

WEBINAR: Intimacy, family planning and PH – A conversation with my partner and my healthcare team?

Episode 8 – Thursday 22 August 2019

DISCUSSION SUMMARY

Overview

On Thursday 22 August 2019, Actelion hosted a patient-facing webinar entitled 'Intimacy, family planning and PH – A conversation with my partner and my healthcare team?' Wendy Hill, PH specialist nurse from Cedar-Sinai Medical Group, was the guest speaker and highlighted the importance of raising conversations about intimacy, an often taboo subject, between people living with PH and their partners, healthcare teams and loved ones. Wendy recommended certain techniques to help improve intimacy for those living with a chronic disease, these included practical tips as well as methods to support with initiating important conversations. Family planning – a critical consideration for people living with PH, particularly women – was also discussed. The webinar was attended by patient group representatives, people living with PH and healthcare professionals (HCPs).

The primary objectives of the webinar were:

- To discuss and recognize the impact of PH on people's sex lives and family planning
- To share best practice approaches to help support conversations between people living with PH and their healthcare team on intimacy, contraception and pregnancy prevention, as a critical part of patient self-management
- To identify sources of quality patient information on intimacy, relationships and family planning

Discussion summary and key learnings

PAH and intimacy: an overview

- PAH has a considerable impact on intimacy: a study by the Pulmonary Hypertension Association found that around 75% of people living with PAH have difficulty being intimate with partners.^{1,2} It was discussed that for people living with PH it is important to remember that you are not alone, there are plenty of people to speak to about PH and intimacy, such as family and friends, your medical team and other people living with the condition
- It is important to understand that the symptoms of PH, such as shortness of breath and fatigue, side effects of medication and concerns over medical devices, can make it difficult to achieve sexual intimacy, however, it is equally important to remember this can be managed with extra planning and consideration
- Sexual intimacy is still possible but certain adaptations, such as choosing the most comfortable position during sex and ensuring oxygen lines are secured, may be needed

¹ Studer et al PHA 2012

² Guillemin et al Eur Respir Rev

- HCPs, patient organizations and others living with PH can provide useful guidance if this is a topic you feel comfortable discussing
- Psychological factors including low self-esteem and negative body image also affect intimacy, with 29% of patients stating low self-esteem is the cause of their low libido.³ For those experiencing this, it is recommended to talk to your medical team and/or patient group about the emotional impact of PH and ask how they can support you with this
- It is important to remember people without PH also commonly experience negative body image, which can affect intimacy. Look for resources online which can support with improving perceptions around body image to help combat this

Starting the conversation

- Most patients do not initiate conversations with HCPs about intimacy unless they have a more serious sexual dysfunction. Know that medical teams can be approached for all aspects of healthcare, including intimacy

Speaking to your healthcare team

- It is recognized that consultations often focus on the clinical management of PH and, largely due to time restrictions, intimacy and sexual health may not be discussed. It's important that if intimacy is affecting your quality of life it should be a priority during consultation discussions and this is something you can bring up if it is not initiated by your HCP – including: your General Practitioner, family doctor, PH specialist, obstetrics and gynecology specialist or urologist and specialist nurses
- Keep in mind that HCPs are sometimes cautious about invading patient's privacy and do not wish to cause offence, but they are more than happy to discuss intimacy when the issue is raised

Speaking about contraception

- PH specialists advise that pregnancy must be avoided for women living with PH due to the danger it possesses for both mother and child⁴
- It is recommended that people living with PH use at least two forms of contraception (birth control) to prevent pregnancy from occurring
- If you have stopped sexual activity after diagnosis or due to symptoms, before resuming sexual activity, it is advised that you speak to a HCP to identify the most suitable contraception methods

Speaking to your partner

- Speaking about intimacy and sexual activities with your partner can help you feel more comfortable and improve their understanding of your situation; keep in mind that low libido and problems around intimacy can affect both men and women
- It can help to discuss preferred sex positions with your partner to minimize your symptoms, for example avoid positions where your partner's body weight puts pressure on your breathing
- Consider ways to minimize interference from lines and pumps, for example extend tubing to reduce resistance or cover the nasal cannula with felt to reduce pressure on your skin
- It may be helpful to adapt your approach to intimacy to conserve energy, e.g. take breaks or plan to be intimate at times of the day when you have the most energy
- Be assured that sometimes everyone has to plan sexual activities. Create an environment that favors intimacy by making time away from busy lives and reducing distractions such as social media

³ Studer et al PHA 2012

⁴ Pulmonary Hypertension Association. Available at: <https://phassociation.org/patients/living-with-ph/young-adults-with-ph/issues/family-planning/> (last accessed August 2019)

Speaking to your patient support group

- Support group meetings can also be a safe space to discuss intimacy with others living with PH. You could even invite a HCP to a group meeting to raise the topic and start a discussion. They will be able to provide useful tips and general advice from a clinical perspective that could help you and the group
- Often people find it easier to talk more openly in small groups, if there is the opportunity within your patient group to invite people to open up and share their experiences, if they feel comfortable to do so, this could be a way to start the conversation among peers about intimacy and family planning

Conclusion

- Intimacy is important and should not be avoided when faced with chronic illness
- HCPs should initiate the conversation, however if they do not, feel empowered to ask questions or raise the topic of intimacy and family planning
- It is recommended to communicate with your partner to improve understanding around sexual activity and enhance intimacy, if desired by both parties

Appendix

For more information on intimacy visit <https://www.phauk.org/living-with-pulmonary-hypertension/ph-and-you/relationships/>

For more information on family planning, visit <https://phassociation.org/patients/living-with-ph/young-adults-with-ph/issues/family-planning/>
