

The Women's Health Activist.®

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What to Expect When You Stop Expecting: Demystifying Miscarriage and Medication Abortion

By Sarah Christopherson



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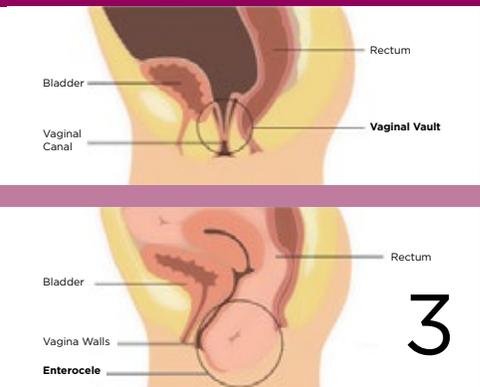
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DIRECTOR'S MESSAGE

When Even the Best Self-advocacy isn't Enough

By Cynthia Pearson



Cynthia Pearson is the Executive Director of the National Women's Health Network.

The NWHN was founded by women who wanted safe drugs and medical devices, honest information about medical conditions, and respectful treatment from doctors. The NWHN founders wanted to have a say in their own health care, which was a radical idea in the 1970s, when “doctor knows best” was a common attitude.

Having a say — or “self-advocacy,” as it’s referred to now — is a great way to ensure that any treatment you receive is best for you. Health care providers, like doctors and nurse-practitioners, don’t always approach patients in a way that supports self-advocacy, though; and sometimes it’s difficult to speak up. To help, Tessa Ruff has written a handy guide to self-advocacy during a family planning visit. Although the family planning field is heavily influenced by the women’s health movement and officially supports clients’ right to choose a contraceptive method that works best for them, the current emphasis on promoting very highly effective methods can be disrespectful to clients. Many family planning clinicians’ counseling style presents the most effective methods first (i.e., IUDs, implants), and doesn’t mention any other methods unless the client insists. The reasoning is that the most effective methods are the “best,” so this counseling approach is, therefore, the most helpful to clients. But, many women have told us that they felt pressured to accept an IUD, and their desire for information about other options was dismissed, as if they were foolish, or were personally disappointing the clinician. We hope this guide will help people who need birth control to feel comfortable advocating for the method that best meets their needs.

Self-advocacy is easier if you need contraception. You know whether or not you need it and there are lots of choices with reliable information about their effectiveness and safety to guide informed decision-making.

This newsletter also explores a condition for which it is much more difficult to self-advocate: pelvic organ prolapse (POP). POP is very common, but women often don’t know what it is until they’re told they have it. Once a woman realizes she has POP, making decisions about treatment is difficult because there’s a lack of information about different treatment’s effectiveness and safety. Sherrie Palm’s article, “The Biggest Secret in Women’s Health,” highlights an all-too-common problem: you can’t advocate for your treatment preferences to be respected if there’s little or no reliable information about your condition, its causes, and its treatments.

What can you do when self-advocacy isn’t enough? Some people feel so passionately about the need for better information, research, and treatment for their condition, they join an activist organization — or even create one while simultaneously coping with the disease’s impact on their lives. I’ve had the privilege to meet many patients-turned-activists, and have enormous respect for them, and their organizations. (See the resource list on our website for a partial list of some of these patient-led, independent organizations.)

But, not everyone has the time or resources to make their health condition their cause. How do they get good care, when self-advocacy isn’t enough? One way is to try to find a care provider who is honest about what they do and don’t know. I wish we had a list like that on our website! Until then, you can count on the NWHN to continue to advocate for better research on conditions that affect women. ❀

“The NWHN founders wanted to have a say in their own health care, which was a radical idea in the 1970s, when ‘doctor knows best’ was a common attitude.”

The Biggest Secret in Women's Health

By Sherrie Palm

We women tend to address everyone else's needs ahead of our own. We nurture our significant others, feed the kids, walk the dogs, pick up groceries, clean the house, and navigate employment. As we address the multitude of things that impact our personal and family flow, we tend to overlook one of the most significant — how we physically feel. And, while we're all aware of basic wellness screenings to address breast, heart, diabetes, and menopausal health concerns, current wellness exams seldom effectively evaluate one of the most common conditions impacting women: pelvic organ prolapse (POP).

POP is the biggest secret in women's health. The condition remains shrouded in stigmatized silence, even though POP impacts an estimated 50% of all women worldwide — probably more.¹ Women mid-teens through end of life. Women of all races. Women of all sizes. Women in every sociocultural demographic. The stigma shrouding POP in silence is unsettling and unacceptable, and prevents women from being diagnosed and treated.

The pelvic organs include the uterus, bladder, rectum, and/or intestines. POP occurs when the pelvic floor's tissues and muscles no longer sufficiently support these organs. As a result, the organs drop from their normal position in the pelvic cavity and push outside the body through the vagina. The top (apex) of the vagina may also prolapse inside itself after a hysterectomy.

"I was shocked to hear how common it was and ashamed that, as a country, we don't do more to prepare women for the after-effects of child birth. We owe women more education, more support, and less stigma wrapped around this problem."
— D.O., New Jersey

POP is seldom life-threatening but is always life-altering. POP's negative impact on quality of life is far-reaching, and affects women physically, emotionally, socially, sexually, and in fitness and employment. Yet, most women aren't even aware POP exists before their diagnosis, which is problematic.

Under the surface of today's climate of female empowerment, millions of women are coping with symptoms indicating they have a condition most have never heard of. How can women pro-actively seek diagnosis and treatment for a condition they aren't even aware exists?

"One of the most gratifying aspects of being a urogynecologist is caring for a patient who believes she is the only person in the world with pelvic organ prolapse. Realizing she's not alone is transformative for the patient's psyche and emotional well-being."
— S. Abbas Shobeiri, MD, Professor of OB/GYN, INOVA Health System

Discovery upon diagnosis is the norm for most women. The *status quo* for POP awareness and wellness screening hasn't changed meaningfully since the condition was first described nearly 4,000 years ago. The recent push to expand women's wellness screening isn't helping either, unfortunately, since women's wellness screenings seldom screen for POP. What's wrong with this picture?

"You hear of and try to prevent major life-changing diseases and conditions like cancer, Alzheimer's, osteoporosis, etc. All I'd ever heard of pelvic organ prolapse before it consumed my life starting in my early 30s was when a friend once joked about her grandma having to shove her uterus back inside of herself. I didn't believe such a thing was actually possible; it didn't even make sense. I also never realized how isolating it could be to be so 'broken' physically. I don't have a pink ribbon, a hashtag 'me too,' or any clichés about being a warrior or strong."
— R.M., Indiana

A multitude of lifestyle, behavioral, and co-existing health conditions compound the risk of POP, including childbirth; age; heavy lifting; chronic constipation; chronic coughing; hysterectomy; genetics; hard foot-strike fitness activities, like running marathons or jogging; or other comorbid conditions including multiple sclerosis, Marfan Syndrome, Ehlers Danlos Syndrome, and spina bifida.

When most women discover a bulge of tissue pushing out of their vagina and **CONTINUED ON PAGE 5**

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The National Women's Health Network improves the health of all women by developing and promoting a critical analysis of health issues to influence public policy and support consumer decision-making. The Network aspires to a health care system that is guided by social justice and reflects the needs of diverse women.

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What to Expect When You Stop Expecting: Demystifying Miscarriage and Medication Abortion

By Sarah Christopherson



In response to the confirmation of two hard-right Supreme Court justices and an increasingly hostile judiciary that threatens women's access to clinic-based abortion, the NWHN has been working hard to demystify medication abortion for the public and push back against medically unnecessary restrictions imposed by states and the Food and Drug Administration (FDA).

We want women to know that medication abortion (abortion induced by taking FDA-approved pills) is physiologically indistinguishable from a miscarriage that occurs on its own. And while every woman is going to feel differently about her experience with either — there is no right or wrong way to feel! — the physical process, symptoms, risks, warning signs, complications, and treatments are the same. In fact, abortion pills are often used to help treat incomplete miscarriages.

But, as we worked to demystify medication abortion and place it in the context of a very normal part of human reproduction, it became clear that we needed to first demystify miscarriage itself. While American women once talked more openly about miscarriage, the late 20th century saw a significant cultural shift, dropping a veil of secrecy and shame over the experience.

Earlier this winter, *CNN Business* ran an article entitled, "Miscarriages are common. But at work, a culture of silence keeps women quiet."

In the piece, a woman recalls: "What's so crazy is through having my miscarriage, I found out how many people I knew had miscarriages. And I'm like 'I wish you would have told me.'"²

CNN identified fear of discrimination in the workplace as one reason women may be reluctant to speak openly about their pregnancies, highlighting research that shows women pay a "motherhood" penalty in lost income and status as soon as they're seen being on the "mommy track." But the anti-abortion movement has also played a key role, aggressively working to confuse women about the science of miscarriage and to punish them when one occurs.

Fake women's health clinics (sometimes referred to as "crisis pregnancy centers" or "pregnancy resource centers") have been known to significantly exaggerate the likelihood of miscarriage in an effort to dissuade pregnant people from seeking desired abortions.³

At the same time, anti-abortion zealots have used a combination of decades-old laws and radical new "personhood" measures to criminalize miscarriage and charge women for "endangering" their pregnancies. In overturning one woman's manslaughter conviction, the New York Court of Appeals cautioned in 2015 that, under the prosecutors' approach, "one could find it 'reckless' for a pregnant woman to disregard her obstetrician's specific orders

concerning bed rest; take prescription and/or illicit drugs; shovel a walkway; engage in a contact sport; carry groceries; or disregard dietary restrictions."⁴

Even without zealous prosecutors, women often blame themselves for a miscarriage and question what they could have done differently. Speaking to *The Cut* last year, health historian Shannon Withycombe captured this phenomenon: "Once you miscarry, especially if you haven't heard the statistics about how common it actually is, it's easy to think it's your fault, or that you did something wrong. Which only encourages women to stay silent."⁵

Here's what you should know:

- A medication abortion is an abortion that is induced by FDA-approved abortion pills — most often a combination of mifepristone (brand name Mifeprex) and misoprostol (brand name Cytotec, among others) — usually within the first 10 weeks of pregnancy.⁶ Some pregnant people may choose a medication abortion with the help of a licensed medical provider, others may choose to self-induce with pills that they acquire and take on their own. The NWHN strongly supports the right of individuals to make these choices for themselves. Read our position statement on this issue here: <https://www.nwhn.org/taking-abortion-pills-nwhns-position-self-induced-abortion-using-fda-approved-medication/>.
- A miscarriage (often called a "spontaneous abortion" in medical parlance) occurs when an early pregnancy (a pregnancy of less than 20 weeks) ends on its own. The American College of Obstetricians and Gynecologists estimates that

"We want women to know that medication abortion (abortion induced by taking FDA-approved pills) is physiologically indistinguishable from a miscarriage that occurs on its own."



10 percent or more of known pregnancies end in miscarriage.⁷

- Miscarriage is almost never directly related to the actions of the pregnant person, and is most often the result of chromosomal abnormalities that happen by chance during early embryonic development.
- And whether an early pregnancy ends spontaneously or as the result of intervention with pills, doesn't impact someone's ability to become pregnant again.^{8, 9} Having one miscarriage does not change the likelihood that a person will be able to get pregnant again if she wants to, and there is no evidence that an abortion impacts future fertility.¹⁰

To combat bad and confusing information and to encourage women to talk more openly about their experiences, we created a Fact Sheet explaining medication abortion and miscarriage, outlining what to expect when experiencing either and what to watch out for: <https://nwhn.org/abortion-pills-vs-miscarriage-demystifying-experience/>.✿

References are available from info@nwhn.org.



Sarah Christopherson is the NWHN's Policy Director

The Biggest Secret

FROM PAGE 3

looking somewhat tumor-like, they panic. But many of POP's symptoms are less obvious. Women often believe urinary incontinence is a symptom of childbirth or aging — simply a “fact of life” they must tolerate. Chronic constipation is incredibly common with POP, but when women bring it up in wellness visits, they're typically told to consume more fiber and water, and get more exercise. What about vaginal pressure? Fecal incontinence? Rectal pressure? Pain with intimacy? Inability to start the urine stream? Lack of intimate sensation? Tampons pushing out? No one tells women these symptoms mean something, have significance, and are flags that something isn't functioning properly in their pelvic cavity. And, women are seldom asked appropriate POP symptom questions during the brief time providers have to perform routine pelvic exams.

“Knowledge is power, and a woman should have all the information she needs to make an informed decision about her body.”

—Roger Dmochowski, MD, Associate Surgeon-in-Chief, Vanderbilt University Medical Center

The steps to stimulating awareness of POP are taking too long. Which is related to the lack of open dialogue about pelvic organ prolapse at the diagnostic level. Which is related to inadequate POP diagnostic clinician curricula and training. Which is related to lack of academic evolution in the gynecologic sector. If our gynecologists, physicians, midwives, and other health care clinicians who provide pelvic exams aren't educated on POP's prevalence and the need for routine screening, how can the *status quo* ever improve?

We need to talk about this — OUT LOUD. Considering the estimated 50% prevalence, POP is undoubtedly an aspect of female health that should be routinely screened for, diagnosed, and treated, just like heart health, breast health, blood pressure, and blood sugar. Silence should no more surround vaginal and pelvic health than any other aspect of women's wellness.

Health knowledge is empowerment. It's imperative that *all* women educate themselves about this common, cryptic condition. Women can pro-actively self-screen for POP by using a hand-held mirror to examine their vagina and

see if tissues are bulging out. You can also request POP screening from one's primary care provider or gynecologist. Ideally, they'll make a referral to a Female Pelvic Medicine Reconstructive Surgery urogynecologist or urologist for a definitive diagnosis. A treatment path can then be developed.

French Perineal Re-Education

The French government pays for “perineal re-education” as part of post-childbirth maternal care. This consists of 10 physical therapy sessions to strengthen the pelvic floor muscles that are responsible for ensuring bladder continence and keeping the pelvic area's organs in the right place. This is an example of a preventative measure with profoundly positive effects on people's comfort and long-term health. The exercises help strengthen the pelvic floor, which helps prevent POP, which is commonly treated by high-risk surgery in the U.S.

As in every under-recognized aspect of health, we don't know what we don't know. Every woman who is newly diagnosed with POP — or suspects she has POP because she's Googled her symptoms — must travel down a complicated path of discovery. There are five types of POP, four levels of severity, numerous types of POP that occur simultaneously, and a diverse array of possible symptoms...the list of variables goes on and on. The only universal factor is that POP occurs to *women* and that women world-wide suffer in embarrassed silence. We must draw back the curtain veiling the biggest secret in women's health.

The next significant shift in women's wellness, screening, and diagnostics protocol is a whisper away. It's time to bring pelvic organ prolapse out into the open.✿

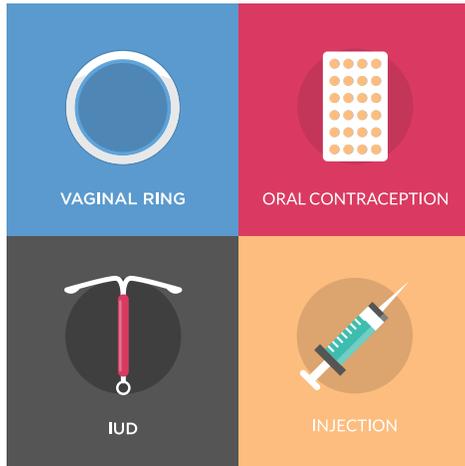
References are available from info@nwhn.org.



Sherrie Palm is the Founder and Chief Executive Officer of the Association for Pelvic Organ Prolapse Support (APOPS). The APOPS website offers resources, as well as a private Facebook-based support forum where women from 177 countries share guidance and support one another.

Contraception Self-Advocacy

By Tessa Ruff



Human sexuality, pregnancy prevention, and pregnancy intention are all complicated issues. And, people must balance a range of trade-offs when selecting the contraceptive option that works best for their unique situation. Many methods are available, which work differently and have diverse side effects, as well as other important considerations. Complicating matters, what one person sees as a benefit, another might view as a drawback.

Unfortunately, too many clinicians pre-judge what's right for an individual before they even walk in the door, rather than letting the individual guide the conversation based on their own reproductive priorities. In the worst cases, implicit or explicit quotas and incentives influence the number and/or kind of birth control methods clinicians prescribe or insert. The NWHN has done a lot of work on this type of contraception coercion, focusing on the ways that clinicians, policymakers, and/or public health funders try to push women into — or away from — particular kinds of birth control. While women across demographic groups report that their medical providers don't always listen to them or respect their decision-making, the problem is particularly acute for women of color, low-income women, immigrant women, LGBTQI individuals, and members of other marginalized communities.¹

Part of our efforts includes helping people become better self-advocates when it comes to their health care. While it can sometimes

be hard, advocating for yourself in the provider's office is a crucial part of ensuring that you get the best care *for you*. No one knows your body as well as you do, so you're the best person to evaluate and make decisions on your behalf. This type of self-advocacy requires people to have the resources and skills needed to assert themselves and communicate their own medical, reproductive, and contraceptive needs. Here are some tips for fostering medical self-advocacy around contraceptive choices.

Before the Appointment

There are many factors to consider when choosing the contraceptive method that's best for you, your lifestyle, and your reproductive goals. Before your appointment, consider what you want from your birth control. If you're currently using contraception, consider what you like and don't like about it. These questions can help guide you:

- What matters to you most in a contraceptive method (i.e., effectiveness, ease of use, etc.)?
- How important is it to you to have a method that is very effective and almost never fails?
- Is it important to be able to “set it and forget it,” or do you want to be able to start and stop the method on your own without going in for a follow-up appointment?
- Is your lifestyle conducive to taking medication at the same time every day?
- Would you like to become pregnant in the future and, if so, when?
- How important to you is it to have a monthly cycle? Would it be an issue for you if your contraceptive method made your period irregular or eliminated it altogether?
- Do you need a method that can be kept private from a partner or parent?
- Are you at-risk of losing health insurance in the next year?

Doing your research doesn't mean you have to arrive at the appointment knowing the exact method you want. But, having a good idea of what you're looking for and what you hope to get out of your contraception will help guide you and your medical practitioner to a method that will work best for you.

During the Appointment

Your provider should encourage you to have a say in your own contraception. This process should not be one-sided, and should not have to fight to make your voice heard. Because of clinician's personal views about contraception — and sometimes about the individual — it can sometimes be hard to make this happen. Here are some tips:

- Express your ideas generated from the questions above. It can help to write your thoughts down before the appointment, or to take notes as you speak with your provider. Many people have a hard time keeping track of all of the details once a conversation starts, risking losing track of important points.
- Evaluate how your provider responds to your needs and concerns. Do you feel that he or she is taking what you say into consideration? If not, ask for additional information, restate your concerns, or consider seeing a different provider (if that's possible, given your insurance, location, and provider options).
- Don't hold back. Your provider is there to provide you with the highest-quality care. The more information you share, the better able the provider will be to assist your decision-making process.
- Ask for clarification if the provider uses terminology that's unfamiliar to you. There are no “dumb” questions when it comes to your body and health care.
- Take the time you need to make your decision.

Preparation and confidence in voicing your own needs will help ensure you can practice successful self-advocacy. People who have the opportunity to make fully informed decisions for themselves are much more likely to be satisfied in the end — and that's good for everyone. ❀

References are available from info@nwhn.org.



Tessa Ruff is the NWHN's Policy Fellow



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YOUNG FEMINIST

Losing My Crown: The Untold Truth about Alopecia

By Afua Nyame-Mireku

I was taught in science class that hair follicles are nothing more than dead cells, but hair has always held much more weight than that for me. Being a Black woman in today's society, I can honestly say that hair is a cultural expression of who I am and how I feel.

Growing up, I always had long, thick, and full hair — even with a relaxer (chemically straightened hair). I would break hot combs and set blow dryers on fire every time I tried to get my hair done.

At home, I was surrounded by nothing but positive affirmations about my hair, but at school it was a completely different story. I never sat at the front of the classroom because, whenever I did, a classmate would exclaim that they “couldn't see over my hair” because it was so large. Between praying for straight hair and

I was ready for well-deserved rest. My mother was cowering my hair when she noticed that she didn't have enough hair towards the nape of my neck to finish the last braid. Confused, I touched the back of my head and, where I was expecting to find a tuft of hair, instead there was a quarter-sized, smooth bald patch. I was extremely panicked, and called my friends to ask if they had yanked it out, and searched Google for “sudden hair loss.” After about an hour of confusion, my mom decided to take me to my dermatologist.

Once at the dermatologist, I was diagnosed with a form of alopecia called “alopecia areata.” Alopecia is an autoimmune disorder that causes the body's cells to view healthy hair follicles as foreign. The cells attack the hair follicles, ultimately resulting

in hair loss.¹ While there are many forms of alopecia, the one I have is characterized by one or more coin-sized bald patches.²

One of the most frustrating parts about this disorder is that there is no cure. Some people experience regrowth of their hair, and others do not. Although alopecia

areata is believed to be caused by stress, it's difficult to treat because researchers are not sure why it occurs.³ The first treatment I used was a topical steroid (Clobetasol propionate) but, as the months progressed, and I continued to lose more and more chunks of my hair, we advanced to corticosteroid injections.

My dermatologist and I tried to fix all of my physical symptoms but no one mentioned any treatment options to deal with the emotional stress of hair loss. My insecurities about my hair reemerged as if they had never left. I was constantly checking in mirrors to make sure none of my bald spots were showing and nervously washing my hair because I did not want to watch it wash down the drain.

At first, when I brought up my hair

loss to my friends, the most frequent expression I heard was “It's just hair.” Though they were trying to comfort me, it made me feel silly for being upset about my diagnosis. The truth is, hair loss is about so much more than “just losing hair.” Alopecia took over every aspect of my life. My hair loss progressed to the point where I couldn't wear my hair in a lot of my go-to natural hairstyles. I dropped out of classes because I was scared of becoming too stressed and losing more hair. For me, losing my hair felt like I was losing my Blackness, losing my womanhood, and losing my sanity.

Baldness is stigmatized in society, especially for women. It is associated with aging and masculinity because it is not uncommon for older men to experience balding at some point in their lives. Seeing a healthy, bald young *woman* is an anomaly for many people. Worse, the “ideal” woman has long, straight hair. When people do not fit inside this box, they're considered “ugly” and “wrong.” The same societal beauty standards that made me nervous about going natural were the same ideals that told me that being bald was not beautiful.

Although my stress levels and anxiety coping mechanisms have substantially improved, my bald spots still haven't grown back — and that's okay! Having alopecia taught me to redefine how I see beauty. I see beauty in my actions, choices, interactions with other people, and how I choose to handle my diagnosis. So many people experience hair loss due to forces outside their control, whether it's alopecia, burn scarring, or cancer. Our hair is a part of us, but it is not our whole story.

The biggest misconception that I had was that losing my crown meant that I was losing pieces of me. I learned that just because I am missing patches does not mean that I am not whole. ❀

References are available from info@nwhn.org.



Afua Nyame-Mireku is studying Public Health Science and Women's Studies at the University of Maryland College Park. She hopes to become a maternal and child health epidemiologist in the future. She was the NWHN Development Intern in Summer 2018.

“Having alopecia taught me to redefine how I see beauty. I see beauty in my actions, choices, interactions with other people, and how I choose to handle my diagnosis.”

begging my mom to leave my relaxers in for longer, I was convinced that existing Black was not enough.

It wasn't until I started college that I finally got up the nerve up to “go natural.” Seeing shameless representations of natural hair from my classmates and in the media changed my outlook on my own hair. I began to understand my hair as a symbol of my blackness — a crown fit for a Black queen.

Unfortunately, while college is a time of self-discovery and acceptance, it's also a time of immense stress. During my freshman year, I did not prioritize my health. Nervously deciding what clubs to join and obsessing over 11:59 pm deadlines led to me forget to take care of myself.

When winter break rolled around,

A New Treatment for Postpartum Depression: Boon or Bane?

By Sophie Krensky and Olivia Shannon

Last November, the Food and Drug Administration's (FDA) Reproductive Health Drugs Advisory Committee voted overwhelmingly in favor of brexanolone, a first-of-its-kind treatment for postpartum depression (PPD).^{1,2} We question whether brexanolone will help mothers or if it's a misdirected silver bullet for a larger, more insidious problem: lack of support during the postpartum period. Brexanolone, developed by Sage Therapeutics, was initially tested — and failed — as a treatment for a dangerous kind of seizure called status epilepticus.³ In 2016, the FDA gave brexanolone “breakthrough designation”⁴ (which speeds the approval process to address “significant unmet need”⁵) for PPD treatment. Brexanolone's evaluation by the Advisory Committee indicates, however, that the FDA wasn't comfortable approving it without external advice.

PPD is characterized by a feeling of hopelessness lasting more than two weeks after giving birth; 1 in 9 new mothers suffers from PPD.⁶ Countries with higher rates of income inequality, maternal and infant mortality, or where reproductive-age women work more than 40 hours a week, have higher PPD rates. A systematic review of studies from 56 countries found that PPD's prevalence internationally was 17.7%, ranging from 3% in Singapore to 38% in Chile.⁷ The U.S. rate is 11.5%,⁸ although multiple speakers at the FDA hearing erroneously claimed a 20% prevalence rate (a rate also cited in brexanolone's clinical trial).

Severe PPD is serious and far less common than the “baby blues” (sadness that lasts three to five days after childbirth and affects up to 80% of new mothers).⁹ But, many mental health conditions are ripe for “diagnostic creep,”¹⁰ which blurs lines between normal function and pathology, expanding the pool of candidates for medical treatment. The baby blues and PPD are ripe for this subtle erasure of differences between conditions. In 2017, Sage Therapeutics launched a PPD “disease awareness” campaign with the slogan “Silence

Sucks,” which showed women sucking on pacifiers and encouraged mothers to talk about PPD.¹¹ The website's been removed and is inaccessible.

The current standard of care for PPD is a combination of talk therapy and antidepressants — usually inexpensive, generically available medications that have been used for decades.¹² In contrast, brexanolone has been studied in relatively few women. The efficacy studies tested 2 doses on 226 women with moderate or severe PPD (213 women completed the trial). The studies found modest but significant improvement for brexanolone compared to placebo. The trial actually included two studies, however, with inconsistent results at day 30: one study showed a benefit while the other did not. Sage's CEO defended brexanolone in a call with investors, stating: “The placebo response was more volatile, which accounted for the inability to show a durable benefit in the moderate study.” In other words, *the placebo worked too well*, putting the drug at a disadvantage.

Adverse events were more common in the brexanolone group than placebo group, including headaches, dizziness, nausea, infusion site pain, somnolence, and fatigue. Three severe adverse events occurred, including altered state of consciousness, severe headaches, and fainting; two patients terminated treatment due to these adverse effects.¹³

These serious adverse effects explain why women must be hospitalized to receive brexanolone, given through a continuous 60-hour intravenous infusion.^{14, 15} The impracticalities are obvious: families with a new baby might struggle with child care and logistics for a three-day hospital stay. The cost of the hospitalization and medication may be tens of thousands of dollars. Further, how much of brexanolone's benefit stems from three days away from the baby, having meals in bed, and not doing housework?

Sage is currently developing a pill form of brexanolone, but it's not yet determined if the same adverse events will occur when a woman receives treatment at home.¹⁶ The effect on breastfeeding babies is also unknown; women were not allowed to breastfeed during this study.

Two Advisory Committee members voted against the proposition that SAGE had adequately described brexanolone's safety for treating PPD, citing concerns about the loss of consciousness events.¹⁷ Most speakers providing public comment had their

travel to the meeting funded by Sage. Although these financial relationships were disclosed, disclosure does not erase bias.

When a pharmacologic intervention is touted as the solution for PPD, mothers and advocates alike should consider if the drug is a BandAid on the larger wound of America's treatment of mothers. How would PPD rates be affected if we adopted policies that support parents, like subsidized child care, paid parental leave, and health care norms that center mothers' choices in childbirth and the postpartum period?

Massachusetts has a PPD program that leverages care providers, psychiatric screenings, and community resources.¹⁸ New York and other jurisdictions have set promising precedents by experimenting with public funding for doula services to reduce adverse childbirth outcomes.¹⁹ Expanding access to postpartum doulas²⁰ — nonmedical professionals trained to help families through the transitional period with a new baby — may not be far behind, as awareness grows about PPD and doula care.

Besides brexanolone's dubious efficacy, it's worth considering the hospital costs, adverse effects, and whether we need a specific PPD drug when numerous antidepressants are already available.

More importantly, nonmedical solutions should be considered with equal — or greater — weight than medication. Pegging the complexities of a new mother's adjustment as a mental illness ignores cultural factors that cause new parents to feel unsupported. Conversations about PPD should be broader than one drug. If brexanolone becomes PPD's therapeutic norm, the onus of treatment will remain where it's always been, on individual mothers — hardly a revolution in postpartum care. ❖

References are available from info@nwhn.org.



Sophie Krensky is the project manager and Olivia Shannon is a research intern at PharmedOut, a Georgetown University Medical Center project that promotes rational, evidence-based prescribing and conducts research on the pharmaceutical industry's influence on medicine.

Rx for Change

Rx for Change: Changing the Culture Around Urinary Tract Infections

By Nancy Worcester and Mariamne Whatley



Nancy Worcester and Mariamne Whatley are Professors Emeritae of Gender and Women's Studies at the University of Wisconsin-Madison. They are long-time women's health educators, writers, and activists who have both served on the NWHN's Board.

Many women may be surprised to discover that what they know about Urinary Tract Infection (UTI) treatment and what, previously, seemed to serve them well is being questioned and may no longer be recommended.

Most UTIs are caused by bacteria and can be treated by antibiotics. Until recently, the identification of bacteria in the urine (by dipstick test or urinalysis) followed by an antibiotic prescription was the usual treatment protocol. UTI management was so routine that women with recurring UTIs (rUTIs) were sometimes given low-dose antibiotic prescriptions for extended time-periods, or single doses of antibiotics to take after sex (if that activity resulted in rUTIs).¹ Some women were allowed to self-diagnose for an antibiotic prescription. There's even a website that promises 24-hour UTI diagnosis and antibiotic prescriptions without a doctor's appointment.²

But, as one researcher noted, UTI is "an ambiguous, expensive, overused diagnosis that can lead to marked, harmful antibiotic overtreatment."³ Now, UTIs are helping change our culture of antibiotic over-prescription, since they are a very common reason for antibiotic use,⁴ they often are healthily resolved without antibiotics, and there are new scientific findings about UTIs' complex nature.

Antibiotic resistance and antibiotics' overuse and misuse

Antibiotic overuse and misuse include: Using antibiotics to treat illnesses, like colds and influenza, which are virally caused and unresponsive to antibiotics; using antibiotics for infections that are self-resolving or can be treated without antibiotics; using

a less-appropriate antibiotic to treat bacterial infections; treating with antibiotics longer than necessary; and stopping antibiotics too early.

Overuse/misuse can cause side-effects, unnecessary expense, and, most significantly, increased antibiotic resistance. Bacteria that are exposed to antibiotics can develop resistance to those antibiotics. As antibiotics kill non-resistant bacteria, the resistant survivors continue multiplying without competition and become a dominant strain among bacteria in any given system. Eventually, antibiotics that were effective in fighting specific disease-causing bacteria may become less effective or ineffective. Bacteria can develop resistance to several antibiotics, causing multidrug-resistance that eliminates antibiotic treatment options. Bacterial infections that cannot be controlled by antibiotics become more common and potentially very dangerous.

The more often someone with a UTI is treated with antibiotics, the more likely she is to experience a recurrence due to the reservoir of antibiotic-resistant bacteria. In addition, since antibiotic treatment disrupts the urinary tract's healthy balance of microorganisms, the environment can become more conducive to the growth of disease-causing bacteria. Many women are familiar with vaginal yeast infections that can develop due to changes in the vaginal flora following antibiotic treatment.

A widespread misunderstanding is that *individuals* become resistant to antibiotics. Individuals who have often been treated with antibiotics may have high levels of antibiotic-resistant bacteria in their systems,

but they themselves are **not** resistant to antibiotics.

New understandings

The urinary tract is comprised of the kidneys, ureters, bladder, and urethra, and hosts many bacteria as part of its healthy environment. These communities of microorganisms (microbiome, or microbiota) are increasingly a focus for our understanding of appropriate health care for the urinary tract as well as UTI prevention and treatment.

Our urine normally contains bacteria (bacteriuria), so its mere presence (asymptomatic bacteriuria) is no longer used to diagnose UTIs and generally does not require treatment. As one researcher noted, "From this perspective, most people who are treated for a 'UTI' would probably be better without treatment,"⁵ although there are some exceptions. The distinction between asymptomatic bacteriuria and UTI is crucial. It is necessary to know which specific bacteria are involved and, if treatment is necessary, to which antibiotics they are susceptible.

Minimizing unnecessary antibiotic use is one way to avoid disrupting the microbiome. Using probiotics may help restore the right balance of microorganisms, thereby reducing rUTIs.⁶ These approaches have helped reduce serious gastrointestinal infections including life-threatening **C.diff**, which often develops after antibiotic use. Recurring and persistent **C.diff** has been treated by doing a fecal transfer from a healthy person to restore the sick person's microbiome. A similar approach holds promise for persistent UTIs, such as by instilling health-promoting bacteria into the bladder.⁷

New research is identifying how UTI-causing bacteria can invade urinary tract cells and attach to those cells and each other, creating an intracellular community that forms a matrix (biofilm) in which the bacteria are embedded and protected. This could explain why UTIs are so hard to eradicate in some women, and offers hope for better solutions.^{8,9}

Now what?

The crisis of antibiotic overuse is being addressed through an emphasis on “Antimicrobial Stewardship” in every health care setting.^{10,11} Consumers may notice the Centers for Disease Control and Prevention’s public education materials from the “Get Smart about Antibiotics” campaign and “Antibiotic Awareness Week.”

On a deeper level, *all* patients and providers need to help change our culture and expectations that antibiotics are always the answer. Many patients have positive attitudes about antibiotic use, and poor knowledge about what antibiotic resistance means — resulting in reduced patient satisfaction when antibiotics are discouraged.^{12,13} Providers report that discussing antibiotic resistance with patients is time-consuming, but that their comfort with **not** prescribing antibiotics increased over time.¹⁴

Changing attitudes toward antibiotics gives women’s health activists new roles in the public health arena. Since UTIs often resolve themselves within a short time (especially with good hydration and over-the-counter treatments) and usually don’t result in more serious issues, many women may welcome the news that it’s responsible and safe to wait about 48 hours before contacting a health care provider. (People who are pregnant or have UTI symptoms accompanied by chills, fever, vomiting, and/or kidney pain should **not** wait to contact their health provider.)

UTIs’ enormous discomforts are a painful reminder that it’s time to think through all of UTIs’ potential causes and what we know works in our own bodies and lives for prevention and treatment. Thank goodness we think of ourselves as informed consumers and active patients! We can question whether antibiotics are necessary and discuss alternatives. The prescription for change, as in other situations, may be fewer prescriptions. (For more information, see the UTI Fact Sheet at www.nwhn.org.)✿

References are available from info@nwhn.org.

Since You Asked!

Question: *Have you ever heard of AlgaeCal? I’m being deluged with ads saying any nutrient supplied in natural form, such as from plants, is absorbed better than nutrients that are supplied from rocks.*

Answer: Many women take calcium supplements in order to improve their bone health and prevent bone loss (osteoporosis). There are two main forms of calcium used in supplements: calcium carbonate and calcium citrate. The calcium is either synthetically created or derived from natural sources like limestone or eggshells, and is absorbed by the body through the stomach lining.

AlgaeCal is a calcium supplement made from red algae. Its manufacturer, AlgaeCal Inc. claims the supplement slows bone loss and increases bone density, and is easily digestible.¹ The company claims that, because algae plants’ calcium and minerals come from seawater, its supplements are “pre-digested” and “bone cell friendly.”² AlgaeCal claims that the body more efficiently absorbs its supplement because the product is derived from plants. But, calcium that comes from algae is still just calcium carbonate — not a new product.

AlgaeCal posted four studies touting its product’s effectiveness. While the studies report positive findings about bone density, none present compelling evidence that AlgaeCal is significantly more effective at improving bone health compared to other calcium supplements.³

The NWHN is also concerned about the study designs. One of the studies was observational, so cause and effect cannot be determined. One studied bone cells (osteoblasts) of mice, so the findings may not apply to humans.⁴ And, participants in two studies also engaged in physical activity as part of the intervention, which in and of itself improves bone health. So, we can’t tell if bone density improvements stemmed from the AlgaeCal supplements, physical activity, or a combination of the two.

One study measured bone mineral density in two groups treated with different doses of AlgaeCal; but, the participants’ treatment regimen also included a *different* AlgaeCal product designed to improve bone density

(a strontium supplement).^{5,6} Again, there’s no way to know which of these products, or which combination of products, improved bone density. It’s also worth noting that strontium supplements can cause inaccurate results on bone density tests, so the study bone density findings might not be accurate at all.⁷

Additionally, studies on AlgaeCal’s effectiveness compared the supplement to either calcium carbonate or calcium citrate. The study compared the AlgaeCal supplement and calcium salts — not to other calcium supplements that contain other minerals, like magnesium, zinc, and vitamin D3, which help the body absorb calcium. It may be that these vitamins and minerals increase AlgaeCal’s effectiveness. So, the increased bioavailability of calcium isn’t a unique feature of AlgaeCal, and AlgaeCal would not be more effective than these common, less expensive alternatives.

AlgaeCal has also posted a 2012 study on its website that looked at the difference in bioavailability between AlgaeCal and Caltrate600,⁸ which appears to suggest that the former product is significantly better than the latter; but no specific data have been posted yet, so it’s really impossible to draw any conclusions.

These factors potentially skewed results and make it impossible to draw any significant conclusion from these studies. For that reason, the NWHN believes that there is currently no compelling clinical evidence to support AlgaeCal’s claims.

The NWHN believes that additional clinical studies are needed to assess whether calcium derived from red algae is any better than currently-available calcium supplements.⁹ There’s just not enough evidence to justify this product’s higher costs. We believe that AlgaeCal appears to be safe but doesn’t seem to offer any benefits that are not available from other, less expensive, over-the-counter calcium supplements.¹⁰✿

References are available from info@nwhn.org.

Online women’s health column: www.nwhn.org/since-you-asked

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SNAP SHOTS

One in every four deaths is related to heart disease, which is the number one cause of death in the US. Quick response from emergency services and rapid treatment are critical in treating cardiac events. Researchers compared the treatment received by men vs. women from Emergency Medical Services (EMS) before arriving at a hospital, to evaluate how often patients received the procedures and medicines (i.e., aspirin) the American Heart Association recommends. The study examined National Emergency Medical Services Information System data on more than 2 million EMS calls for chest pain and cardiac arrest in adults aged 40 and older. Compared to men, women were less likely to be given aspirin, and were significantly less likely to be transported to the hospital using lights and sirens. Women were also less likely to be resuscitated in the event of cardiac arrest. **We need to fix disparities in care women and men receive both in the hospital *and* before arrival.**

Women's Health Issues,
December 2018

Women who suffer from migraines seem to have a reduced risk of developing Type 2 diabetes. Researchers used data from a French cohort study, which collected data on 74,247 women from 1990 to 2014. Researchers tracked these women's migraine incidence and initiation of diabetes medication. In the 24 years prior to a diabetes diagnosis, women's migraine prevalence steadily decreased and remained lower for 22 years after the diagnosis. The authors speculated there may be a role of both hyperglycemia and hyperinsulinism on the occurrence of women's migraines. Further research is needed to determine the exact link between migraines and diabetes.

JAMA Neurology, December 2018

Having a baby reduces breast cancer risk, but this benefit may not appear for several decades. Researchers used data from 15 prospective cohort studies that tracked groups of women under age 55 for 9.6 million person-years of follow-up, to assess childbirth's impact on breast cancer risk. Women who had given birth had a higher risk of estrogen receptor-positive breast cancer, compared to women who never gave birth. The cancer risk lasted for 24 years, peaking 5 years after childbirth (hazard ratio of 1.80, declining to .77). The risk was higher among women who had a family history of breast cancer, were older at first birth, and had more than one child. Breastfeeding, which also reduces breast cancer risk, did not change the slightly higher risk in the years immediately post-childbirth. **The average age of breast cancer diagnosis is 62, so the slightly increased risk is outweighed** by the longer-term reduced cancer risk over the lifespan. Women should take any symptoms seriously and get checked out, whether or not they've given birth.

Annals of Internal Medicine,
January 2019