to ask my doctor or nurse about alternative forms of treatment? These are just a few of the many questions we all need to answer.

I remember having a conversation with my mother a few years ago, when my dad was ill. I was concerned that he was getting different advice from each of his physicians, and I suggested that my mom discuss this with his healthcare team. She told me she couldn't challenge my dad's doctors—that they knew what was best. This got me thinking about how much healthcare has changed over the past several decades.

When my parents were young, many doctors made house calls and knew each patient personally. Flash forward two decades, to when I was young: now,

doctors were much busier, but there was still that personal touch. Move ahead some more: in today's world, we're lucky if we get more than 15 minutes of a doctor's time, if we meet with a doctor at all! This is why it's crucial to make the most of the time you have with your treatment professional, and to have a list of concerns and questions ready. Prioritize the questions you want to ask, and make sure you ask the most important ones first. Part of being a healthcare champion is being able to tell your story to your healthcare provider. Who knows you better than *you*?

In today's fast-paced, connected world, we can no longer assume that our clinical team has the time to really get to know each of us personally. Instead, it's up to us—the patients receiving the care—to educate ourselves and become our own healthcare champions. We can't all become experts on insurance, but we can make a plan to learn more about our own healthcare. If you live with a bleeding disorder, you're lucky to have a lot of information at your disposal—sometimes, it seems like too much—but knowing where to go, who to ask, and how to get educated can make life a lot easier.

### Let's Take a Quiz!

Before you educate yourself about insurance and healthcare, you need to know what you don't know! Let's test your knowledge on current healthcare events. One more challenge: Put down your phone and close your computer so you can do this the old-fashioned way!

1. What is the common name for the Affordable Care Act, or ACA?
2. Name four areas of the ACA that have benefited the bleeding disorder community.
3. What is a Health Insurance Marketplace?
4. What percentage of people with hemophilia are covered under Medicaid? What about people with von Willebrand disease (VWD)?
5. Are there programs for people with bleeding disorders that can provide assistance with insurance copayments and deductibles?
6. Do the Democrats and Republicans agree on healthcare reform? Did they agree on the ACA?

*Answers at end of article!*

### Making It Crystal Clear: Basic Insurance Terms

How did you do on the quiz? It's time to learn some basic insurance facts, so you can become your own champion. First, what were some of the key insurance issues for the bleeding disorder community before the ACA?

**Lifetime Caps:** In many cases, patients would exhaust their health insurance benefits because they had reached the maximum amount, or "cap," that their insurance company would pay.

**Limited Medicaid Availability:** Originally, Medicaid was created for children and for women with families. In most states, it was very difficult for a male adult with hemophilia to enroll.

**Preexisting Conditions:** When patients changed insurance companies, many private insurers would not cover their health conditions that had existed for a defined amount of time. All bleeding disorders would fall into this category.

**Coverage for Young Adults:** Before the ACA, many young adults were dropped from their parents' policies after they reached age 18, or possibly 23 if they were enrolled in school.

**High-Risk Pools:** These were created specifically for patients with high-cost, chronic conditions. The pools were very expensive and often unavailable because of overenrollment.

We sometimes view healthcare as slow moving, but the ACA reforms that positively affected the list above happened relatively quickly, and have had a positive impact on the bleeding disorder community.

Why should you know all these insurance terms and concepts? Because it's essential to have a basic understanding of basic insurance language if you want to become a healthcare champion!

**Coinsurance:** The percentage of costs of medical services paid by the patient. Coinsurance usually is about 20% of the cost of medical services after any deductible is paid.

**Copayment:** A cost-sharing arrangement in which a covered person pays a specified charge for a specific service, such as a fixed dollar amount for each prescription received. Example: \$5.00 per generic prescription, \$10.00 per preferred brand-name prescription, and a higher charge such as \$25.00 for a non-formulary product.

**Deductible:** A fixed amount of healthcare dollars the insured is required to pay under a health insurance contract, before benefits become payable.

**Out-of-Pocket Limit:** The most you have to pay for covered insurance services in a plan year. After you spend this amount, your private health plan pays 100% of the cost of covered benefits.

**Prior Authorization:** An administrative tool used by health plans that requires prescribers to receive pre-approval for prescribing certain drugs to qualify those drugs for coverage under the terms of the pharmacy benefit plan.

### **Keeping Your Head above Water: Understanding Insurance Plans**

When you shop for a car, you do your research. Same goes for buying a new phone. Why not do the same thing when selecting insurance?

Sometimes it's tough to find answers to your insurance questions. But it's not impossible if you understand the terminology. Let's start with the basics. There are three major types of insurance:

**1. Private or Commercial Plan:** Insurance plan that is not part of a government insurance program (such as Medicaid or Medicare). Often, premiums are shared with an employer. Examples: companies such as United Healthcare and Anthem.

**Third-Party Payer:** Public or private organization that pays for (or "underwrites") coverage for healthcare expenses for another entity, usually an employer, such as Blue Cross Blue Shield, Medicare, Medicaid, or commercial insurers.

**Managed Care:** System of providing healthcare (for example, by an HMO or a PPO<sup>1</sup>) that is designed to control costs through managed programs in which the physician accepts payment ahead of time on the amount charged for medical care, and the patient is limited in the choice of a physician.

**Self-Funded/Self-Insured Healthcare Coverage:** Health services that are delivered by providers; but the member's employer, not the insurance plan, bears the risk for any expenses incurred.

**2. Medicaid:** Healthcare program that assists low-income families or individuals in paying for long-term medical and custodial care costs. Medicaid is a joint program, funded primarily by the federal government and run at the state level, where coverage may vary.

**3. Medicare:** Federal health insurance program for people 65 or older, certain younger people with disabilities, and people with end-stage renal disease. Medicare Fee-for-Service (FFS) consists of two main parts: A and B. There are two additional parts to Medicare: C and D.

**Part A (Hospital Insurance):** Covers most medically necessary hospital, skilled nursing facility, home health, and hospice care.

**Part B:** Provides benefits to cover the costs of physicians' professional services, whether those services are provided in a hospital, a physician's office, an extended care facility, a nursing home, or an insured's home.

**Part C (Medicare Advantage):** Plan administered by a group of private health insurance companies approved by Medicare health insurers. Similar to a managed care plan.

**Part D (Medicare Prescription Drug Benefit and Medicare Advantage Prescription Drug Plan):** Provides benefits to cover the costs of outpatient prescription drugs. Administered through private health plans.

### **Go Ahead, Dip Your Toe in the Water!**

It's important to take time to understand the basics of insurance, whether public or private. Often, you'll have a summary of insurance coverage that will give you a high-level understanding of what your plan does and does not cover. Take the time to read through it. Talk with your friends or family about their understanding of insurance—you never know where an expert is hiding! Friends and family may also give you pointers on what has been helpful for them.

And don't underestimate the value of the social worker at your HTC or clinician's office; these professionals deal with insurance issues constantly, and they may have great suggestions for you. Same goes for the reimbursement specialists at your specialty pharmacy or HTC. They spend a lot of time dealing with insurance companies, submitting insurance claim forms, and coordinating denials. They may have more expertise than you think.

### **Setting the High-Water Mark**

Are you becoming a healthcare champion? Ask yourself these questions:

- What are you currently doing to make sure you have the best health insurance coverage for you and your family?
- Are you confident that you're up to speed on your current insurance coverage benefits?
- How closely do you currently follow healthcare issues in the news?
- Do you know if you have commercial- or government-sponsored health insurance?
- Do you leave healthcare decisions to someone else?

### **Have you asked yourself why?**

- How has your insurance situation changed over the past several years?
- Do you ever discuss your insurance with your HTC or other healthcare professionals?

### **5W1H: Build Your Personalized Plan**

Having a personalized healthcare plan and knowing where to go for help and information will provide a measure of certainty in the coming years. When I face uncertainty, I always use the acronym 5W1H: who, what, where, when, why, and how?

Let's see how we can use 5W1H to begin creating a list of questions related to health insurance.

- Who at my employer or insurance company should I talk to if I have a problem?
- What information do I need to gather?
- When do I need to update or reenroll in my insurance?
- Where can I go to get the necessary healthcare information?
- Why is it so important to keep a list of the people I talk with at my insurance company?
- How much will my insurance cost me per year? How can I budget for this?

When you visit your healthcare professional, write a list of questions ahead of time. I usually jot down questions on a post-it note and stick it on my insurance card. This way, I'm certain that I won't forget! Find out what type of communication works best for you and your clinician: maybe emails are the best route; maybe an online portal; maybe the doctor wants to talk with you right away. Don't be afraid to bring someone with you to an appointment. Sometimes it's easier to have a friend or relative ask the tough questions or make sure you fully understand what's being discussed.

If you're unsure about the guidance your clinician has given you, don't leave the office until you're comfortable. Then, as soon as you leave, write down the key facts that were discussed. Even better, sit down with someone that night and talk about what was shared with you. There may be times where you think you heard one thing, but a few hours later you're not sure; this kind of information needs to be clarified. National Hemophilia Foundation (NHF) has a great toolkit<sup>2</sup> to help you create questions and develop your personalized healthcare plan—a plan that's focused on your healthcare needs and tailored specifically to you. Just as no two people are alike, the same goes for your healthcare plan. Think personalized!

### **Jump In, Start Swimming**

Remember, your personalized healthcare plan doesn't have to be extremely detailed or contain a bunch of fancy terms, but it does need to be specific for you and able to be adjusted if necessary. Make the commitment to making your plan personal.

Think of what Craig did. He created a plan, implemented it, and then adjusted it as his healthcare situation changed. In the end, he was freed from a financial burden and gained more certainty in his life.

Over the next week or two, make a promise to yourself to become a healthcare champion, and begin creating your own personalized plan. Often, the hardest part is dedicating the time to get started. It may be a good idea to share your plan with someone else and work together to set specific goals for yourself. This doesn't mean that you have to create a formal plan. What it does mean is that you're beginning to take control of your own healthcare journey, and that you're taking a lot of the uncertainty out of your life.

When creating your plan, think 5W1H: who, what, where, when, why, and how? You'll be surprised how easily you can progress when you start with these simple words. Read the resources available to you, and don't be afraid to seek help from others. They'll probably be happy that you did ask, because there's a good chance you may help them at the same time. That's what being a healthcare champion is all about.

### What's Next?

We may not have a crystal ball to tell us the future of healthcare, but we do know that coordination between healthcare providers and health plans will increase, and that patients will have a lot more say about their own healthcare. These changes will also bring the consolidation of hospitals, health plans, and physician practices. Health insurance companies will demand that they get the best value for their money, and that their patients' health improves. We also know that patient out-of-pocket expenses will probably increase as the government and employers try to manage the skyrocketing costs of services, procedures, and drugs.

Change is never easy. The uncertainty it brings can cause many of us to fear the future, but this doesn't have to be the case. Creating a personalized healthcare plan of action and dedicating yourself to being your own healthcare champion can ease the fear of the unknown, and can help you set a path for certainty in the years to come.

*Michael Bradley is vice president of business development for the Access Group. Before consulting, he spent 24 years at Baxter, Baxalta, and then Shire. He has been involved in the bleeding disorder community for over 30 years and is currently vice president of Hemophilia Council of California.*

### Answers to Quiz

1. Obamacare
2. a. No lifetime caps. b. Medicaid expansion in many states. c. Insurance cannot be denied if you have a preexisting condition. d. Adults up to age 26 can receive benefits through their parent's private insurance policy.
3. Organizations set up to facilitate the purchase of health insurance in each state in accordance with the ACA.
4. Hemophilia = 25%–30%; VWD = 20%–22%
5. Most factor manufacturers have financial insurance assistance programs to help consumers with private insurance (see page 13 for phone numbers). Other companies, such as Patient Services Incorporated (PSI), can also provide financial assistance for qualified applicants with both private and public (Medicare and Medicaid) insurance.
6. No and No. The primary goal of the ACA, which was backed by the Democrats, was to make sure that most Americans obtained health insurance. Republicans, on the other hand, want to make health insurance more accessible and more affordable so that people can buy policies. Though we can argue that neither of these will truly happen, this contrast does point to the fact that there are major differences between two parties.

1. HMO (Health Maintenance Organization): Type of health plan that usually limits coverage to only doctors who work under contract with the HMO. Enrollees normally pay a monthly set fee that is not directly tied to actual health insurance costs. PPO (Preferred Provider Organization): Type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. Enrollees pay less for care if they use the providers that belong to the plan's network.
2. [www.hemophilia.org/Advocacy-Healthcare-Coverage/Advocacy-Tools-Resources/Personal-Health-Insurance-Toolkit](http://www.hemophilia.org/Advocacy-Healthcare-Coverage/Advocacy-Tools-Resources/Personal-Health-Insurance-Toolkit)

### **Additional Financial Assistance**

1. Did you know that most factor manufacturers have financial assistance programs to help you pay your insurance copays, coinsurance, and deductibles? Both Hemophilia Federation of America and National Hemophilia Foundation have great overviews of these programs on their websites.
2. NHF: [www.hemophilia.org/Newsroom/Advocacy-Legislative-News/Find-Patient-Assistance-Programs-to-Help-Cover-Your-Insurance-Costs](http://www.hemophilia.org/Newsroom/Advocacy-Legislative-News/Find-Patient-Assistance-Programs-to-Help-Cover-Your-Insurance-Costs)
3. HFA: [www.hemophiliafed.org/resource-library/additional-resources/navigating-patient-assistance-programs/](http://www.hemophiliafed.org/resource-library/additional-resources/navigating-patient-assistance-programs/)
4. HFA Dateline Federation:  
[www.hemophiliafed.org/uploads/HFA\\_Dateline\\_Special-IssueG.pdf](http://www.hemophiliafed.org/uploads/HFA_Dateline_Special-IssueG.pdf)
5. Shire: 888-229-8379
6. Bayer HealthCare: 800-288-8374
7. Bioverativ: 855-692-5776 (Alprolix)
8. 855-693-5628 (Eloctate)
9. CSL Behring: 800-676-4266
10. Aptevo Therapeutics: 855-494-6489
11. Grifols: 844-693-2286
12. Novo Nordisk Inc.: 844-668-6732
13. Octapharma USA: 800-554-4440
14. Pfizer Inc.: 888-240-9040