10 Things You
(And your Health Care Provider)
Should Know About
Vulvodynia, Vestibulodynia, Pain and your Brain

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Vulvodynia is a term used to describe chronic pain or discomfort of the vulva or vestibule in the absence of other anatomic findings. Whether you have been recently diagnosed with vulvodynia or vestibulodynia, or have been suffering for many years from one of these conditions, recent research on the brain, vulvar pain, and chronic pain in general may help you find new ways to think about, manage and treat your condition.

This fact sheet summarizes some of the recent cutting edge research on vulvodynia, vestibulodynia, pain and your brain. Rather than looking at vulvodynia and vestibulodynia as “all in your head” OR “all in your vulva,” its underlying cause is better understood within the system of mind-brain-body interactions related to genetic and psychosocial risk factors, biological and/or infectious triggers, coping skills, and personality traits that affect how the brain is able to perceive, process and manage pain. Hopefully this information will help you better understand your condition, improve your coping, and open you to greater avenues of support that will lead to successful treatment.

1. What does Vulvodynia have to do with my Brain?

• Historically, women who reported vulvar pain or pain with intercourse were often told that the pain was “all in their head.” Being told to “just relax,” “have a glass of wine,” or to see a therapist can be very dismaying for women with vulvodynia, who may have suffered for months or years from their condition, often without a diagnosis.

• Stress is an ambiguous term that is used widely in our culture and is often assumed to be something we have control over – but often we don’t. The brain constantly tries to process everyday physical, environmental, social and psychological stressors through a process of communicating cells and hormones known as allostasis (Sterling & Ayer, 1988). Allostasis is the process by which the body meets stressors and then returns the body to a steady state of balance known as homeostasis. When the body is no longer able to return to homeostasis, resilience is lost.

Allostasis is the body’s way of self-regulating to stay balanced, promote healing and be resilient.

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• Researchers use a term called *allostatic load* to describe “the ways in which the body fails to cope with psychological, environmental and physical challenges” (McEwen & Seeman, 2009). Social context and fear, including social fears, are a significant source of allostatic load (Ganzel, Morris & Wethingon, 2010).

For women with vulvodynia, social fears may include those about their self-image as women, their body image, sexuality and relationships (Basson, 2012).

• It is now understood that repeated exposure to stress either through early or chronic exposure causes wear and tear on the body’s ability to sustain balance and resilience. This occurs through several pathways, most notably through a remodeling of the brain to be less efficient at restoring homeostasis. These changes can alter levels of stress hormones and other neurotransmitters, which in turn affect our thoughts, actions and emotions (Arnstien, 2009) and can also lead to changes in the immune system, gut, and skin (Chrousos, 1997 & 2000; Basson, 2012). Subsequently, a negative feedback loop can develop that alters the body’s cellular communication and hormones towards greater sensitivity to and signaling of pain. A 2008 study by Schweinhardt et al. showed that women with chronic vulvar pain do have differences in their brain anatomy (as compared to aged matched controls), lending further support to the idea that the brain is an important modulator of pain in women with vulvodynia.

2) You are not alone.

• An estimated 7-8% of women in the United States describe vulvodynia-like symptoms. As many as 16% of women may experience symptoms suggestive of vulvodynia in their lifetime (Harlow & Stewart, 2003; Reed & Harlow at al., 2012). Women with vulvodynia report feeling isolated and invalidated (Nguyen et al, 2012).

• Women with vulvar pain experience significant reductions in quality of life (Sargeant & O’Callaghan, 2007). In one study, 42% of women with vulvodynia felt out of control of their lives; 60% reported feeling out of control of their bodies (Arnold et al., 2006).

What can you do?
Seek support from friends, family and/or other women with vulvodynia. Some online resources include:
www.nva.org
www.v-matters.org
www.issvd.org
3) The terms vulvodynia and vestibulodynia describe symptoms but are not necessarily one disorder.

- The pain or discomfort of vulvodynia can be localized or diffuse and provoked or unprovoked (by things such as touch, tampons, clothing or sexual intercourse). These symptoms probably result from more than one cause, or often a combination of factors that may include yeast infections, local peripheral inflammation, pelvic floor muscle pain or tightness, central nervous system pain regulatory pathways and even genetic factors – all of which may differ from woman to woman and activate allostasis that compromise resilience (Bohm-Starke et al., 2001; Witkin, Gerber & Ledger, 2002; Gerber at al., 2003; Foster, Sazenski & Stodgell, 2004; Granot et al., 2004; Haefner et al., 2005; Zolnoun et al., 2006, Andrews, 2011; Leclair et al., 2011; Reed & Payne et al., 2012).

- In some cases, genetics may have something to do with your pain. Women with vestibulodynia may have a genetic variation that makes them more prone to inflammation, which may be triggered in some cases by yeast infections (Foster, Sazenski & Stodgell, 2004; Lev-Sage et al., 2009).

- Women with vestibulodynia have been shown to experience increased sensitivity to touch in other parts of the body including the forearm and foot (Basson, 2012). This is considered evidence of something called Central Sensitization. Central Sensitization is a term used to describe abnormal signaling between the periphery (i.e. the vulva) and spinal cord, and between the spinal cord and brain, which may play an important role in causing and continuing chronic pain (Basson). Future research on vulvodynia has focused on and will benefit from collaborate efforts with the broader pain research community (Eunice Kennedy Shriver NICHD, 2012; Institute of Medicine, 2011; Bachmann et al. 2006).

What can you do?

Although you can’t do much to change your genetics, you can find a healthcare provider who has experience diagnosing and treating vulvodynia. She or he can help you sort out all the possible causes and offer treatment options depending on your particular situation.

4) The pain of vulvodynia is not all in your head, but the effect that anxiety and mood disorders have on the brain probably play a role in the development of vulvodynia in some women. Conversely, vulvodynia can cause recurrent or new anxiety and mood disorders.

- Women with mood or anxiety disorders are 4 times more likely than women without to develop vulvodynia (Khandker et al., 2011).
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- Vulvodynia can increase your risk of new or recurrent anxiety and depression (Khandker, et al.).

- Depression is known to alter pain processing in other conditions such as fibromyalgia. (Basson, 2012).

- People with depression and anxiety tend to perceive pain differently and tolerate pain less, and are also less likely to be able to be distracted from their pain (Meltzer-Brody & Lesserman, 2011).

- Pain contributes to chronic stress that leads to allostatic load and associated psychopathologies such as anxiety and depression. (Juster, Bizik, et al., 2011; Dominick, Blyth, et al., 2012).

5) It may not be a coincidence if you have other chronic conditions.

- Women with vulvodynia and vestibulodynia are significantly more likely than women without vulvar pain to have other chronic pain conditions including interstitial cystitis, fibromyalgia, chronic fatigue syndrome, headache, as well as irritable bowel and chronic fatigue syndrome (Reed & Harlow et al., 2012; Andrews, 2011). Pain increases stress that tips the body’s immune balance toward inflammatory processes and threatens the body’s ability to self regulate itself to stay healthy and balanced. (Dominick, Blyth, et al., 2012). Unfortunately, the more conditions you have, the harder it may be to completely recover from vulvar pain (Heddini et al., 2012), but read on to learn about skills that may help.

- Having multiple conditions as described above is seen as additional evidence for central sensitization, whereby genetic, environmental and psychosocial factors may cause abnormal changes in the processing of pain at the periphery, spinal cord and brain (Basson, 2012).
6) **It is possible that stressful or traumatic life events in your past may have “primed” your brain in such a way that contributed to the onset of (or may play a role in) your ongoing pain** (Plante & Kamm, 2008).

- Most studies show that women with vulvodynia have not experienced higher rates of sexual abuse. However, several studies have shown that women with vulvodynia do report more adverse life events, such as adverse previous relationships, parental divorce or adverse childbirth experiences than women without vulvar pain (Plante & Kamm).

**What can you do?**

*Speak with your health care provider and therapist if you have concerns about how earlier life events may have influenced you today.*

- In one population based study, women with vulvodynia were 2.6 times more likely to report lack of family support (comfort, encouragement and love). Women who developed vulvodynia as adults were significantly more likely to report childhood abuse (physical or sexual) than aged matched controls. (Harlow & Stewart, 2004).

7) **How you cope with stress, worry and fear probably impacts how your body experiences pain and how it heals.** Let’s face it – we all have different temperaments and personalities. Some of us tend to see the glass half full, others half empty. Our genes shape some of these traits while others are probably influenced by our environment and life experiences.

- Women with localized provoked vulvodynia reported more signs of stress and showed statistically significant evidence of systemic stress (changes in levels of a stress hormone called cortisol upon awakening) as compared to women without pain (Ehrstom et al., 2009).

**What can you do?**

*The good news is that a large body of research suggests that we can learn new coping skills, and when we do, we reduce the effects of allostatic load – or stress – on the brain. Over time, these new habits may reduce stress hormones, inflammation, improve pain perception and help with healing.*

- Women with primary vestibulodynia showed higher levels of somatization, anxiety and distress as compared to women with secondary vestibulodynia (Zolnoun et al., 2008).

- In chronic pain patients, a tendency to focus on pain (called attentional bias) increases pain, disability and distractibility (Van Ryckeghem et al., 2013). Focusing on pain is also thought to trigger the fear response, which can increase stress and attention to pain.
• Women with higher levels of self-efficacy reported less pain intensity after treatment with both topical treatments and cognitive behavioral therapy than women with higher levels of baseline fear of pain and catastrophizing (Desrochers et al, 2010). As maladaptive coping increases risk for allostatic load, adaptive coping is protective. (Juster, Bizik, et al., 2011).

• As mentioned in the introduction, fear, including social fear, is a significant trigger of the stress response (Rodrigues, LeDoux & Sapolsky, 2009; Ganzel, Morris & Wethington, 2010).

• Thoughts come from the underlying beliefs of emotions and those that trigger stress such as catastrophizing are associated with depression and anxiety, two significant predictors of vestibular pain in postmenopausal women with painful intercourse – while hormone levels were not (Kao et al., 2012).

• After vestibuleotomy (surgical removal of the painful vestibulodynia tissue) women with higher levels of stress and distress tend to have more pain with intercourse than women with lower levels of stress and distress/anxiety (Eanes et al., 2011).

• Research has shown that women with higher positive affect and lower negative affect report lower levels of pain (Zautra, Johnson & Davis, 2005).

• In older adults with arthritis, greater “dispositional optimism” (a positive personality trait) was associated with lower levels of pain catastrophizing (Goodin et al., 2013).

What Can You Do?

Catastrophizing refers to predicting negative outcomes and assuming that the negative outcome will be catastrophic. To overcome this tendency, focus your thoughts on the experience of the present moment in what is known as mindful awareness. Try to catch yourself having these kinds of negative thoughts, and then try to replace the negative thoughts by considering other neutral or positive outcomes instead (Boyes, 2013). In fact, positive expectation applied to your ability to cope and to your body’s ability to heal, triggers the brain to release pain and stress-buffering chemicals (McEwen and Kalia, 2010).

Self-efficacy refers to one’s belief in one’s capabilities. People with a strong sense of self-efficacy view challenges as opportunities, have a deep interest in and a strong sense of commitment to their activities and recover quickly from setbacks and disappointments (Cherry, 2013).
8) **Women with vulvodynia experience significant sexual side effects including pain with sex and loss of sex drive/desire/libido.**

- 41% of women indicated that vulvodynia had a severe effect on their sexual lives (Arnold et al., 2006).

- Chronic vulvar pain has a negative impact on the couple relationship and causes significant distress related to sexual activities (Sargeant & O'Callaghan, 2007).

- Social factors and experiences – not only the pain itself - also influence women’s experiences of sexual pain (Farrell & Cacchioni, 2012).

9) **In the same way that life stressors, stress, anxiety and depression may “prime” the brain to be more susceptible to inflammation and pain, there are also helpful skills that you can learn and cultivate that help to reverse these stressors.** Such skills have been shown to decrease stress, improve coping, reduce pain and increase well-being, which all together work to reduce allostatic load and support the body back to resilience and normal physiologic balance.

- Resilience (allostatic load is a loss of resilience) is a term used to describe a healthy body, one that is able to bounce back from stress and illness. A number of attitude and behaviors have been shown to strengthen the body’s ability to sustain or restore resilience and as such buffer against allostatic load. These very useful attitudes and behaviors includes: optimism, humor, cognitive flexibility, acceptance, religion/spirituality, altruism (helping others), social support, role models, moderate physical activity/exercise, ability to recover from negative events, and positive emotions (Southwick, Vythilingam & Charney, 2005; Feder, Nestler & Charney, 2009).
• Positive emotions can undo negative emotions, improve resilience and build personal resources, leading to greater wellbeing and more optimal functioning over time (Fredrickson, 2004). These skills can be learned and do make a difference in people’s lives (Cohn & Fredrickson, 2010; Seligman, Rashid & Parks, 2006). One simple method is to increase your experience of appreciation; one of the most studied positive emotions.

• Yoga (taught within the framework of meditation) can improve mood and reduce anxiety to a greater extent than walking (Streeter et al., 2010).

• Listening to music has also been shown to decrease pain in men and women with a variety of pain disorders (Guérin et al., 2011). When listening is such a compelling focus that it inhibits the ordinary consciousness of day to day thinking, it becomes a form of meditation. In this way, music allows thoughts, images, and feelings to come to mind, in a moment-to-moment experience of oneself.

• Mindfulness is another form of meditation that refers to a way to improve conscious attention and awareness and has been shown to improve wellbeing, decrease pain catastrophizing and increase positive emotional states (Brown & Ryan, 2003; Basson, 2012).

• In just a few weeks, novice meditators have been shown to develop brain changes associated with memory, learning, emotion regulation, self-awareness, cognitive flexibility in support of perspective taking and less stress. The brain scans of long term meditators evidence even more of these desirable changes (Lazar, et al. 2005; Holzel, Carmody, J., et al. 2009; Holzel, Carmody, et al. 2011). Several studies have also shown meditation positively impacts the immune cells at a genetic level (Jacobs et al., 2011).

What can you do?
Increase your positive emotions when you exercise, help others, engage in enjoyable social interaction or a pleasant activity, play, laugh, learn something useful, and practice mindfulness or a meaningful spiritual activity. (Catalino & Fredrickson, 2011).

Before you go to bed at night jot down several experiences from the day that lead you to appreciate yourself, others, or life in general. Next, in your imagination, relive each of these experiences until you feel appreciation. Amazingly, by focusing your mind in this way, it will only take about 30 seconds to feel each appreciation. (Damasio, Grabowski, et al. 2000).
10) There are growing numbers of resources and mind body approaches that show promise in decreasing pain and improving wellbeing.

- Vulvodynia experts advocate an interdisciplinary approach to treatment, which may include physical therapists, sex therapists, social workers and/or psychologists trained in cognitive behavioral therapy (CBT) or mindfulness –based cognitive therapy (MBCT).

- The Benson Henry Institute for Mind Body Medicine at MGH is a leader in the field of mind-body-resilience medicine. They conduct research on mind/body interactions and on interventions that treat a variety of conditions that include autoimmune disorders, chronic pain syndromes, heart disease, infertility, and mood disorders. They offer individual counseling that includes meditation skill building, cognitive behavioral therapy as well as group programs that have been shown to increase resilience and improve symptoms and their underlying imbalances.

- Mindfulness –Based Stress Reduction (MBSR) is a mindfulness-based program that has been shown to reduce stress and the associated cortisol and immune responses. It has been tested with a number of medical conditions including pain cancer, depression and anxiety (Grossman et al., 2004; Basson, 2012).

- Additional benefit will likely be achieved from any method that engages mind body pathways that lead to relaxation or a positive shift in mood. These include, but are no means limited to: acupuncture, Reiki, Healing Touch, and massage.

In addition to many books & tapes available about meditation/mindfulness, courses specific to health are offered at:

The Benson-Henry Institute for Mind Body Medicine
http://www.massgeneral.org/bhi/about/

To find an MBSR program worldwide:
http://w3.umassmed.edu/MBSR/public/searchmember.aspx

To find a yoga instructor near you:
http://www.yogajournal.com/directory/

Keep learning as much as you can about Vulvodynia. Knowledge is powerful!
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