



## Patient Advocates: Expanding the Landscape of Patient and Family Support

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# THE BERYL INSTITUTE

## About The Beryl Institute

The Beryl Institute is the global community of practice dedicated to improving the patient experience through collaboration and shared knowledge. We define the patient experience as *the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.*

## Introduction

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One of the most critical needs we hear people raise in healthcare today is to have someone stand with them and/or for them and as needed to guide them through what can be a chaotic, complex and sometimes confusing process. An advocate by definition is one who supports or promotes an interest; one who pleads the cause of another. An advocate by nature is active and selfless, is focused and purposeful, and that is what we find as we explore the topic of patient advocacy in this paper.

Over five years ago we were excited to support the legacy and continued history of the patient advocacy community by welcoming in the Society for Healthcare Consumer Advocates (SHCA) into The Beryl Institute community. Our commitment then as it remains now is to reinforce the vital role of the very action of advocacy for those we serve in healthcare and what that means to our capacity to deliver on the best in human experience. And while SHCA historically focused on those who delivered on the vital role of advocate from inside healthcare institutions as the complexity of our healthcare system became more evident, so too grew the need for those who could advocate independently of the healthcare system in which one found themselves or their loved one seeking care. Independent advocates have expanded the landscape of support and guidance to patients and families. Therefore, a conversation on what advocacy is today, why it is critical to healthcare and the very real impact it has, is important.

We have always seen the role of patient advocacy as vital to patient experience, but we must also acknowledge it in many ways provided the roots from which patient experience as a movement has grown. It fed the idea with purpose and grounded it back to a connection in history that has led us from the early ideas of patients' rights, through advocacy and service, to the conversations on human experience we have today. And with that, it is hard not to see the vital role advocacy not only played, but does and will continue to play in ensuring the best in experience for all in healthcare today.

That is what this paper hopefully helps us to do. While no one publication can answer every issue, our hope is that this work can spark a continued conversation by grounding people in knowledge

about the purpose and function of advocacy and patient advocates and how they can help both those who are seeking or in the midst of care, as well as those delivering it. On the pages that follow you will not just learn about the concept and how from both inside healthcare organizations and independently advocacy plays an important role but also you will hear from the very voices of advocacy that make this work so significant and profound.

In healthcare we do more than treat illness, for while that is central to what we do, we see a growing recognition that we must address the whole person in front of us. Patient advocates across all settings have always recognized this: that patients, their families and support networks have needs, questions and concerns. They need help when we make mistakes and guidance when they are confused; they need a hand to hold and someone to walk with on the journey. And yes, while advocates also have to tackle some of the hard realities of complaints, considerations and policy, what they truly represent is the best of humanity at the heart of healthcare. Our hope is by knowing what they do, how they do it and truly why, we can all be better in our commitments to ensuring the best in experience for all touched by healthcare.

**Jason A. Wolf, PhD, CPXP**  
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## Purpose and Scope

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Initiated by the volunteer leaders of The Beryl Institute's Patient Advocacy Community, this project surfaced in recognition of the need to better inform the healthcare community about the role patient advocates play in impacting experience. We hope to educate patients and family caregivers about the function and services of patient advocates so they will be better enabled to call on their services when needed. We also strive to better inform healthcare team members on the purpose, challenges and opportunities of the patient advocate role to facilitate a better understanding of how they might partner to improve experiences for patients and families.

While the Institute's Patient Advocacy Community is primarily comprised of advocates employed by a hospital or healthcare organization, the presence of independent patient advocates is on the rise and these individuals are becoming increasingly important contributors to the healthcare landscape.

Both organization-based and independent advocates play an important role in supporting patients and family members through their healthcare experiences, but the structure and services provided by each differ in many ways. We divided this paper into two sections to share the most accurate representation of the two roles by exploring the services provided, challenges and potential impact of each.

We conducted qualitative interviews with individuals in both types of patient advocate roles and share their reflections throughout these pages. To learn more about the backgrounds of these individuals and what led them to this work, see the Contributor section starting on page 18.

## Part 1: Organization-based Advocates

### Overview and Services Provided

As explored in The Beryl Institute's 2015 white paper, *Patient Advocate: A Critical Role in Patient Experience*, there are many titles for patient advocates employed directly by healthcare organizations. They are often referred to as patient representatives, patient liaisons, ombudsmen and of course patient advocates, in addition to other designations. While there is much diversity in professional title for this work, survey results in a recently published research paper, *Establishing Evidence-Based Benchmarks & Guidelines for the Field of Patient Advocacy: Survey Results*, indicate that over fifty percent of those surveyed cited the professional title 'Patient Advocate' is used in their hospital-based organization.

Regardless of professional nomenclature, the roles these individuals play within healthcare organizations are varied and their contributions numerous. The patient advocate usually fills one or more of five complementary roles in a healthcare organization:

- Patient advocate
- Information resource
- Institutional change agent
- Partner in collaboration between the community and the organization
- Grievance coordinator

Additionally, many are involved in mediation, ethics consultations, staff education, interpretive services, organizing patient/family advisory councils, arrangements for international patients (including coordination of housing and transportation), discharge planning, response to codes to provide emotional support, lost and found, services for patients with special needs in compliance with the Americans with Disabilities Act, organ donation, advance directives and hotel management for out-of-town patients and families.

Many of these types of responsibilities are added to the patient advocate role because of the focus of these staff on the broader support of patient and family needs. They are also delegated these responsibilities because many administrators believe

that patient satisfaction is the common denominator in each of these resources. Ideally, patient advocates who take on added responsibility also take on the authority necessary to carry them out either as leaders of or part of an organization's overall patient experience function.

Some of the foundational areas of focus for patient advocates are looking at prevention and helping patients to actively participate in their own healthcare decisions. Patient advocates maintain many opportunities to advance this process in ways such as:

- Explaining policies and procedures that patients question
- Mediating disputes among patients, families and staff
- Investigating complaints on behalf of patients, keeping them out of the center of conflict
- Introducing and discussing advance directives with patients and their families

### Managing Complaints and Grievances

Organization-based advocates are arguably best known for being the individuals tasked with handling complaints and grievances from patients and family members. Advocates work to respond to these situations in a manner that honors what is right for patients and is in accord with the healthcare facility's policies, state laws and federal regulations.

According to guidelines from the Centers for Medicare and Medicaid (CMS), if a verbal patient complaint cannot be resolved at the time of the complaint by staff present, is postponed for later resolution, is referred to other staff for later resolution, requires investigation, and/or requires further actions for resolution, then the complaint is considered a grievance. Written complaints and situations in which a patient or patient's representative telephones the hospital with a complaint are also considered grievances.

Developing processes and expectations for any patient feedback that comes in to their office is key to the patient advocate role. "I like to tell people that we don't just manage complaints and grievances.



We do also take compliments and suggestions," said Pamela Segura, Director of Regulatory Patient Affairs/Patient Relations and Service Excellence, Cook Children's Health Care System. "But we do want to handle complaints as real-time as possible. We talk to the family in person or over the phone and try to resolve their issues. If we can't resolve it at that moment, then we try to resolve it within 24 hours."

If a complaint becomes a grievance, more investigation is necessary, and patient advocates maintain written communication with the patients or family members throughout the process. Most organizations we interviewed attempt to resolve grievances within seven days when possible but noted up to 30 days may be needed when more extensive research is required. Segura explained, "We work in a triangle team with Risk Management and Legal and make sure that everybody is in the loop from a quality standpoint to review the case. We meet together to discuss the grievance and make sure we're responding with the most accurate information and with a satisfactory resolution for the families."

Patient advocates handle complaints and grievances in a systematic way using guidelines established by CMS. All grievances must be responded to in writing in a "timely manner" and must include the steps taken to rectify or resolve the grievance. Results from the research paper *Establishing Evidence-Based Benchmarks & Guidelines for the Field of Patient Advocacy: Survey Results* indicate there are inconsistencies in meeting CMS standards for response timeliness, demonstrating the challenges patient advocates have in tightening up processes and procedures at their facilities. According to the report, "Regardless of time to respond, nearly 100% of the patient advocates reported creating a formal written response to grievances. This is consistent with CMS standards and should be considered a best practice." At the end of the day, once the healthcare system reviews their complaints and grievances, the data should be used to create action plans to address any trends.

Brenda Radford, former Director, Guest Services, Duke University Hospital shared that Duke works hard to have at least 85% of all their grievances resolved within seven calendar days. According to Radford, the key is developing relationships with appropriate leaders throughout the organization, "Our advocates work directly with the leaders in the particular areas where the issue occurred. If it's with a physician, they work directly with the physician. If they need to, they'll bring the chief medical officer in on the issue or the leader of that particular service

line," Radford explains.

Patient advocates also play a key role in educating staff about the management of complaints to ensure all hospital and federal guidelines are followed. "We have worked with several departments on service recovery and talking to them about complaints and grievances," said Robert Riley, Manager of Patient Relations & Guest Services, Marianjoy Rehabilitation Hospital. "The departments can take a complaint and will bring it to us to help decide whether it's a grievance or not. That helps us maintain control over the grievances to make sure that they're handled in a timely manner."

Our contributors acknowledged that while receiving complaints and grievances is sometimes unavoidable, one of the most important parts of their role is learning from each situation and helping their organizations make improvements to address issues. "We have expectations on the leaders and myself to do an investigation to really drive that opportunity for improvement, what can we learn from this patient sharing their feedback, and to make sure that it influences change in our organization," said Elizabeth Mendoza, Manager of Patient & Guest Relations and Service Excellence at Advocate Sherman Hospital.

She shared an example of receiving multiple complaints about their discharge process which clearly signaled an opportunity for improvement. "We revised our discharge envelope, created standard work for our nursing staff on how to approach discharge and communicate effectively, and revamped our teach-back model," shared Mendoza. "We saw a significant decrease in the patient complaints post-discharge about discharge instructions. That was a huge win to really drive that change and create a process to effect a better patient experience."

## Structuring Patient Advocacy Departments

Just as the titles for organization-based patient advocates vary, so do the sizes and structures of the function within healthcare organizations. Most of our contributors cited having small teams (2-4 members) while others were one-person departments. The largest group had 21 individuals supporting an integrated healthcare system.

Reporting structures varied as well, most reporting into a patient experience or service excellence director with the larger teams reporting into a Chief Medical or Nursing Officer. "One of the benefits here is that the patient advocate role is seen as a leadership position," said Mendoza. "I think that's

crucial in being able to have the level of influence that you need to effect change with this role."

In research published in the Institute's 2017 white paper, *Structuring Patient Experience: Revealing Opportunities for the Future*, 73% of organization-based patient experience departments reported including patient advocacy as a functional area.

## Challenges Facing Organization-based Patient Advocates

The patient advocate role is evolving as patient advocates take on more responsibilities based on the needs of the patients and family members and the complexity of the healthcare environment. With these changes, there comes challenges for patient advocates.

### Supporting Patient and Family Members

With competing priorities and responsibilities, patient advocates often find it difficult to accept the limitations of their role. They want to support patient and family members but sometimes find there is not always enough time to spend with them or the opportunity to resolve all of their concerns. Ashley Doyle, RN, Patient Advocate Manager, The University of Vermont Health Network shared the challenge of not always being able to provide a complete answer to the family. She remarks, "There are things I wish I could change, but sometimes there are things we can't change. We are talking about people that these families love. We're talking about patients who are dealing with really unexpected diseases or situations, so sometimes it's just really hard when I can't fix it for them."

The organization-based advocates also expressed that advocates face a unique challenge in that it is imperative that the role maintain an objective perspective honoring both the views of patients and families and that of the organization they serve. This position allows the patient advocate to raise issues in support of the patient when there is concern with the actions of the organization. In contrast, the organization also looks to the mediation skills of the patient advocate when the patients' expectations are not realistic.

### Evolving Role of Patient Advocates

With the changing healthcare environment, advocates are experiencing an increased need to understand more than the aspects of clinical care and are being required to also navigate financial situations and insurance policies in order to better

help patients with billing questions and issues. As Segura shared, "Patients are feeling more stressed. When they come in to receive services, they question more about why something costs so much, and why something costs a lot to have it done in the hospital setting versus outpatient clinical settings."

Because of this, patient advocates are having more conversations across departments, trying to understand the charges for labs, pharmacy, the emergency department and others, so that they can explain to patients what can be expected from a cost perspective. This challenge does provide an opportunity for patient advocates to build relationships across departments and to grow their knowledge regarding processes and procedures. The relationship building is also beneficial, as patient advocates can face a negative perception from staff on what their role entails as discussed in the next challenge.

### Recognition of Role

Another common theme shared is regarding staff's perception of the role patient advocates play. One view of a patient advocate is as a patient representative who handles complaints about services and staff, so the reaction when an advocate is called in can be a negative one. Staff may think they will be punished because they did something wrong. Lynn Charbonneau, Manager, Patient Relations, Guest Services, Tampa General Hospital noted, "Part of our struggle is that at one point it was viewed that if you had a case in Patient Relations, it was punitive. Instead, staff need to view us as their partners."

This was echoed by other patient advocates we interviewed. The advocates view these situations as opportunities for staff education and building rapport and partnerships. Robert Riley shared that he's been working on getting a seat at the table. From that effort, he now presents at new hire orientations so new employees have a chance to connect with him. "I want them to come through the door knowing that I'm here to support them...because sometimes they see the patient advocate and think, 'Uh oh, here he comes again.'" Riley stresses to the new hires that he is part of the team.

Often viewed as just facilitators of complaints and grievances, patient advocates would rather be seen as researchers and counselors, doing the hard work of investigating to really understand an issue and offering helpful advice. Instead of just "fixing" the problem, patient advocates desire to partner and collaborate with hospital staff to significantly impact

the patient's experience. Mendoza noted, "It would be a misstep on our part to not partner intentionally with our clinical team members and with nursing our radiology or whoever it is, and work with those leaders to investigate and understand where those opportunities are and be seen in a consultative role."

Lynn Charbonneau reinforced this sentiment in her comment about partnering with nursing staff at her organization, "We are not just the firefighters. We are the people that can be out there to help...one by one."

### Involvement in Organizational Processes

Another common challenge acknowledged by the advocates is not being involved in the process from the beginning. Some patient advocates shared that they don't feel like they have a voice in the structuring and implementation of organizational processes. Oftentimes, patient advocates are brought in late to provide a resolution in a situation where if they had been involved sooner it may not have escalated. Riley shared "Sometimes I think as an advocate we go in there, and we listen, and we look through the lens of the patient all the time. I feel like sometimes if I could be involved a little earlier, we might be able to [better] control the situation."

Patient advocates may see the same issues happening again and again for different patients. This can present a challenge in maintaining engagement and a positive outlook for advocates when they are faced with negative encounters on a daily basis. As Mendoza shared, "It's hard to hear the same things over and over again from patients that you aren't doing well and feel like you're not making a difference, or it doesn't matter. We want to make a difference and identify where those opportunities are." Alignment of values between the advocate and the organization and having a platform to effect change, says Mendoza, are critical. "If I'm hearing the same thing over and over again and nobody else in my organization cares and nothing changes, I just can't do this job every day. If I'm the only one who's upset that this happened to someone, then I can't do this."



# Seeing the Impact of Patient Advocate Efforts

## - STORIES FROM THE FRONTLINES -

Being a former stroke patient, I spend a lot of time on the stroke unit trying to motivate my patients. I had this one particular patient who was [very] motivated, and at the end of the day I got a call that he wanted to see me. When I went over there with a tear in his eye he said, "*Robert, I took three steps today.*" That was huge to me. It was huge because I know what it feels like. Three steps to the average person is nothing, but that's a lot of work for a stroke patient. So it's that warm feeling that says, "You know what, I better go every time someone asks for me. When I feel like I can't do it, I better go ahead and take that step and just do it."

*Robert Riley*

Back in 2007, I had a patient at my previous hospital that I would frequently round on who danced with the Radio City Rockettes in 1947 in New York. She had retired to Arizona and was a socialite in the community. Eventually she was admitted to the hospital, and she would ask for me specially to help her with small concerns. My advocacy efforts grew with her. I loved all her stories about her previous life, working with the Rat Pack (Sammy Davis Jr., Dean Martin, Frank Sinatra), Radio City New York, and living in Los Angeles in the 1970's. She was in and out of the hospital for a year prior to her last visit. I had never met her family until she had her last visit, and she was eventually critically ill in the ICU, and non-verbal. When I met her family, all they could talk about with me is how much I had impacted their mother by visiting with her every time she was in the hospital. Since they lived out of state, they told me how much they appreciated my efforts. They even asked me to please stay with them when she was passing, and to hold her hand while she took her last breaths. I will never forget this moment.

*Pamela Segura*

About 10:00 one night I received a phone call from a mother of an eight-year-old girl and she was devastated. This was a patient I had known and worked with for years, and they lived in Statesville, North Carolina, which is about two and a half hours away from here. Her daughter had a congenital heart issue, a lot of different congenital issues, but this particular issue was related to her heart. She was going to be airlifted to Duke, and we don't put parents in the helicopter when they come.

This mother had never been away from her child, and she was devastated. She called me crying, "They won't let me ride in the helicopter." I said, "She will be fine in the helicopter. Don't worry, I will be there when she gets here, and I will stay with her until you get here." I went to the hospital and I waited until I saw the helicopter landing and I walked out and I was there at the helipad when she got there and I walked in with her and stayed with her in the emergency room until her mother was able to arrive.

It was helpful to the mom to know that, even though she was going to be in the helicopter for a few minutes with people that she didn't know, that somebody who knew her daughter well was going to be there to be with her when she got off the helicopter. I stay connected to this family to this day and, fortunately, this child, who we never thought would live this long, is doing amazingly well.

And those types of things make a huge difference, and it's those kinds of stories that bring joy because you are able to make a difference in someone's life, even if it's a very difficult time. That's what I believe I was put on this earth to do.

*Brenda Radford*

We had a patient who unfortunately passed away in the middle of the night. We had some significant opportunities in the coordination of the notification to the family. By definition, we met our process, but for the impact that it had on this family, just significant opportunities. So it was wonderful that they were able to call my office. I was so grateful to be able to hear their story, listen to their concerns. They were just a wonderful caring family who said, "No family should have to experience what we experienced. There are opportunities for you to improve this. We want you to know so you can fix it."

I had multiple conversations with the family and then once we completed our investigation, we invited them back to the hospital and they met with our chief nurse, our director of inpatient nursing. We had some really great dialogue with them and thanked them again for sharing, apologized, of course, for their experience, and really we were able to share with them some of the significant changes we were making in our policy and our process to be able to better support patients and families in the future when something like this happened again. You were able to visibly see peace come over them by the end of the meeting, they were actually happy, and they were smiling and laughing. It was just one of those moments where I took a beat and I was able to just be so grateful that I could help them and that they wanted to help. It's really just a wonderful story of hearing the patient feedback and really identifying what could we do differently so that this doesn't happen again.

*Elizabeth Mendoza*

## Joy in Work

As diverse as patient advocates are from a background and experience perspective, one common thread weaves through the tapestry of their work: they find joy in making a difference. Overwhelmingly obvious about our group of advocates was their expression of reward for doing what they believe is their calling. Radford put it this way, "You are able to make a difference in someone's life, even if it's a very difficult time, even if it's when someone is passing away, but you are able to be there to help that family or that patient in a very vulnerable time in their life to make a difference. That's what I believe I was put on this earth to do."

*Vulnerable*, a word our advocates used frequently during our interviews to describe the patients they represent and what it means to them as professionals to be there when their patients and families are scared. Often it is just providing a listening ear or sharing one's own story that makes a difference to the patient. Riley finds great joy in sharing his own patient experience journey with his patients to reduce fear. "Being a former stroke patient, I will spend a lot of time on the stroke unit, and I try to motivate the patients and say, 'Hey, you know what? I've been there and I know it's hard and I know you may have a day where you just feel frustrated. It's okay.'"

Mendoza finds delight in empowering people to effect change. She lives up to a quote hanging in her office that promotes nurturing and building up others and looking for the best in people. She finds this motto works especially well in healthcare, and in her role, Mendoza too feels it's her calling to be an advocate. "I just feel like this role totally allows me to live in my skill set and use the gifts that I've been given and feel like I'm making a difference," she states.

Across the board, our advocates shared that the greatest reward is when patients express their humble appreciation by how the advocate has impacted their patient journey. Even the smallest successes are huge to patients, remarks Riley, and when his patients want to share a success with him, he is elated. He remembers telling his boss one day, "I just got the biggest reward for what I do." He goes on to explain, "It wasn't a monetary value, it wasn't a raise, but it was probably the biggest reward for the things that I've done."

Doyle speaks of finding joy in those *unexpected* times of appreciation from patients. She is motivated in her work by finding great outcomes and being able

to "fix" something, she explains. As her own worst critic, she sometimes feels as if she has not fixed the problem to the satisfaction of the patient and family. In those moments, Doyle's inner voice says, "*Oh my gosh, I did not help them at all. I tried everything, but clearly they were not satisfied.*" She continues saying, "And then you get a message months later saying 'Thank you so much' or you get flowers. It kind of hits you. *Oh my gosh, I did really help!* I think it is those times, where it's unexpected, is when I get the most joy."

While making a difference was a key component of finding joy in patient advocacy amongst our panel, another common weave found in this question was *respect* – respect from team members, from other employees, and from the clinical staff. Segura finds joy in the people she works with. "I have the most fantastic team," she says. "We laugh a lot. We smile a lot. It's amazing. When we get to the floors, and we get up there with such a positive attitude, the staff always tell us, 'I can't believe that you guys are so nice and smiling all the time with all the stuff you have to deal with,'" she continues.

Apart from her team, Segura speaks to the respect she feels from the clinicians and nurses with whom she and her team interact. "We have a lot of autonomy in our office and a lot of respect from the people that we assist. That, I think, brings us joy as well; people really do respect our opinion. They seek us out to help them with immediate situations and to get involved with conflict resolution. They see what we're capable of doing, and they respect that. I think that really brings us joy to our job," she comments. Finding joy in the workplace is easy in a positive work environment, according to Segura. She credits her organization for its commitment to employee recognition and resulting high level of employee engagement.



## Value of the Patient Advocate Role

### *Reflections from Family Member Barbi Beard Wolfe*

My thirteen-year-old son, William, has down syndrome as his main diagnosis and then a plethora of others that go with that. We've been going to Cook Children's since he was two days old, and we have several providers there, as well as a few at Cincinnati Children's where we also travel for William's care. I've worked with patient advocates on multiple occasions, but one that was especially memorable was when I had a hearing with the Texas Health and Human Services Commission regarding William's Medicaid. They had been paying for us to go to Cincinnati, but all of the sudden, Medicaid said they were no longer able to pay for us to go there.

My patient advocate helped me prepare for the hearing pulling a lot of information to plead my case. Then, she actually attended the hearing with me. It was very personal for me and I felt a little bullied by the system, so I was so blessed to have her there. She was a great communicator and helped me come up with the right questions to ask. It all worked out in the end and I felt so blessed to have her stand by me to help get through that situation.

Patient Advocates are great decoders and great translators because they take the feelings and the emotions out from patients and can communicate with the facts, with the clinical knowledge and expertise that the medical people understand. I have also found them to be also great mediators, and I use the term mediator because sometimes that's what they're doing. They're having to mediate between the families and the institution.

My advice to other family members or patients is to remember that the healthcare staff are people too. I know there are some things that are emotionally hard. I get that. I've been there. I'm there now, but that I think you have to still have respect for the staff. The other thing is to know that as patients and families, you have a choice. If they don't like the answer you get from a member of the team, don't give up. Just keep going until you find somebody. Listen to your gut.

A hospital environment is so personal and most of the time when you need an advocate, it's because things aren't going well, which means the personal boat is being rocked and you're going to have a ton of emotions. I've found patient advocates to be the best kind of people to wade through the minutia and pull out what needs to be done to achieve the best outcome.

## Part 2: Independent Patient Advocates

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### Overview and Services Provided

Independent patient advocates are compassionate individuals who are committed and dedicated to helping clients make sense of their healthcare experiences. Not bound by hospital policies, procedures or allegiance to one provider, independent advocates put rigor into providing services that are as diverse as their own backgrounds and experience. The independent advocates that we interviewed for this paper unanimously hang their hats on descriptors of their role that transcend the threshold of meeting basic patient needs. This group uses terms like educator, connector, communicator, researcher, planner, coordinator and translator all with the main goal of fulfilling needs that have the potential of elevating, improving or totally transforming their clients' healthcare experience.

Independent advocates are like miners in a mine field. They look to find safe footing for their clients, and where there are potentially dangerous areas, steer their patients onto alternative paths toward better outcomes. Service offerings within advocacy agencies range from the very narrow to extremely broad. Three out of six of our interviewees have niche companies specializing in one area of advocacy or cater to one specific client population. The other three advocates offer a broad range of solutions. Solutions offered, whether diverse or concentrated, generally fall into the categories of research, education, coordination and communication/translation.

### Research

One common offering of independent patient advocates is research. Research is a broad task encompassing exploration into all kinds of things. Barbara Abruzzo, President and Founder of Livingwell Care Navigation creates value for her clients by performing due diligence on renowned surgeons, sometimes from around the world, so her clients can have a choice of receiving a second and third opinion to ensure they receive the absolute best care possible. Abruzzo's due diligence includes research on a doctor's medical school and specialized fellowships. She looks into whether the doctor is a clinical professor and up-to-date in his/her field of practice, what she refers to as "being on the cutting-edge".

Anne Llewellyn, Founder, Nurse Advocate and a 40-year critical care nurse, shared her personal story about how her patient advocate's research saved her life. "I had a brain tumor. I went to a very small community hospital. The neurosurgeon said 'Well, we're going to drill a hole in your head and then we'll take a piece of the tumor and test it and give you chemotherapy.' He was too cavalier," says Llewellyn. On Llewellyn's behalf, her patient advocate then researched neurosurgeons and made a recommendation for one in a much larger health system who specialized in her client's type of tumor. Llewellyn recalls, "I don't know what would have happened if I didn't leave that hospital, but I really do attribute my survival to being moved to another hospital. Nobody in that hospital would be able to do that for me unless I had an advocate who took it on her own to look for an alternative place for care."

"Surprise medical bills" is a term independent patient advocates hear often. Medical bill advocacy fills a great need in our healthcare environment today, and research in this area is a common service offered by independent advocates. Surprise medical bills typically occur after an emergency room visit in an in-network facility where patients are urgently treated by several providers, some of whom are not in the patient's insurance network. The surprise comes when the patient receives the bill from the out-of-network provider for the entire balance. Independent advocates are experts in breaking down an insurance company's Explanation of Benefits and the associated hospital bill. While this task is daunting for the patient, it is a simple one for an independent patient advocate. Linda Michelson, President, The Medical Bill Advocate LLC says "I can help anybody who's had a complicated stay, a long stay in a hospital, or they have a high balance," summarizing her services which include assessing for errors or overages on the bill, evaluating if proper coding was used, determining if insurance was applied correctly and investigating denials. Oftentimes, according to Michelson, independent advocates file insurance appeals on behalf of their clients to reconcile these high-dollar and complex issues.

Another service line of independent advocates within the research category is evaluation of medical equipment. Nicole Broadhurst, Senior Patient Advocate, Tennessee Health Advocates is assisting patients and families in obtaining



information regarding their medical situations and then determining what medical device best suits their individual circumstances. Guidance in pricing, whether to purchase or rent and researching providers in their local area who best meet the patient's treatment needs helps families in the decision-making process or leads them to secure a second or third opinion.

## Education

As educators, independent patient advocates are often called upon to teach their clients about health insurance. Llewellyn talks of the seriousness of not understanding how the insurance system works. She tells the story about how one of her clients cashed in a 401(k) policy to pay a doctor bill for her open-heart surgery. Llewellyn coached her client about waiting for her Medicare coverage first before paying cash and protected her client from unnecessary financial burden.

Michelson reports that she is helping her clients understand health insurance by teaching them about basic critical components like co-insurance, deductibles, and out of pocket maximums. At the highest risk, all the advocates agree, is our aging population. The elderly often do not understand the monthly insurance papers that arrive in their mailbox. The stacks of papers create feelings of helplessness and confusion, so with the help of the independent advocate, simply reviewing and organizing monthly bills on an on-going basis helps patients feel more in control of their healthcare situations.

## Coordination

Coordination of care and acting as an intermediary between patients, families and providers are also among the primary service offerings of independent advocates, according to our panel. "The need is high," comments Abruzzo, who remarks about our current healthcare environment. "Making sure the right hand knows what the left hand is doing...it's really a problem in our system," she says. According to Abruzzo, the best outcomes are those where the patient functions as his/her own advocate. Most often, though, people don't have that ability. They don't have the skillset or perhaps the person is too ill. Abruzzo gives an example of the value of care coordination services by saying, "If you're going to a physician, and you're not saying, *'Well, I saw my neurologist last week, and this is what he said, and this is what he did,'* it's never going to go on your record with your PCP. Each doctor needs to know what the other physicians are doing in order to have

coordination of care. Physicians frequently say to me how helpful it is to them to have me as a member of the team."

Care coordination is problematic globally, concurs Isabela Castro, CEO and Founder, P2P Care Solutions. Castro is a dentist treating children in Brazil with disabilities and a patient advocate dedicated to getting her patients' care team all on the same page. She saw the need for improvement and decided to take the lead in patient advocacy in her area of practice in Rio de Janeiro. "I had to deal and communicate with all the other professions involved, like physiotherapists, physicians, voice therapists, psychologists and occupational therapists. I saw that the family had difficulty connecting to all of them together and also had difficulty connecting with one another," she states. She goes on to say, "There are lots of connection points between the professions, and they have to communicate."

Coordination services are particularly prevalent among our interviewees in the arrangement of senior care. "As people get older, they typically need more services, so the treatment plan can get complicated," says Broadhurst referring to the special attention needed for this demographic. Common services of the independent advocates on our panel include a wide spectrum of assistance including research for housing, outpatient treatment providers, skilled nursing centers, independent and assisted living providers, hospice, as well as arranging for private home care.

Liisa Ogburn, Owner, Aging Advisors NC considers herself a problem-solver around a huge variety of issues that come up in the last years of life. Ogburn took personal responsibility for touring 80 facilities in her area and developed tailored reports for her clients, providing pros and cons and pricing for the different options. "I walk with families through the process to find residential care for a family member," she says reflecting on her commitment to giving personal attention to the elderly.

Care coordination also surfaces in simply helping patients get timely access for appointments and services. With their knowledge of the healthcare system, advocates are often able to better navigate the system, discovering who the right people are to talk to, explaining a patient's situation and advocating for a greater sense of urgency. Llewellyn shared a time when a client was told he would need to wait three months to get an appointment to discuss a kidney transplant, and she was able to intervene and get him seen within a couple of days. "It might not be a week or a couple days all the time. It might be



two weeks, which is still better than three months. But many people don't know they have the right to question healthcare providers in these instances and they may not have the knowledge to work the system. That's where an advocate comes in," Llewellyn states.

During our interviews, much was also said about care givers. Advocates find that family members are oftentimes overwhelmed with what's needed for their loved one, so the advocate provides guidance around the importance of managing self-care. They are also offering direction in living wills and ensuring a healthcare proxy is in place. According to our interviewees, the stress around these issues often creates conflict and tension between the patient and the family or among the family members themselves. During those moments, the independent advocates are called upon to act as third-party mediators to help the patient and family reach agreement about treatment strategies, care plans and end-of-life realities.

### Communication/Translation

Independent patient advocates are often engaged by clients to act as liaisons between providers and patients and families to improve the communication between all the parties. The need for advocacy in this area is great due to the medical jargon that most people outside of medicine don't understand. Broadhurst says, "There's a certain language that the medical community speaks, and it becomes difficult for patients and families to be able to understand those terminologies. I find myself doing a lot of translating so patients and families can understand what the healthcare professionals are saying".

It is not only the spoken word that independent advocates are instrumental in breaking down for patients and families. Castro reports that translation of printed forms is also helpful for patients in her country of Brazil. For patients struggling to understand forms that are written in English and not the patient's native language, she offers translation services so her clients can understand the terms printed on the forms.

### Patient Populations Most Benefiting from Independent Advocates

While our contributors acknowledged many types of patients and families can benefit from the services of independent advocates, they shared several of the most common situations in which they assist including someone with a new diagnosis, someone who may be scared, worried or frustrated.

Patients with complex medical conditions tend to especially benefit from services of an advocate as they can help streamline communication, coordinate appointment schedules and help the patient proactively manage their treatments. "When a patient has multiple conditions, they have lots of mixed attitudes about their care and they have lots of professionals visiting during the week. We help to establish communication," explained Castro.

Another patient population often utilizing independent advocate services are those referred to as 'solos.' Especially common in the elder care area, these are patients that have minimal support systems in place. They are often widowed, never had children or may not have an extended family or friends to assist them with hands-on care or decisions. "This particular type of patient can maximize the benefits of having additional support available to help them to make decisions and navigate their care," shared Broadhurst.

### Interacting with the Care Team

Working with the care team is a primary function of an independent patient advocate. Our interview panel recognizes that communication skills are essential in their role, as interactions cover a broad range of healthcare professionals and family members.

The first step for any independent advocate representing a client is to ensure that proper consents are in place to allow them to interact with the care team. All the advocates on our interview panel stressed this important step, emphasizing that the policies about representation by an advocate may be different among the clients' different providers. Always following the rules is the best course of action for the client, agrees the panel. Independent advocates, when representing hospitalized clients, generally begin with the case management or risk management department to complete this critical step in their work.

Meeting directly with the care team is the next crucial step as an advocate. Getting answers and cutting through the red tape is key to helping their clients understand their healthcare situation. According to Llewellyn, "The consumer is being asked to pay more and more money of the healthcare bill, so we're starting to demand more information," she states. Communication among the care team is often the most difficult to facilitate and oftentimes lacking between the care team and the families. Llewellyn speaks of attending staff meetings with doctors and nurses and bringing in the family members, because

the family doesn't understand what is going on with their loved one. She tells the story of an extreme case about her friend who found it almost impossible to connect with her mother's doctor. After multiple attempts to reach the doctor by phone, her friend found it necessary to take a day off work, arrive at the hospital at 7:30 AM just in time to "catch" the doctor when he arrived. "So, should it be that hard? Should it be that complicated?" poses Llewellyn on the topic of communication.

Communication with the patient also entails education, says Llewellyn. "When patients are in the hospital, this is a good time for them to learn something about their health conditions," she remarks. Llewellyn makes it a practice to interact with hospital educators to request they teach her clients about their conditions like diabetes or stroke or about the medications they take.

For our advocate in Brazil, interaction with the care team begins with the parents of the child she is advocating for. "I start the discussion as a leader of care when the mother or father or the family nominate me as the leader of the care," says Castro. She goes to great lengths to bring stakeholders and professionals together on major decisions for her clients, such as whether or not to do a tracheotomy, to continue palliative care or to address end-of-life decisions. Topics such as these create tension among the parties, according to Castro, and she is personally rewarded by advocating for what is best for the patient while managing the emotions of the family. As an advocate, Castro understands the pressures on the family and stands by them, so they don't feel they are alone. She gains strength through the strength of the families who are faced with devastating diagnoses about their child, stating, "They teach us much more than we can teach them."

Sometimes the interaction with the care team is not so direct, says a few of the panel of advocates. "I'm working to increase my interaction with direct providers and attending more appointment visits and getting more involved with that side of advocacy," states Broadhurst. Because a majority of her work is in relation to insurance and billing issues, she interacts with the care team mostly via telephone and email with medical billing representatives. Broadhurst's personal goal is to get her clients to get their own electronic health record set up, and she interacts often with the medical records staff to coordinate that process.

## Challenges Faced by Independent Advocates

While being an independent patient advocate can be incredibly rewarding, our contributors also acknowledged that it comes with its share of challenges.

### Building Relationships with Healthcare Teams

There can be a hesitancy from hospitals and health systems to engage with independent advocates. As a relatively new member on the healthcare team, increasing awareness and educating organizations is a primary focus to get everyone comfortable with the thought of an independent advocate being a participatory team member. "If there are health care workers that are unsure of my role, then obtaining information and getting a collaborative working relationship is challenging," said Broadhurst. "I need to develop that trust, develop that relationship where I'm just a member of the team. We're all here to get the best possible outcome for this patient and I am part of that."

The Alliance for Professional Health Advocates (APHA) cites that healthcare professionals who have worked with patient advocates are some of the biggest champions of the advocacy profession. Many private advocates report that doctors and nurses are recommending their patients connect with an advocate to improve the journey for all. For example, advocates can help make sure the patient follows discharge instructions, which can potentially keep the patient from returning to the hospital within the 30-day time period that becomes expensive for the hospital.

### When Family Members Disagree

The overall goal of advocates is to provide patients and caregivers with the support and education they need so they can make their own decisions about their next steps. At times, that can lend itself to unique challenges in managing the dynamics between patients and family members who may not always agree on care plans. This is especially common when assisting elderly patients with multiple family members weighing in with different perspectives.

"Questions I always ask are: *Who else is involved? Should we get them on a conference call?*" said Abruzzo. "I've been doing this a long time and I know that if everybody isn't on the same page, things are not going to move forward."

## All Situations are Somewhat Unique

The reality for advocates is that no two patients, families or situations are alike regardless of the level of complexity of the services needed. Ogburn shared, "I don't always know what I'm walking into." As in any field, many obstacles, situations and processes are common within the role of the independent advocate, but even with the commonalities, each situation can be very unique and require a different approach or skill set. Advocates must be adept at handling different personality types – both with clients and with the healthcare team – as well as have the patience to undergo significant research with each new case. In addition to understanding each unique diagnosis and treatment plan, they are tasked with navigating the nuances of multiple healthcare systems, insurance plans, billing systems and legal rights.

## Running a Business

Most people who go into advocacy do so to help people and might not have a background as a healthcare professional. Often, it's a personal experience that inspired them to enter the field in hopes of making the healthcare experience easier to navigate for others. They might not have marketing experience or understand other key facets of running a business.

Even knowing how to charge for services can be a challenge. "I still struggle with how to charge clients the right amount given the hundreds of hours in research needed to make the best recommendations," said Ogburn.

Organizations like APHA offer resources to help independent advocates balance their skills between advocacy and business based on the recognition that many of those people with the very best of advocacy skills don't always have the necessary business skills which are vital to that success.

## Joy in Work

A consistent theme within our independent advocate interviews was the love they have for their work and their desire to make a difference in the lives of others. They spoke of how rewarding and fulfilling it was to provide peace of mind to the patients and families they serve.

"I think the best is seeing the system work the way it should because we do have a great healthcare system," said Llewellyn. "We have very caring doctors and nurses; we have a lot of support in the system. When it works, it works well. And if I can help people get through a tough period, then that's where I get my satisfaction from."

Broadhurst also acknowledged the reward in helping people make knowledgeable choices about their healthcare and feel confident about those choices. "I love helping patients find solutions to their problems. I've put together a lot of comparison charts so that patients and families can look at a chart and see the options. Then I love watching them take that information and make the best choices for them specifically. I don't have all the answers. I don't know what's best for every single family. Only they know that."

## Seeing the Impact of Patient Advocate Efforts

*A Story from Nicole Broadhurst*

I recently worked with an elderly woman who had cancer and had come to the end of her treatment. She chose to utilize hospice services after we went through what that means, what it looks like and what it could mean for her. She felt this was the best option for her; unfortunately, she had a son who was unsure of her choice. It's never easy to come to terms with losing a parent, and there was part of him that wanted to do more, that wasn't ready to let her go.

As an independent advocate, part of my role is to advocate for my patients' choices, and she was very confident in making this choice. I had the opportunity to work with her son and educate him what hospice services are, what the purpose is, what it would look like, what to expect and to help him come to terms with his mom's choice. It was very different than what he had expected. He was able to participate in her care in the last days and even got to the point where he was able to administer medication to ease her pain.

Later he shared with me his appreciation of my willingness to have those difficult conversations with him. The conversations allowed him to be grateful to be of service to her and not harbor negative emotions around his mom's death. To be a part of that for him was extremely satisfying. I was honored to be a part of his journey from discomfort to understanding and respect for his mother's choice.

## Conclusion

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Through the voices of our contributors, this paper has explored the important role that patient advocates, both organization-based and independent, play in supporting patients and caregivers. The individuals in these roles are passionate about creating positive experiences for people who are going through very difficult times. They are committed to understanding what patients want and need in order to make a positive impact on their healthcare experiences and outcomes.

The future of the Patient Advocate is solid. The role will continue to evolve as the healthcare industry changes and moves forward in its goal to improve quality and control costs to ensure patient experience excellence. Advocacy is key to these changes, as it encourages patient and family engagement. Advocacy has the opportunity to support patients from inside the hospital as well as through outside independent advocates.

Patient advocates bring knowledge to healthcare; they bring information, they bring comfort and understanding, they tackle tough issues, some painful, and work to resolve opportunities that elevate joy and hope. To see this role as anything less than essential to healthcare today is to miss the very essence of what we mean in saying healthcare is fundamentally about human beings caring for human beings. We hope this exploration helps others understand how to engage with this role, who the incredible people are who take this on as their life's work and why it is important to healthcare today.

## Contributors - Organization-based Patient Advocates



**Lynn Charbonneau**  
Manager, Patient Relations,  
Guest Services,  
Tampa General Hospital

Lynn Charbonneau's journey in patient relations started in the hospital billing department in the late 1980's. Charbonneau oversaw the patient accounts representatives that took calls from patients in regard to their medical bills. Hearing of the concerns that the patients were having motivated her to reach for solutions on a much larger level.

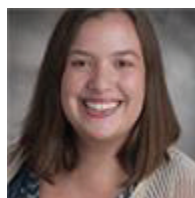
Charbonneau took her thoughts to the vice president and proposed the idea of doing more for the patients and asked for the opportunity to expand the patient relations department. This was a thousand bed academic medical center with only one patient advocate, and Charbonneau was able to join that individual and work to create and build a department that would ensure better experiences for future patients and their families. She continues to be a large part of these efforts.



**Ashley Doyle, RN**  
Patient Advocate Manager  
The University of Vermont Health  
Network - Champlain Valley  
Physicians Hospital

In Ashley Doyle's career as a nurse, she found it came naturally to revolve her care around patients' needs. When the opportunity arose for her to magnify her relationship with her patients and their families, she wondered if it might be a good fit. This new position in patient advocacy would allow her to interact with her patients on a deeper level, to ask different kinds of questions, and to really get to know them as a whole.

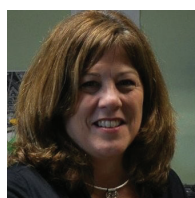
Having been a nurse for six years, Doyle questioned whether she was the right person for the job, but reassurance came when a leader at her organization approached her asking if she had considered the position. Now, as a Registered Nurse Patient Advocate Manager at University of Vermont Health Network, CVPH, Champlain Vermont Physicians Hospital, Doyle states "...putting that patient first, and being a patient advocate, you can't ask for a better job title than that."



**Elizabeth Mendoza**  
Manager of Patient & Guest  
Relations  
Advocate Sherman Hospital

Elizabeth Mendoza stumbled upon the field of patient advocacy while working in healthcare about nine years ago. She had been in the healthcare industry for most of her career and was in search of her next move, considering the possibility of nursing or pharmacy work.

When Elizabeth found out about a position in advocacy, she felt as though it had the best qualities of the paths she had been considering. It would give her the opportunity to support patients and be their voice when they needed to be heard most. She made the decision to be a part of affecting positive change by way of advocacy.



**Brenda Radford**  
Former Director, Guest Services  
Duke University Hospital

When Brenda Radford was 12 years old, her father was in a severe car accident and was taken to Duke University Hospital for care. Even though he was not expected to live, Radford recalls the wonderful care they took of her father and his family. Her dad did recover, and she knew from then on that she wanted to find a way to give back to the organization that had given so much to her family in a time of need and vulnerability.

Radford worked at Duke University Hospital for almost 40 years, and served as Director, Guest Services for 22 of those years. Although she is moving on to serve another community, she was able to be a part of the growth of a formal patient advocacy system in the place that had shown her the importance of the patient and family experience years before.

Her experience in the many different roles she was able to be a part of showed her the importance of understanding that everything people do and say impacts the experience of the patients and their loved ones. She believes that in order for the experience to be whole, it needs to be led not only by patient advocates, but by the staff of entire organizations. Radford believes that every position



under the roof of a healthcare organization is that of a caregiver, and she has made a career out of caring, connecting, and providing a compassionate environment for patients and their families.



**Robert Riley**  
Manager of Patient Relations &  
Guest Services  
Marianjoy Rehabilitation Hospital

Robert Riley found his career in patient advocacy after working in a corporate setting for over 30 years. The switch for him came after suffering from a stroke. Through that experience of being the patient, he found his passion in advocating for other patients. In his personal experience as a stroke patient he recollects having many questions but was unsure of how to go about getting them answered, so he set out to be a guide for those in similar situations. His experience has allowed him a true patient perspective in his work.

Riley has been changing the lives of patients in Wheaton, Illinois, for over seven and a half years.



**Pamela Segura**  
Director of Regulatory Patient  
Affairs/Patient Relations and Service  
Excellence  
Cook Children's Health Care System

Pamela Segura began her journey as a patient advocate at a hospital in Scottsdale, Arizona where she worked in the food and nutrition department. The effort she put into meeting both the nutritional needs of the patients and the cafeteria retail needs of the staff was noticed by the Chief Nursing Officer, who was looking to begin a patient advocacy department. Segura was asked to take over the new department as a result of her dedication to providing quality experience and spent the next four years building an advocacy team before moving on to Cook Children's Medical Center in Fort Worth, Texas.

Segura has been in her role as Director of Regulatory Patient Affairs and Service Excellence at Cook Children's for 11 years. She has taken her experience and knowledge in the field of patient advocacy to continue to build and grow with her current team.

## Contributors - Independent Patient Advocates



**Barbara Abruzzo, RN**  
President, Founder  
Livingwell Care Navigation, Inc.

Barbara Abruzzo started her healthcare journey as a Registered Nurse. She was an intensive care nurse for five years before she realized she wanted to affect the hospital system in a different way. As someone who likes to see change happen, the effort it took to make a high-level difference in her position did not sit well with her. She decided to go into the business side of healthcare, eventually starting her own tri-state hospital staffing business for specialty nursing as well as pediatric critical care homecare services that care for ventilator-dependent infants in the home.

Abruzzo had been hospitalized numerous times for orthopedic surgeries beginning when she was just five years old. In her 40's, she found out that she was challenged with a genetic neuro-muscular disorder. The combination of her nursing experience, her staffing and homecare businesses and being an ongoing patient gave her unique perspectives of hospital operating procedures and the patient's experiences from multiple vantage points.

Five years after selling her business in 1994, she found herself being asked questions regarding healthcare issues by friends and family about themselves or their family members. Abruzzo found that it came naturally to coach these people in the direction of health, and after multiple successes and positive feedback from those she had assisted, she started to build her business as a patient advocate using her unique approach from her personal and professional experience, and has since built a successful patient advocacy medical decision support service.



**Nicole Broadhurst, BCPA**  
Sr. Patient Advocate  
Tennessee Health Advocates

Nicole Broadhurst began her journey working in healthcare admission, billing and marketing. Over this 26-year career, she helped patient and families navigate their needs and found that while she was certainly helping them, she also felt that she was being pulled in many different directions due to the responsibilities of her position in the healthcare system.

Broadhurst found that her true passion was for the patients and their families, and also recognized that she didn't have the capacity to both do her role and fulfill her passion, so she made the jump to independent patient advocacy. This decision has allowed her to devote as much time necessary to each individual patient, creating relationship-based experiences and fulfilling not only her passion, but the tailored needs of those who seek her help.



**Isabela Castro**  
CEO & Founder  
P2P Care Solutions

Isabela Castro is a Dentist and Patient Advocate whose journey began in the Brazilian Air Force, leading the special-care section of dentistry. In Brazil, special-care dentistry involves any patient with a disability, no matter the nature. Some of these disabilities include chronic diseases, mental diseases and neurological diseases. She worked out of a hospital, and therefore was faced with situations beyond dental health.

Isabela has her own experience with disabilities, as her sister has lived with Cerebral Palsy. She began to see herself and her family in the faces of the patients and families she was surrounded with and found herself becoming more and more willing to do anything she could to help people. While her start in advocacy was informal, over time she began to gain knowledge and awareness in order to build on this part of her life.

With gratitude to God and to the Air Force for this opportunity, Isabela continues to work with patients with disabilities. She sees this as an opportunity to be of great use to her community.



**Anne Llewellyn**  
Founder  
Nurse Advocate

Anne Llewellyn has been in healthcare for about 40 years as a Registered Nurse, working in various positions including critical care, medical-surgical, risk management, care coordination, and education. She is currently a board-certified RN case manager. While she is well-versed in the healthcare system, it was her experience as a patient that lead her to further comprehend the importance of patient advocacy.

After finding out she had a brain tumor, she began to experience the complexity of the healthcare system in a new way. As a result of her condition, she found herself cognitively unaware and unable to make decisions. Her husband never left her side and battled throughout the entire journey. He asked the questions she was unable to ask herself, kept track of differing answers and opinions, and made sure to advocate for his wife to ensure she received the best care possible.

Having the support of her husband in this difficult time reinforced Llewellyn's career and gave her a new perspective on what it means to advocate for a patient. It showed her that in these difficult times, the patient needs someone, they need the kind of support she received from her husband and she seeks to provide just that.



**Liisa Ogburn**  
Owner  
Aging Advisors NC

Liisa Ogburn taught for a decade before finding her way to patient advocacy, specifically as an Elder Consultant. While teaching, she also cared for her mother and father-in-law in her home before they passed away. During this time, she was moved to write about her experience being in the Sandwich Generation, which is the generation of people who take care of both their aging parents and their children.

Her article was published in the New York Times and went viral, which began the process of people reaching out for speaking opportunities as well as help navigating their own family situations. She continued growth in the industry through volunteer work and certificate programs for credentials on her way to becoming a consultant. She now runs her own firm to assist in planning and responding to the needs of individuals and their families in the last stages of their lives.



**Linda Michelson**  
President  
The Medical Bill Advocate LLC

Linda Michelson is a medical bill advocate who worked in medical billing for over 25 years at two world-renowned academic centers in St. Louis, Missouri and in Palo Alto, California before making the switch to advocacy. This experience allowed her to gain significant understanding of billing processes and how they do and do not work. She was able to get perspective from both her own experience and that of the patients she worked with. Part of what she witnessed in her time doing this work included slow-payments, denials, non-payment and payment errors.

Several years ago, Michelson retired from work in this area. She decided to use her vast background and knowledge to help people that are overwhelmed with their medical bills. Her background has made her an efficient advocate for patients in managing the financial side of their experience.

# Appendix

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## Code of Conduct – Organization-based Patient Advocates

Members of the Patient Advocacy Community of The Beryl Institute who serve as patient advocates are committed to conducting their professional relationship in accordance with the following principles:

- Patient advocates have a primary responsibility to the patient.
- Patient advocates are fair, objective and caring within the scope of their professional liabilities.
- Patient advocates have an obligation to inform patients of their rights and responsibilities and advocate on their behalf.
- Patient advocates promote the autonomy and dignity of each individual and act to prevent discrimination.
- Patient advocates protect and promote the confidentiality of those served and educate patients to the limits of that confidentiality.
- Patient advocates maintain the integrity of the profession by identifying, developing, and utilizing knowledge to set standards for professional practice.
- Patient advocates are committed to continuing education to maintain professional excellence.
- Patient advocates permit no exploitation of their position. They do not endorse, promote or sell commercial products. This stipulation does not include professionally related activities such as public speaking, consulting and publishing.

## Code of Conduct & Professional Standards - Independent Patient Advocates

Source: <https://healthadvocatecode.org>

- Health advocates practice with compassion and respect for the patients, clients and families with whom they work.
- Health advocates' primary commitments are to promote the health, safety, and rights of their patients and clients.
- Health advocates will, at all times, be transparent in their work with clients. They will disclose to clients their credentials, experience, pricing structure, and any financial relationships they hold with other professionals, businesses or institutions.
- Health advocates will, at all times, maintain privacy on behalf of their patients and clients and will keep confidential all activities and records according to agreements among them, and any applicable laws.
- Health advocates will guide and assist their clients-patients in medical decision-making but at no time will make decisions about health or medical care or payment for medical services on their behalf.
- Health advocates will promote use of their client-patients' values and belief systems as the foundation for their decision-making.
- Health advocates will, at all times, practice within their competency. Any requests for services outside the advocate's expertise will be referred to someone else who is equipped to provide those services to ensure the client-patient is benefitting from the best knowledge base.
- Health advocates will, at all times, work within their professional boundaries and will reject any requests or demands that would cause them to violate those boundaries. Such violations may include, but not be limited to, accepting money or gifts as compensation for referrals to or from other professionals, businesses, or organizations; fulfilling requests to perform illegal or unethical actions; agreeing to provide services outside any geographical limits; developing a romantic or sexual relationship with a client or someone related to the client; agreeing to perform any duties without the disclosure or input needed from the client; or any other circumstances that could result in conflicts-of-interest or the inability to fully perform the work the two parties have agreed upon.
- Health advocates will not discriminate. They will at no time refuse to work with someone due to that person's race, religion, culture, gender, or sexual orientation.
- Health advocates will continue to pursue education to further their knowledge base, skill set, and practice in order to provide client-patients with the most current information relevant to his/her health situation.



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## About the Authors

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### Stacy Palmer, CPXP

Senior Vice President and COO  
The Beryl Institute

Stacy is a visionary thinker and pragmatic strategist who has been a leader in the expansion of patient experience as a central conversation in healthcare. With a commitment to gather, understand and integrate insights and ideas from The Beryl Institute community, she has helped establish a resource library of proven practices and research sharing how healthcare organizations around the globe are creating positive experiences for patients, family members and caregivers. She also works closely with resource providers offering the latest in patient experience related solutions and services to broaden industry awareness of the tools available to impact overall experience efforts. She has co-authored numerous white papers from The Beryl Institute. In addition, she is a regular contributor to the Patient Experience Blog and stays connected to the work on the front lines of care through visits to healthcare organizations, sharing their experience journeys through the *On the Road* series.

### Terri Ipsen, CPXP

Content Editor  
The Beryl Institute

Terri is a Certified Patient Experience Professional (CPXP) dedicated to the patient experience movement. She successfully completed The Beryl Institute's Patient Experience Body of Knowledge and holds a Certificate in Patient Experience Leadership. Terri jumped into the field of PX in a hospital setting where she successfully launched the hospital's first Patient & Family Advisory Council. She was instrumental in raising awareness on patient- & family-centered care throughout the organization via hospital-wide events and delivered multiple departmental trainings on the core principles of PX to interdisciplinary care teams. Terri has contributed to the Patient Experience Blog with a story about her own healthcare experience and has authored a variety of case studies on the influence factors of patient experience. She holds a bachelor's degree in Organizational Management from Palm Beach Atlantic University and lives in Palm Beach Gardens, Florida.

### Michelle Garrison, CPXP

Senior Director, Membership  
The Beryl Institute

Michelle ensures that members and guests of The Beryl Institute have the information necessary to meet their needs and strives to deliver the best member experience at all touchpoints. She is committed to furthering the vision of the Institute as the global community of practice and premier thought leader on improving the patient experience. Prior to joining The Beryl Institute, she spent twelve years working as a sales assistant and event coordinator for a regional brokerage firm. Before that, Michelle experienced the world of healthcare by working as a radiology reading room technician and as a phlebotomist. She holds a bachelor's degree from Texas Woman's University.

### Lindsay Nelson

Community Experience Coordinator  
The Beryl Institute

Lindsay is the first point of contact for The Beryl Institute community, focusing on effective interactions and acknowledgement for members and non-members. She aims to provide ample information and assistance to the community in regard to the numerous resources The Beryl Institute has to offer. Lindsay provides support for her fellow team members in membership data, technical assistance, and member and non-member inquiries. She believes the human experience begins at the first moments of interaction and is committed to improving the patient experience, by providing a leading example of care and commitment. Prior to joining the Institute, she was an Executive Assistant for a private residence in Silicon Valley, and managed membership processes and financial data for a fitness organization. Lindsay is a student at The University of Texas at Arlington College of Nursing and Health Innovation, currently working towards her bachelor's degree in Public Health.

## Also from The Beryl Institute

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### 2019

Innovating the Patient Experience: Trends, Gaps and Opportunities

Improving Patient and Family Experience in the NICU: A Practical Application of the Experience Framework

Role of Nurse Executives in Patient Experience

### 2018

To Care is Human: The Factors Influencing Human Experience in Healthcare Today

Consumer Perspectives on Patient Experience 2018

Interconnected: An Exploration of Improvement Efforts Connecting Patient Experience and Communication

What Patient Experience Can Learn from Child Life Professionals

### 2017

Connected: Improving the Patient-Physician Relationship – And Health Care Itself – Through Communication

State of Patient Experience 2017: A Return to Purpose

Supporting the Emotional Needs of Staff: The Impact of Schwartz Rounds on Caregiver and Patient Experience

Structuring Patient Experience: Revealing Opportunities for the Future

### 2016

Guiding Principles for Patient Experience Excellence

The Role of Family Caregivers throughout the Patient Experience

Reflections from PX Professionals Impacted by Personal Healthcare Experiences

The Role of the Volunteer in Improving Patient Experience

The Role of Technology in Patient Experience: Insights and Trends

### 2015

The Critical Role of Spirituality in Patient Experience

Leadership and Sustaining Patient Experience Performance

State of Patient Experience 2015: A Global Perspective on the Patient Experience Movement

A Dialogue on Improving Patient Experience throughout the Continuum of Care

Patient Advocate: A Critical Role in Patient Experience

The Power of Person-Centeredness in Long-Term Care: A View Across the Continuum

### 2014

Defining Patient Experience: A Critical Decision for Healthcare Organizations

An Invisible Barrier to Compassionate Care: The Implications of Physician Burnout

The Power of Selection and the Use of Talent in Driving Exceptional PX

The Association between Patient Experience and Hospital Financial Performance

The Chief Experience Officer – An Emerging & Critical Role

### 2013

Voices of Measurement in Improving Patient Experience

Voices of Physician Practices and Medical Groups: Exploring the State of Patient Experience

Enhancing the Patient Experience through Live Entertainment

Voices of Patients and Families: Partners in Improving Patient Experience

Voices of Practice: Exploring the Patient Experience in Action - Highlights from On the Road with The Beryl Institute

Voices of the Future: Student Perspectives on the Patient Experience

Voices from the C-Suite: Perspectives on Patient Experience

### 2012

The Role of Organization Culture in a Positive Patient Experience: A Leadership Imperative

Patient Perspectives on Outstanding Experiences: The Impact of Emotionally Intelligent Staff

The Role and Perception of Privacy and its Influence on the Patient Experience

Structuring the Patient Experience Effort: An Inquiry of Effective Practice

Charting a Course to Quiet: Addressing the Challenge of Noise in Hospitals

Physician Perspectives on Patient Experience

Benchmarking the Patient Experience: Five Priorities for Improvement

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