Supporting Menstruation Management

Support Person Fact Sheet

Key Facts

Managing one's menstrual cycle is not a problem for most people with I/DD. Yet, some will need clear information and support to help manage their periods.

Helping a Person Manage their Periods

All people should be given the opportunity to manage their own periods. They might need:

- **Education**: The person should be taught to manage their periods as independently as possible. Some will learn quickly, while others need formal teaching programs and regular refreshers of their knowledge.

- **Support**: Some people need someone to change their pads and underwear. Some need reminders to change pads or someone in the background prompting them through the process.

  If you are helping a person with their periods, be respectful of their dignity and privacy. Let the person choose who supports her with this personal task. Also, people's religious and cultural beliefs can affect how they manage their periods.

  When supporting any person with personal care, remember the basics of good hygiene, such as washing one's hands after using the restroom or changing pads.

Problems with Periods

Families and support workers should watch out for:

- Painful Periods: Ordinary pain relief medication may help.

- Heavy Periods: Close monitoring is needed. It may be a person's normal period, but heavy bleeding can make a woman feel tired and ill, and should see a doctor.

- Irregular Periods: Some people do not have regular periods. Keep notes of the changes to help the doctor understand what is happening.

- Pre-menstrual syndrome: (PMS) can include tender breasts, headaches, mood swings, and bloating. PMS occurs before a period starts.

Sometimes, epilepsy can be harder to control around the time of a person's period. If any of these problems are having an impact on the person's life, a visit to the doctor is necessary.

Also, the person should see a doctor if their periods stop. This could mean pregnancy, menopause or other conditions. Sometimes, a person may not even start to have periods. Ask the doctor to investigate why this is so.

Role of the Primary Care Provider

A PCP may do some tests to understand what is happening. These might include a physical examination, a blood test, an ultrasound, a Pap test, or a pelvic examination. This may be frightening or uncomfortable for someone with I/DD, and they may need a lot of support from someone they trust. Sometimes, the PCP will refer a woman to a doctor who specializes in women's health: a gynecologist.

Surgery to Stop Periods

Occasionally, major health problems lead a person to consider surgery that will stop their periods permanently: a hysterectomy or an endometrial ablation. This is the same for people with or without a disability. Special laws apply to these operations since they result in sterilization of the person so they can never have children

Treatments for Problems Periods

If a person is having major problems with their periods, the doctor might suggest a treatment or medication to control or even stop the periods. These include the contraceptive pill, a hormone injection or implant, which works for an extended amount of time, or a hormone releasing intrauterine device (IUD). As with other medications and/or treatments, these may cause some side-effects. Ask the doctor what to watch out for. It may take time to find the treatment that best suits the person.

The person may need support in understanding the treatment(s) and making the decision that is best for them. Their support person or guardian can help to explain the options in a way they understand. If a guardian has to make the decision for them, the decision must be based on what is best for the person. Menstruation should not be stopped to make life easier for caregivers.

For more information:

Click here for tips on managing menstruation: (URL: https://www.webmd.com/women/video/cm/corio-normal-menstrual-cycle)

Click here for information on contraceptive care in Oregon (URL: https://www.oregon.gov/oha/ph/HealthyPeopleFamilies/ReproductiveSexualHealth/Pages/index.aspx)

Related fact sheets:

Support Person Fact Sheet: Supporting Annual Wellness Checks

This fact sheet was created in June 2021.

The fact sheet contains general information only and does not take into account individual circumstances. It should not be relied on for medical advice. We encourage you to review the information in this fact sheet within the context of educational purposes and when appropriate, share it with your health professional to decide whether the information is right for you.

This module was adapted from NSW Council for Intellectual Disabilities (2009), Australia. The toolkit and its components were supported in part by the grant or cooperative agreement number DD000014, funded by the Centers for Disease Control and Prevention and by the University Center for Excellence in Developmental Disabilities Administration on Community Living grant #90DDUC0039. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention, Administration on Community Living, or the Department of Health and Human Services

OSAC Oregon Self Advocacy Coalition

OHSU

OCDD Oregon Council on Developmental Disabilities