



When Treatment is Delayed or Refused – by the Providers

When you have a medical issue, you seek treatment. What would you do if a provider would not treat you because you had another medical issue with which the provider did not have experience? This situation has happened in my family and is impacting a member of the CAPS Consumer Advisory Panel.

First my family story. My daughter had a number of surgeries to advance her jaw due to micrognathia (recessed lower jaw) that caused extreme airway issues. She lived for many years with a tracheotomy. The jaw advancement surgeries resulted in issues with TMJ (temporomandibular joint) including, at one point, a dislocated jaw. A dislocated jaw is extremely painful. It also interferes with eating, drinking and speaking. Generally, dislocated jaws are treated on an emergent basis.

However, my kiddo had to wait for treatment for a month. The oral surgeon would not manipulate her jaw back into place until her airway specialist, an ENT (ear nose & throat) surgeon, was able to be in the operating room with him to manage the difficult airway. The only day they could both be in the operating room was a month away. The expectation was that a young teen would maintain on opioid medications for pain and oxygen support for airway issues for that month.

Most other patients with dislocated jaws would have been taken into the operating room on an emergency basis, with an oral surgeon, or other provider, managing the manipulation of a jaw and an anesthesiologist managing the airway. Needless to say, this situation was extremely frustrating. It was not, however, life threatening.

This month's Consumer Advisory Panel member profile features Patricia (Trish) Pooley. Trish has lived for decades with a transplanted kidney. Trish also receives all of her nutrition needs from formula given through a tube into her veins, a process called total parenteral nutrition or TPN. Trish has required TPN due to losing most of her intestines after a bout with cancer.

Trish's transplanted kidney is failing. She needs a process called plasmapheresis as an in-patient in the hospital. But hospitals in her hometown of Kansas City have indicated they do not want to accept a plasmapheresis patient who also receives TPN. Trish has tried to work with the hospitals to get providers to work together to make this life saving treatment possible. As of the date we are publishing she has not received treatment. Her kidney function continues to decline.

Ideally, a person or persons at the facilities one uses would intervene in these types of issues and make coordinating care easier. Some facilities have complex care case management that can facilitate complex care from multiple providers. Generally, large urban medical centers can provide complex care. What should a patient do when living with a situation where treatable issues go untreated due to other issues the patient faces? If you have feedback regarding how this problem can be addressed for Trish specifically or in general, please let me know! (lisa.morrise@gmail.com) -Lisa Morrise

Pg. 2 – Trish Pooley profile.
Pg. 4 – AI diagnostic tool pilot site opportunity.
Pg. 5 – Safer Care Through Shared Decision Making by Ilene Corina & John James
Pg. 7 – In Memoriam Becky Martins
Pg. 8 - Take Charge Step 3 is Make a List of ?s
Pg. 9 – Graphics Garden

Consumers Advancing Patient Safety is a 501c3 not-for-profit organization that envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just. CAPS champions patient safety led by consumers in partnership and collaboration with providers. To support CAPS's work, please consider donating through your VENMO account to @CAPS-PatientSafety. If you prefer to use PayPal, our account is under Consumers Advancing Patient Safety or go to www.paypal.me/patientsafety.

CAPS Consumer Advisory Panel Profile



Patricia (Trish) Pooley lives in the Kansas City metropolitan area with her three rescue cats. Her dog, Dash, recently had to go live elsewhere because of Trish's current situation. Trish has been a dog trainer, artist, hippie, stockbroker and managed a commercial photography studio. She has lived in St. Louis, Topeka, Nashville, Seattle, Lincoln (NE), Hot Springs and Kansas City. Trish stays in touch with her kidney transplant donor family. Her late husband shared her love of nature, dog training and art.

CAPS: When did you start your advocacy?

Trish: Ten years prior to starting dialysis. I was born with adult dominant polycystic kidney disease (PKD). It's fairly common, but not very well known by most people. My father died at age thirty-three due to this kidney disease and a ruptured aortic aneurysm. As a teen I had spinal meningitis. When they looked at my kidneys, they found I too had PKD. I was then monitored for kidney disease for years. I had to take care of my kidney health when I went off to college as a teen.

CAPS: How has your advocacy evolved over the years?

Trish: It has changed as my degree of contact with the medical system increased, as I became aware of how important my role is in my health. I have long seen my body as an organic, holistic meditation. I found that in the system, you are no longer whole, you are instead a collection of body parts. I saw specialties laying claim or planting flags on the body part that was "their" turf. I wanted to preserve my sense of self as whole, rather than allow medicine to view me mechanistically. I saw this as an issue early on that is problematic to both patients and providers.

As a young adult, just seven weeks after starting hemodialysis, my nephrologist sent me to the emergency room with what he thought was appendicitis. The appendix had ruptured, but in surgery they found the cause was I actually had a rare cancer. The cancer, which is only found in 4% of patients worldwide, led to the removal of my small bowel. I had told three of my doctors over a nine-month period that I had symptoms consistent with colon cancer. To address the cancer – which had metastasized – required removing half my colon and lots of my small intestines.

I lived! The surgeon told me they had removed all the cancer and recommended no further treatment. He said, "Why go through treatment, you have failing kidneys." I was so young! I thought, there's a good chance some cancer cells remained, and I may need treatment for those. I asked for a referral for a second opinion. So, thirty years ago, with 49 staples I went to the Mayo Clinic in Rochester, Minnesota and came back with a treatment protocol. I believe it is wise to get opinions from several specialties as there is seldom a consensus as how to proceed.

CAPS: What projects have you worked on?

Trish: I was on dialysis for ten years. I joined with 2-3 patients to establish a peer support group. Back then, staff didn't think we should talk to one another. I was part of a grassroots group to establish kidney groups in Missouri and Kansas. We were part of the beginning of the End Stage Renal Disease Networks. We worked to try to bring the patient perspective to the clinical setting and a grassroots effort to get state kidney programs established and funded.

They asked me to work with recalcitrant patients. For example, one patient I worked with had lost a sister who had undergone peritoneal dialysis. The patient didn't want to undergo dialysis because it would interfere with playing sports. No one had talked to him about a fistula as an option. He also wanted to get engaged. But he had been prescribed blood pressure medicine that was causing erectile dysfunction. I suggested he explore his options. No one had done shared decision making with him based on his lifestyle and concerns. I listened. That's all. The patient started dialysis three days

later. The last time I saw him, he was still competing in his sport, he was engaged, and he was attending college on vocational rehabilitation grants.

I've been on total parenteral nutrition (TPN) for over thirteen years. I have helped many other patients. I have been asked by doctors to teach other patients and caregivers how to manage self-care of their central line. I've had only three infections in thirteen years, each introduced by a healthcare worker who was not using sterile technique.

It is vital to test all assumptions. Ask for a second opinion if your concerns and questions aren't being answered. I did this recently and discovered that my kidney transplant is rejecting as I suspected.

CAPS: What can persons do to advocate for quality and safety in healthcare?

Trish: Be knowledgeable. Begin educating persons on a care team right away. Don't hesitate to speak up. Promote collaboration on your team.

One time a nurse took my medicines out of their packaging prior to bringing them in the room. They didn't look like the same medicines I had been taking. One was missing. The nurse said, "Oh, it was discontinued." I asked by whom? What was the reason? I also said I wouldn't take the unidentified pills she wanted to give to me.

I don't live on a patient unit. I live in the world. It seems like when you are a patient you move from being helpless and dependent to, BOOM, on your own. When I am in-patient, the staff tend to not want me to connect to my own care, even though I have a better safety track record. It's as if when you come into a unit, you automatically relinquish control to staff who take full responsibility for your care. Persons who want to advocate for themselves need to remain aware and maintain a sense of autonomy.

CAPS: What can facilities and systems do to advocate for quality and safety in healthcare?

Trish: Get patients involved on committees and making recommendations for improvement. Patients need to be a part of the bedrock of patient safety. Decisions need to be made with patients.

CAPS: What are your future plans?

Trish: My transplanted kidney is failing. My nephrologist needed a biopsy to know what was happening. It took over a month for me to get that biopsy. They found almost no scar tissue or fibrosing – but it is failing. I am trying to get a facility in Kansas City to support in-patient plasmapheresis with a patient receiving TPN. It's exhausting and I am reaching for help 24/7. I feel like I have to be very careful in how we talk about this because I don't want to experience retaliation.

I remember once I was in the Emergency Room for a clot in my arm. A staff member kept shouting, "Are you ready for me to do the arm yet?" I said, "Hey, let me introduce myself. I'm the arm, but you can call me Trish." I found a way to introduce humanity into that moment.

Hi, I'm the kidney and I'm the central line needing TPN. But you can call me Trish. Right now, I'm fighting for my life while I am preparing for my death.

If you can help Trish solve her treatment dilemma, please contact her at trishpooley@gmail.com.

The videos in a series of COVID-19: Patients, Families and Providers in Conversation may be found at this link:

<https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>

These videos are a collaboration of three organizations:

Consumer Advancing Patient Safety (CAPS), Project Patient Care (PPC) and Healthcare and Patient Partnership Institute (H2Pi).

You can view all of these videos on the Consumers Advancing Patient Safety YouTube Channel. Please go the link and be sure to hit subscribe **and** notify so you will know when a new, relevant video has been uploaded!



Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here:

Steven Charlap, MD, reached out to CAPS to visit about medical diagnostic errors. Like so many of us, a family member of his went undiagnosed for cancer until too late despite a strong family history of early cancer. The resulting treatment delay was catastrophic, and Dr. Charlap's family member passed away.

Dr. Charlap notes that over 12 million diagnostic errors are made each year. Cancer and heart disease are among the most often mis-diagnosed diseases. Dr. Charlap and his colleagues at SOAP (Subjective, Objective, Assessment, Plan) Health have developed a three-component system using artificial intelligence (AI) to augment physician diagnostic expertise. These tools have been validated at Stanford™ and elsewhere.

1. The Perfect Medical Interviewer™ is a patent-pending, conversational AI-powered digital human application. It has been clinically validated to collect actionable data from patients. The app can collect more information than a doctor or nurse can collect prior or during an average visit. In a recent pilot, it collected twice the data and 44% more actionable data in 20 minutes than a team of doctors and nurses could collect.
2. Riskvue™ is a decision support application using 400+ algorithms that evaluate the collected data for early disease risk. It also uses a symptom triage tool to generate a presumptive list of diagnoses.
3. The Smart SOAP™ compiles the data into a 50-90% completed clinical note pre-visit.

Dr. Charlap's hope is that these tools will save millions of persons from premature death by providing early disease detection and better diagnosis. He is seeking pilot sites to test the application that his team has developed. If you are interested in improving early disease risk detection and diagnoses at your facility, contact Dr. Charlap at scharlap@soap.health or 617-319-6434.

The SOAP Team: Steven Charlap, CEO, is a Yeshiva BA, NYU MD, Surgeon, Harvard MBA, Stanford Fellow, Published Researcher, and Grant Recipient, Harvard Visiting Scientist, and serial medical entrepreneur, founder of HealthDrive, a 2-time INC 500 company, largest US provider of medical and dental services to extended care facilities, and developer of the first US mobile, multispecialty electronic health record system (company sold to private equity firm.) Sinhwa Kang, PhD, Director of Digital Humans, is a 12+ year digital human researcher. Tom Mercier, CTO, is a 20+ years engineering manager for new product releases.

Safer Medical Care Through Shared Decision Making: Is Informed Consent a Patient Safety Issue

By Ilene Corina, BCPA, [Pulse Center for Patient Safety Education & Advocacy](#) and John James, PhD, [Patient Safety America](#)

Many people believe that informed consent is a legal issue and doesn't belong in the patient safety conversation.

Ray was working when he received the phone call that his mother was going to have a procedure to remove gallstones. As his mother's legal healthcare surrogate, he was informed about any healthcare decisions that needed to be made since she had mental illness and did not, in most cases, understand medical procedures.

Ray was told they were going to perform an ERCP but first do a CT scan and then an MRCP, and finally the ERCP. Having worked in a hospital setting, Ray knew that they were looking for his [informed consent](#). He stopped them and asked what exactly the procedures were, how they are done, and what the expected outcome was. He asked what the risks of harm were, and whether there were any other choices, including doing nothing. He also knew to ask if his mother would be given any drugs off-label (not approved by the FDA for her specific age). Ray was asking for shared decision-making before he gave his informed consent. When the answers he received were incomplete, he asked for more complete information. Not everyone knows to do that.



[Shared decision-making](#) is a dialog between clinician and patient in which the physician elicits the patient's preferences for treatment given the available options for care. For example, if one option for treatment is a powerful chemotherapeutic drug, the patient may prefer to forgo treatment if his quality of life will be seriously impaired by fatigue, nausea, or mental disturbances. At the age of 90, Kevin was diagnosed with pancreatic cancer and offered chemotherapy. During shared decision-making, Kevin learned that the side effects were debilitating. These days, two years later, Kevin is doing well with only minimal growth of his tumor.

According to the American Medical Association, informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information and ask questions about recommended treatments so they can make well-considered decisions about care.

In a hospital, patients are often handed a sheet of paper to sign, saying that they consent to a procedure. Informed consent should be the end result of shared decision-making between patient and clinician. The process leading to becoming a fully informed patient may require assertive questions. For example, the patient may be told that there is a risk of infection from a proposed procedure. The patient should ask, "What is the probability that I will get an infection and how will it be treated?" Another example is the probability of getting a life-threatening cancer from uterine fibroid surgery if the tissue is ground up before removal from the body. Originally thought to be about 1 in 10,000, it is now known to be about 1 in 350. Even the statistic of one out of thousands can be scary to some, but for others too low to worry about. Still, it is the patient's right to decide if they want to take the chance, whether risky or not.

People don't know what to ask, or whether they are, in fact, getting enough information, so they may "google it," which clinicians may frown upon. There are websites for viewing how surgery is done and what a patient can expect. There are useful online sources. Decision aids for patients should be an integral part of shared decision-making. Ideally, these aids should be viewed by the patient before the patient begins the shared decision process with her clinician. Ask your clinician if the decision aid you are using is trustworthy. The proper approach to this is to communicate to the doctor that you are curious or educating yourself, not that you do not trust the clinician.

You may also ask for a second, independent professional opinion if there is appreciable risk and uncertainty associated with the proposed invasive treatment. Do not be pushed into signing a consent form until you are confident you have made an optimal decision about your care.

Although we think of informed consent as the paper we sign, it's actually the process of informing the patient and/or family. The signature means that the discussion happened, and the signer is satisfied with the information. But what if you don't know what information is being given? How do we know if what we are being told is enough information to warrant getting that procedure? For cancer treatment, for instance, consider reaching out to support groups either in your area or through social media. Find out about others' experiences and what questions you should ask. This needs time, so this process should be done long before the procedure itself.

When told she had an arrhythmia, a woman aged fifty said that sounded scary, and she knew it was something potentially dangerous. She was glad to get a diagnosis. The treatment, the doctor explained, was an implantable electrical shock device to impel her heart back into a normal rhythm. The woman asked to think it over and at her next visit told her doctor that surgery was not an option. "So, what now?" She asked the doctor about other options. The doctor started her on medication. "That was ten years ago," the woman explained. "I had to speak up and ask for the alternatives. I have never regretted that decision, nor have I had another arrhythmia episode."

While most people will say that informed consent is a legal and ethical issue, it can also be seen as a patient safety issue and should be part of the patient safety conversation.

The process must include the patient's full disclosure and honesty with their clinician. A full list of medications, medication reactions, past medical history and allergies are all important for the shared decision-making process. People hesitant to share their abuse of alcohol or pain medications open themselves up to potentially dangerous outcomes if the medical team is unaware of a full and accurate history of the patient. A 33-year-old woman had a dental procedure that could result in serious pain, so her dentist prescribed an opioid painkiller for her. That night she took sufficient pain pills to unintentionally kill herself. The dentist was unaware of her tendency of addiction to opioids.

The wise patient will have her questions prepared beforehand and make notes during shared decision-making. If you are not up to it, a family member, friend or even a professional patient advocate might be a good resource to ask for help. It's always a good idea to have a support person available if you're about to make a decision that can be as serious as surgery. A support person can help think of additional questions to ask.

The full medical history, medications and concerns should be part of any conversation that might help decide if the procedure or surgery is even appropriate for the patient. These conversations often happen at the bedside, moments before the procedure is to be done. The doctor may come to the patient in scrubs and carrying a clip board. This is not the appropriate time. It needs to happen long before that moment.

Jim had been feeling troubling symptoms and was referred to a neurosurgeon. He diagnosed a pituitary tumor and told Jim he could remove it. Jim agreed, but did not recover as expected from the surgery, and later learned that it had not even been necessary. Because most pituitary tumors are not malignant, Jim could have chosen watchful waiting, avoiding the risks associated with surgery. The state medical board assigned six hours of training to the neurosurgeon and fined him \$3,000. This was a clear case of failure to give the patient sufficient information to make a safer decision. In many cases, there will not be an unplanned outcome such as death or injury. Still, it is the patient's right to have this information.

<https://www.ama-assn.org/delivering-care/ethics/informed-consent>

In Memoriam Becky Martins

With great sadness we recently learned of the death of one of the founding members of CAPS, Becky Martins of Warren, Maine. Becky attended the inaugural meeting of CAPS in 2003 and remained active with us throughout the years. She was a significant figure in the early years of the patient safety movement, as a member not only of CAPS but of the National Patient Safety Foundation's original Patient Advisory Council. She was the founder of the voluminous Voice4Patients website, a valuable compendium of resources for patients. Her passing is a loss to all of us who work in patient safety. Please see the following tribute published by TMIT Global, where Becky also served as a longtime patient advocate:



“Becky Martins’ advocacy spirit derived from the days when she was driving a family member 150 miles round-trip, three days a week, to dialysis treatments. She spent countless hours at the unit visiting with patients and their families. It was through their stories that she learned of the many challenges faced by patients living with chronic illness. It was by their example that she learned of the resilience of the human spirit to face health and health-related challenges head-on.

“The unit was her classroom, and her teachers were the patients and families, along with the unit staff who cared for them. The experience became the impetus for her advocacy on behalf of end-stage renal disease patients. In 1996, Becky was the recipient of the Kidney Foundation of Maine Board of Trustees’ Service Award for 10 years of service. In 2002, Becky founded Voice4Patients.Com: an initiative to empower patients to be their own health care advocates. The site advocated building partnerships between patients and providers – and provided information and tools to strengthen consumer skills.

“Becky Martins was a champion of patient- and family-centered care, effective communication in health care, and patient and family involvement: from the board room to examining room. She was a TMIT Patient Advocate Team Member; a Patients for Patient Safety Champion of the World Healthcare Organization’s World Alliance of Patient Safety; and a past member of National Patient Safety Foundation’s Patient & Family Advisory Councils. She was a contributor to “Opportunities for Patient and Family Involvement” – Chapter Nine of the National Quality Forum’s Safe Practices for Better Healthcare – 2009 Update: A Consensus Report.

“The 121st Maine Legislature presented Ms. Martins with a Special Sentiment for her patient safety advocacy. She is a recipient of the Pete Conrad Patient Safety Excellence Award. Becky Martins passed away in July of 2020. Her wonderful words, affirmations, and voice of the patients expressed through TMIT Global webinars will be remembered forever. A woman of faith and true community leader with a servant’s heart, she will always be a role model to patient safety champions.”



TakeCHARGE Campaign Moves to Step 3: Prepare for Doctor or Hospital Visits — Make a List of Questions

#3 of public awareness campaign’s “5 Steps to Safer Health Care” aims to prevent “doorknob moments”

The TakeCHARGE Campaign: 5 Steps to Safer Health Care is pleased to announce that June is the month for people to follow Step 3: Prepare for Doctor or Hospital Visits — Make a List of Questions.

When we visit a doctor or hospital, we are often worried and stressed. In other words, we're not thinking as clearly as we'd like. We may be getting bad news, or having to make critical decisions about treatments. Often, we forget what we meant to say. This leads to "doorknob moments", when at the last second, while the clinician has a hand on the doorknob to leave the room, a patient suddenly remembers a question they'd meant to ask, or a detail they'd forgotten to mention.

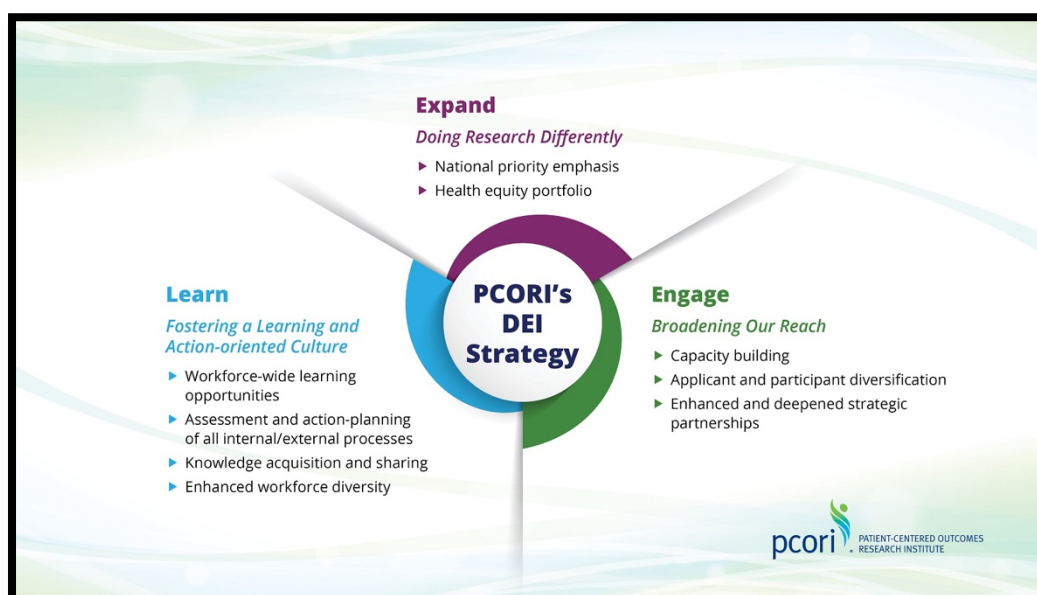
For more suggestions about Step 3, please visit <https://takecharge.care/step-3/>.

To learn more about the TakeCHARGE Campaign, please contact [the TakeCHARGE organizer](#).

I can't *believe* I forgot to ask the Doc if headache is a symptom of covid-19! Next time I'll write it down.

Step 3 of the TakeCHARGE Campaign:
Prepare a list of questions and symptoms *before* you visit your doctor or go for a procedure or to the hospital.

Graphics Garden:

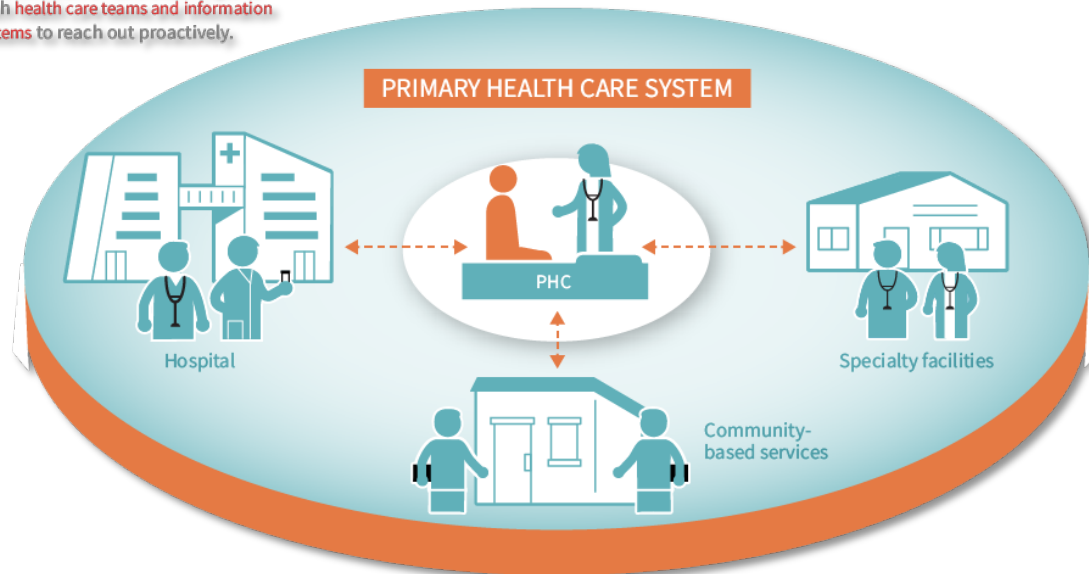


HIGH-QUALITY PRIMARY HEALTH CARE IS

Coordinated

High-quality primary health care is coordinated around a person's needs and preferences throughout treatment and across various care sites. Coordination ensures appropriate follow-up treatment, minimizes the risk of error, and prevents complications.

Coordination of care often requires both **health care teams and information systems** to reach out proactively.



BE PROUD. BE HEALTHY.



LGBTQ INDIVIDUALS HAVE UNIQUE HEALTH CARE EXPERIENCES AND NEEDS.
AT CHASE BREXTON, WE TAKE PRIDE IN KNOWING ALL ABOUT THEM.

You can feel safe discussing your gender identity and/or sexual orientation, behavior, and history with our expert providers so they can provide the most appropriate care possible.

LESBIAN	GAY	BISEXUAL	TRANSGENDER
<ol style="list-style-type: none"> 1. BREAST CANCER 2. DEPRESSION/ANXIETY 3. HEART HEALTH 4. GYNECOLOGICAL CANCER 5. FITNESS/OBESITY 6. TOBACCO USE 7. ALCOHOL CONSUMPTION 8. SUBSTANCE USE 9. INTIMATE PARTNER VIOLENCE 10. SEXUAL HEALTH/STDs 	<ol style="list-style-type: none"> 1. DISCLOSURE/COMING OUT 2. HIV/AIDS, SAFE SEX 3. HEPATITIS IMMUNIZATION AND SCREENING 4. FITNESS/EATING DISORDERS/OBESITY 5. SUBSTANCE USE/ALCOHOL 6. DEPRESSION/ANXIETY 7. STDs 8. PROSTATE, TESTICULAR, AND COLON CANCER 9. TOBACCO USE 10. HUMAN PAPILLOMA VIRUS (HPV) 	<ol style="list-style-type: none"> 1. DISCLOSURE/COMING OUT 2. HIV/AIDS, SAFE SEX 3. HEPATITIS IMMUNIZATION AND SCREENING 4. FITNESS/EATING DISORDERS/OBESITY 5. SUBSTANCE USE/ALCOHOL 6. DEPRESSION/ANXIETY 7. STDs 8. CANCER (PROSTATE, TESTICULAR, BREAST, CERVICAL, AND COLON) 9. TOBACCO USE 10. HUMAN PAPILLOMA VIRUS (HPV) 	<ol style="list-style-type: none"> 1. ACCESS TO HEALTH CARE 2. DISCLOSURE OF HEALTH HISTORY 3. HORMONES 4. HEART HEALTH 5. CANCER 6. STDs/SAFE SEX 7. ALCOHOL CONSUMPTION/TOBACCO USE 8. DEPRESSION 9. INJECTABLE SILICONE 10. FITNESS/OBESITY

QUEERS
THERE ARE NO "TOP TEN" HEALTH CONCERNS FOR ALL THOSE WHO IDENTIFY AS QUEER. INSTEAD, HEALTH CONCERNS ARE INDIVIDUAL SPECIFIC. TALK WITH YOUR PROVIDER TO DETERMINE YOURS.

SOURCE: GUTENBERG

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