

Sexual Health and OI

Sexual health is an important aspect of overall well-being, and it deserves attention and consideration for individuals with osteogenesis imperfecta (OI). While OI can present certain challenges, people with OI can still have an enjoyable, fulfilling, and safe sex life.

Sexual Self-Esteem:

There are many untrue myths in American society that lead people with disabilities to be viewed as non-sexual beings, which is far from true. Myths and misinformation can lead to low sexual self-esteem in people with OI, which impacts overall life satisfaction and the ability to experience intimacy, love, and pleasure. It is important to address your feelings about the way you experience life as a sexual being who has OI.

Common Concerns:

A person living with OI may have to approach sexual activities differently, and because of that, they may have questions and concerns related to how sex can impact their physical and emotional health. Common concerns reported in the disability community are:

- concerns about physical attractiveness
- concerns about finding a partner
- a lack of confidence about sexual abilities and/or performance
- anxiety over communicating needs
- concern about communicating pain or injury
- concerns about not being viewed as a sexual being
- concerns about a lack of sexual health education

There is power in communicating these concerns with trusted individuals for understanding and support. Open and honest communication with partners and future partners is also essential. Discuss your boundaries, desires, expectations, and consent for all parties involved.

1. Physical Considerations:

There are unique physical concerns that people with OI may experience that can impact their sexual lives:

2. Positioning:

It is essential to explore positions and activities that minimize the risk of injury. Bone fragility concerns can be addressed by utilizing positions that avoid placing the partner's weight onto the individual who has a fracture or who is at risk of fracturing. A side-lying position may be beneficial, as the partner's weight is not a concern. Some individuals with OI may experience limitations in joint mobility and flexibility. Adapting sexual positions and using supportive cushions or pillows can enhance comfort and accessibility during intimacy.

3. Pain: Chronic pain can impact the desire to participate in sexual activity; however, sexual pleasure may also provide some pain relief as endorphins are released into the body. Deep breathing or relaxation techniques can assist with pain management and mental alertness by increasing the flow of oxygen to the brain. It is especially necessary for any pain or discomfort that is experienced while engaging in sexual activity to be communicated immediately.

4. Medication: Some medications have sexual side effects and could impact your sexual interest. Experiment with timing sexual activity before or after taking medication to see what works better for your body. Talk to your healthcare provider about any sexual side effects that you may be experiencing. Additionally, medications, particularly, used in men can increase sexual activity.

5. Fatigue: Pain, injury, recovery, and living with mobility impairments in general can impact energy levels and sexual desire. Take note of when your energy is best throughout the day and consider engaging in sexual activity then. It is also important to take frequent breaks and

This fact sheet was prepared with assistance from Michelle Fyran, PhD, LMHC, Deborah Krakow, MD and other publications. June 2024

communicate the effects of fatigue with sexual partners.

6. Limited Independent Mobility: Those who have limited independent mobility may prefer to request the assistance of an attendant to help them prepare for a sexual encounter, whereas others may prefer the assistance of their partner. If the latter is true, it is recommended that creativity be used to incorporate transferring/disrobing and positioning into the sexual activity. Consider what other sexual pleasures can be experienced without the need to transfer to a bed.

7. Contraception: You have the right to make your own informed decisions about contraception. Each individual should discuss the pros and cons of each available method of contraception, including potential effects on bone. Other considerations include medical complications unrelated to OI. For more information on family planning, see OIF's Planning a Family fact sheet.

8. Sexual Health Wellness Checks:

- **STI/STD Screening:** Because of common misconceptions that people with disabilities are not sexually active, health care providers may mistakenly assume that STI/STD checks are not required¹. If you are sexually active, talk to your health care providers about your sexual history to determine which STI/STD tests you need and how often you should be screened. Remember that many people with STI/STD do not exhibit symptoms, so it is important to follow your doctor's recommendations on STI/STD testing and to discuss any next steps required following your test results². You should also have an open and honest discussion about your sexual behavior to determine what safe-sex practices may be beneficial for you.
- **Viral Hepatitis:** The Hepatitis B virus can be transmitted through sexual activity³. Adults who have multiple partners and those who have sex partners with chronic hepatitis B infection are at an increased risk for transmission³. While less common, Hepatitis A and C can also be transmitted through sexual activity³. You should speak with your provider about your sexual history and sexual behaviors to determine if it is recommended for you to be vaccinated against the Hepatitis virus.
- **HPV vaccine:** Everyone, no matter their gender, should discuss getting the HPV vaccine with their medical provider before the age of 45^{4,5}. The HPV vaccine prevents against certain strains of HPV (human papillomavirus) that can increase certain risks of certain cancers⁵.
- **Cervical Cancer Screening:** Research has found that women with physical disabilities are less likely to have cervical cancer screenings when compared to those without a physical disability⁶. Pap test (or Pap smear) and HPV test can help prevent cervical cancer or detect it early⁵. A Pap test is a vaginal examination that looks for precancerous cells on the cervix⁵. HPV test, which can be tested for during a Pap test, looks for the virus (human papillomavirus) that can cause changes in cells that increase an individual's risk for cervical cancer^{4,5}. It is important to talk with your providers about your sexual, medical, and family history to determine when to start getting a Pap/HPV test and how frequently.
- **Prostate and Testicular Cancer Screening:** A cross-sectional study found that men with a disability are less likely than men without a disability to undergo a Prostate Specific Antigen (PSA) test to examine if there is a problem with the prostate gland, including prostate cancer⁷. If your PSA levels are high, your provider may recommend a biopsy to check for prostate cancer⁸. Discuss your medical and family history with your provider to determine when you need to start having prostate cancer screenings and how often. For testicular cancer screening, there is currently no standard or routine screening test used for early detection; however, there are ongoing clinical trials⁹. More often, testicular cancer is identified during a self-exam or by chance and is sometimes found by doctors during a routine physical exam⁹. Therefore, it is important to speak with your provider about how to perform regular self-examinations.

Focus on Pleasure:

Information about sex and disability tends to focus on function and fertility and not on pleasure and love. Once physical considerations are addressed, what to do and how to do it is solely the choice of those who are involved. Regardless of the sexual activity that one chooses to partake in, it's important to know that it is best to ignore the archaic belief that intercourse is the only "true" way to have sex. Sexual expression should instead be a dynamic, evolving, individual experience that allows time for the enjoyment of the, at times humorous, trial and error process. Ultimately, the main goal is to give and receive pleasure. With the help of sexual education, adaptive tools, communication, and a bit of planning, a satisfying sexual life can transform from a possibility to a reality.

This fact sheet was prepared with assistance from Michelle Fyran, PhD, LMHC, Deborah Krakow, MD and other publications. June 2024

Resources:

With that said, it is natural to feel frustrated about the impact that OI has on this personal aspect of your life. If these concerns feel overwhelming, or if they are leading to distress, talking with a sex therapist, clinical sexologist, relationship coach, therapist, or trusted healthcare professional would be beneficial. Educating yourself on the topics of sex and disability can also be helpful.

References:

1. National Study of Women with Physical Disabilities – Sexually Transmitted Diseases, Baylor College of Medicine, last accessed 11/9/2023: <https://www.bcm.edu/research/research-centers/center-for-research-on-women-with-disabilities/a-to-z-directory/national-study-of-women-with-physical-disabilities/sexually-transmitted-diseases>
2. STD Testing, Centers for Disease Control and Prevention, last accessed 11/9/2023: https://www.cdc.gov/healthyouth/healthservices/infobriefs/std_testing_information.htm#:~:text=Many%20STDs%20don't%20cause,get%20pregnant%20later%20in%20life.
3. Sexual Transmission and Viral Hepatitis, Centers for Disease Control and Prevention, last accessed 11/9/2023: <https://www.cdc.gov/hepatitis/populations/stds.htm#:~:text=Sexual%20Transmission%20and%20Hepatitis%20C&text=Having%20a%20sexually%20transmitted%20infection,shown%20to%20transmit%20hepatitis%20C.>
4. What Should I Know About Screening, Centers for Disease Control and Prevention, last accessed 11/9/2023: https://www.cdc.gov/cancer/cervical/basic_info/screening.htm
5. Basic Information about HPV and Cancer, Centers for Disease Control and Prevention, last accessed 11/9/2023: https://www.cdc.gov/cancer/hpv/basic_info/index.htm#:~:text=The%20International%20Agency%20for%20Research,of%20the%20tongue%20and%20tonsils.
6. Baruch, L., Bilitzky-Kopit, A., Rosen, K., & Adler, L. (2022). Cervical cancer screening among patients with physical disability. *Journal of Women's Health*, 31(8), 1173–1178. <https://doi.org/10.1089/jwh.2021.0447>
7. Leong, J. Y., Pinkhasov, R., Chandrasekar, T., Shapiro, O., Daneshvar, M., Jacob, J., Sanford, T., Bratslavsky, G., & Goldberg, H. (2022). Prostate-specific antigen testing in men with disabilities: A cross-sectional analysis of the Health Information National Trends Survey. *European Urology Focus*, 8(5), 1125–1132. <https://doi.org/10.1016/j.euf.2021.07.009>
8. What is Screening for Prostate Cancer?, Centers for Disease Control and Prevention, last accessed 11/9/2023: https://www.cdc.gov/cancer/prostate/basic_info/screening.htm
9. Testicular Cancer Screening (PDQ – Patient Version, National Cancer Institute, last accessed 11/9/2023: <https://www.cancer.gov/types/testicular/patient/testicular-screening-pdq>