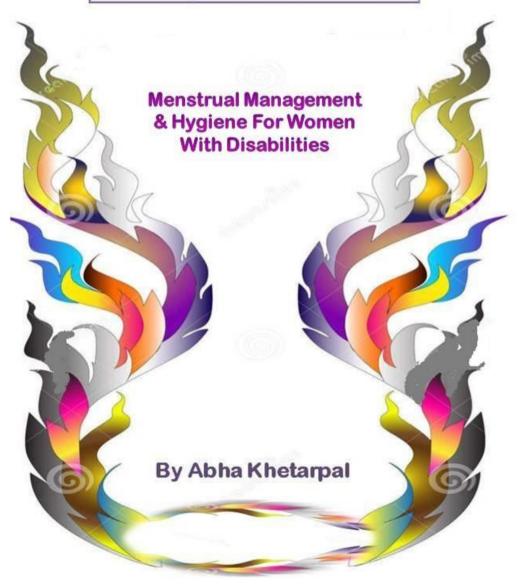
# **Going With The Flow**



# GOING WITH THE FLOW

### A Handbook On Menstrual Management & Hygiene

For Women With Disabilities

By

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(MA in English, MA in Economics, MS Counselling & Psychotherapy)

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Rs 315

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Cross the Hurdles

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### Preface

In every 28 days across this planet, fifty percent of the world's population menstruates. Yet despite this one of life's most natural occurrences, for hundreds and thousands of girls and women with disabilities in our country menstruation is a significant challenge. The inability to afford sanitary napkins during menstruation, lack of information, lack of accessibility and due to lack of money income these women are forced to use primitive alternatives, such as newspaper, rags of cloth, bark, ashes, banana leaves, hay or mud, which are both ineffective and unhygienic. They are totally oblivious of fact that these alternatives may lead to long-term health risks such as Reproductive Tract Infections, Toxic Shock Syndrome or Cervical Cancer.

Women with disabilities and high support needs vary in their abilities as well as dependence. Some have difficulty in using their hands or have locomoter disabilities, some have difficulties communicating verbally or some have cognitive problems. Others might be able to perform their daily routine work and can communicate easily but still they would be requiring ongoing support and care.

I, being a woman with disability, can affirmatively say that situation for each young woman with disability and her family is different. So the solutions to their problems also do not go by any rule book. 'One size can never fit all'. Therefore I sat down to write this handbook in order to focus primarily on the on the needs of younger women with disabilities as written or educational material catering to their need is all together missing in our country. I believe the information provided in this may also be useful for the older women with high support needs.

I do not claim that this menstruation management approach is comprehensive. My only aim is to make this handbook a resource for the general community.

Abha Khetarpal President Cross the Hurdles Dedicated to

Womanhood

### Acknowledgement

Art work and many sketches are contributed by our volunteer <u>Tanya</u> Chawla. We are really thankful for her dedicated cooperation.

Special thanks to Mr Rajendra Maurya for his contribution towards editing and formatting the book.

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### Foreword

#### The Upturned Stone

It takes immense courage to upturn an unturned stone that has been rigidly placed over certain issues lying in the cocoon of psyche. Menstruation is one such aspect, which is invariably evaded and seldom talked about, even amongst normal healthy women. I



personally never liked the word "disabled " and this write up has incorporated a beautiful phrase" individuals requiring a ''little higher support system". Every woman has lived some part of this, during her recumbency after childbearing or short term illness of any kind. Not drifting from my flow of emotions, when Abha asked me to put a foreword in this write -up, I opened it with a preconceived notion that I shall be outpouring multiple things, facts and suggestions as I am reading it through, a woman's eye and mind who is also specially abled and a gynaecologist.

Honestly, I was dumbfounded, as she has touched upon every aspect of this topic, from statistical details to medical complications, care and awareness of the kith and kin at all levels primary secondary and tertiary and covering all the minor a details like even the costs of hygiene. I fail to refrain myself from saying that an issue, so sensitive, entangled within a mesh of taboos, and this diverse and multipronged approach, undoubtedly makes this write up much above a paper coming from a Doctor's Desk , a Social Worker's Desk, or a Counsellor's Desk.....It is an outpour of a sensitive heart and is captivating too. For.... "Who Knows The Pain Of Broken Wings, But The Bird".

It is my sincere wish that those who are at the Giving End of the 'Higher Support' must read this. It is an eye-opener to them as they can count on the blessing's that God has showered on them and also realize that those who are at the Receiving End are indigenously blessed by the Almighty, as they are fighting and winning a battle with each breath of theirs. God Bless You Abha! Your positivity and dedication puts a smile in moments of despair, on countless faces.

Dr Shyamli Rastogi

MBBS; MS (GYNAE/OBS)

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### Introduction

The census of 2011 says that country's disabled population has increased by 22.4% between 2001 and 2011. The growth rate of disabled population is more in urban areas and among urban females. The decadal growth in urban areas is 48.2% and 55% among urban females. Among scheduled castes it is 2.45%.

There are around 355 million women of reproductive-age in India. And according to WHO 10% to 15% of any population has some kind of disability. That means the number of women with disabilities in reproductive age in India would be approximately around 35 to 40 million. And is this not a small number. For them reaching the age of adolescence is not the process of becoming a woman rather it becomes a matter of discomfort, humiliation, and an obstacle to their learning, education, healthcare and involvement in the workplace.

Across the world's largest democracy, where a decade of economic growth nearing 8% a year has tripled per-capita income, millions of women still are held back by shame around their most basic sanitary needs. According to World Health Organization, India accounts for 27 percent of the world's cervical cancer deaths. The incidence rate here is almost twice the global average, and doctors say that the basic reason behind this is poor menstrual hygiene. Menstrual hygiene is also an insufficiently acknowledged problem in relation to MDG 7, especially in official programmes.

Women with disabilities (WwDs) are less well educated and less likely to get married than their nondisabled peers. They are more likely to live in poverty, due to lack of education and employment. They are as likely sexually active as other teenagers without disabilities but are at greater risk for forced sexual encounters. They need appropriate education on hygiene, contraception, sexually transmitted infections, and abuse prevention measures.

Gynaecologic health care of women with disabilities has to be a comprehensive one along with taking care of the following things:

- She must not be treated as an infantile
- To assess if a women or the girl has proper knowledge about menstruation, sexual activity, safety and ability to give consent
- Her dignity must be affirmed
- Maximization of her interest and avoiding harm
- Opportunity to be viewed in private
- Direct communication with the woman unless there is cognitive disability

### What is Menstruation?

Menarche is the beginning of menstruation. It signifies the transition of the girl from childhood to adulthood. It symbolizes the beginning of the reproductive phase of a girl. Signs that menstruation is about to occur may include breast development, appearance of pubic and underarm hair, light white discharge from the vagina, and rounding of the hips.

Menstruation is the normal, healthy shedding of blood and tissue from the uterus that leaves the body through the vagina. It usually lasts between three and seven days. The menstrual cycle provides important body chemicals, called hormones, to keep a girl/woman healthy. It also prepares her body for pregnancy each month. A cycle is counted from the first day of the first period to the first day of the next period. The average menstrual cycle is 28 days long. Cycles can range anywhere from 21 to 35 days in adults and from 21 to 45 days in young teens. The process of menstruation itself is painless. Some girls experience cramps or other symptoms before or at the start of their period. The amount of menstrual fluid which passes from the uterus (womb) is approximately 5 to 6 tablespoons (110 mls or  $\frac{1}{2}$  cup), during each period. Only 30-50% of the fluid is blood. Menstrual fluid also contains vaginal secretions, mucus from the cervix and particles from the endometrium as well as blood, which can sometimes be clotted. Most of the fluid is lost during the first and second day. Perceptions of menstrual flow vary, because all women have different experience and ideas.

There is no need to be scared about getting the periods. It is completely a normal and natural process.

# **Changes During Menstruation?**

A woman may experience physical or emotional changes around the time of her period but some may not feel anything. 85% of women experience the physical and emotional symptoms of premenstrual syndrome each month. Some of the changes are:

Physical symptoms– Cramps, pain, bloating, weight gain, food cravings, swollen or painful breasts, swollen hands or feet, skin





problems, headaches, dizziness, or irritability.

**Emotional symptoms** – Short temper, aggression, anger, anxiety or panic, confusion, lack of concentration, nervous tension, fatigue, or depression. As hormone levels rise and fall during a girl's menstrual cycle, it can affect the way a girl or woman feels, both physically and emotionally. Sometimes taking pain killers, hot water compresses, herbal teas, or other local remedies can give her relief from menstrual symptoms. If these do not help, a woman must visit a health provider and discuss the matter.

# **Menstruation and Disability**

Menstruation restricts the mobility and behaviour of a woman because of myths, misconceptions and taboos in our country. And for the disabled women it becomes all the more difficult and challenging because of their dependence, ignorance and proper lack of training along with the above mentioned factors.

All teenagers may have irregular cycles during the first 2–5 years after menarche, but adolescents with disabilities may have additional reasons to experience menstrual irregularities in teenagers with Down Syndrome who are on mood stabilizing medication, and teenagers with seizure disorders.

Disabled women have the same menstrual disorders as their non disabled counterparts. But for many disabled women normal and particularly abnormal menstruation causes hygiene problems and increases the need for attendant care. Parents of girls with cognitive disabilities worry about mood changes and pain in their daughters during their periods. Cognitive disabilities include AHAD, Dyslexia, Aphasia, Brain injury, Learning Disabilities, Mental Retardation etc.

CP, Spinabifida, and other congenital disabilities usually do not affect the pattern of menarche. Young girls who have had traumatic brain injury (TBI) or SCI may have delayed menarche or even an early puberty. Most women with SCI will resume normal menstruation within 6 months post injury. A study shows that roughly 25% of women with SCI have *perimenstrual dysautonomia* i.e. gooseflesh, headaches, flushing, and sweating.

Women with previously normal menstruation may experience certain menstrual disorders after becoming disabled. Women with chronic disease conditions, such as diabetes mellitus or obesity, may have menstrual irregularity. Women with rheumatoid arthritis have later onset of menarche and increased rates of ovulatory dysfunction. Women with SCI, Traumatic Brain Injury and Multiple Sclerosis have an increased frequency of *hyperprolactinemia* i.e. is stopping of menstrual periods or decreased menstrual flow. Disabled women may have significant hygienic problems due to menstrual irregularities. Many may have risk of osteoporosis.

Once menarche occurs, girls with Developmental Disabilities (DD) may have physical challenges that may make menstrual hygiene difficult, or they may be unable to deal with menstrual pads. Developmental Disabilities include Cerebral Palsy, Epilepsy, Autism, Down Syndrome, Mental retardation, Spinal injury and Brain injury.

The teen may remove the pads in inappropriate places on account of a heightened sensory awareness of discomfort from the pads. Some may

not physically be able to change their own pads, which may interfere with their ability to be independent. This may be seen in girls with Cerebral Palsy or SpinaBifida. Some of the girls may even have difficulty communicating about the menstrual cycle.

Women with epilepsy have an increased incidence of reproductive endocrine disorders, including irregular menstrual cycles, *anovulatory cycles* (absence of ovulation), *amenorrhea* (abnormal absence of menstruation) and *oligomenorrhea* (infrequent or very light menstruation). Approximately half the women of childbearing age who have epilepsy report an increase in seizures around the time of their monthly menstrual period. The hormonal changes during the menstrual cycle are the most likely cause of changes in seizure frequency.

Teens with swallowing problems or feeding tubes may have such a low weight that they experience either absence of menstruation or a very light and infrequent one.

Cyclical behavioural changes are a common issue for women with disabilities. The cyclical behaviour in women with Developmental Disabilities may be very different. Premenstrual Syndrome (PMS) in adult women may include temper tantrums, crying spells or self-abusive behaviour. Doctors should be consulted in case of severe problems.

# Something for the doctors to note

The decision to treat the patient's menstruation must be based on an individual assessment of the menstrual cycle, the tolerance of the patient of her periods and the products used, as well as the impact of the cycles on her daily activities. Some of the parents may go to the extent of opting for hormonal or even surgical suppression of menstruation. Physicians evaluating disabled women must have the knowledge of the effects of various disabilities on the menstrual cycle. Routine requests for suppression of puberty and menstruation without any particular identified problem should be resisted.

# Management For Women With Disabilities

Menstrual management refers to range of strategies that women with disabilities can use during menstruation so that she is comfortable with her menstrual flow and is able to manage her periods with dignity, privacy and hygienically. Management of menstruation can be one of the more difficult self care tasks for disabled women.

### Establishing Aims and Goals for Management

For long term menstrual management of women with disabilities aims and goals may include:

### For the young woman:

- To accept her menstruation and experience it without anxiety or distress.
- To feel comfortable during periods while getting help to manage pad changing, bathing and washing tasks for her.
- To behave in an acceptable way during her menstruation (e.g. not to remove her pads during menstruation).
- To participate in some, or all, menstrual management tasks.
- To be aware of a set schedule when pads need changing.

### For those assisting the young woman:

- To feel comfortable about assisting the young woman to manage her period.
- To be aware of approaches for managing discomfort arising before or during periods.
- To have knowledge of menstrual management plans and established menstrual care schedules.
- To bring in menstrual management into other aspects of life education, for example, self-care, human relations, education and health care.
- To have a consistent approach both between their assistance and across different environments.

Getting periods for the first time can be overwhelming for all the girls irrespective of whether they have a disability. But for a girl with disability, even the people around her may worry that with impairment, the girl won't be able to manage her periods. For the most part however, she should be able to manage her period or ask for help when she needs it.

A girl's disability might mean that she may have to take a few more things into account. If she has visual impairment, it will be much easier to identify her period by smell. If she has limited mobility, she may need some assistance. For example, she may be okay with someone changing her sanitary pad, but she may not like to take help from anyone to insert a tampon. If she has spastic (tight) hip or thigh muscles and is not able to open her legs very wide, it may be easier to use a method that doesn't involve inserting anything into her vagina.

Doctors must be concerned about the vulnerability of this population. If the cycles are limiting the patient's ability to participate in her regular activities and are clearly affecting her life, treatment can be initiated with periodic evaluation of the need for continuation.

# **Teaching Women with Disabilities**

Every woman needs to learn about menstruation. Young women with high support needs must be prepared for their first menstruation (menarche) before it actually happens.

Providing information is an initial step in effective preparation for menstruation. Those who cannot speak may be able to understand and use objects, signs and symbols as part of their menstrual preparation and menstrual management. These messages and symbols may also be used by older women needing explanations and hints for menstrual management. But for others it must be less complex i.e. there must be lesser use number of symbols per message. While some may be able to understand messages and express their needs and preferences with different kind of symbols. Text should be more "user-friendly" by placing each message on a separate card/page OR using difference colour paper for each message.

Those involved in teaching menstrual management and hygiene must keep instructions easily accessible for the woman i.e. on the toilet door, hanging beside the toilet roll, etc. A woman who needs help might experience pain or discomfort and may be unable to communicate. This can be a matter of great concern to those helping her. Individualized plans have to be developed women for effectiveness of strategies for easing discomfort.

Since reproductive tract infections have become a silent epidemic, proper menstrual hygiene and correct perceptions and beliefs can protect the women from this suffering. So the girls must also be educated about:

- The facts of menstruation
- Physiological implications of menstruation
- Significance of menstruation
- Development of secondary sexual characteristics
- Proper hygienic practices with selection of disposable sanitary menstrual absorbent

All this can be achieved through educational television programmes, school nurses/health personnel, compulsory sex education in school curriculum and knowledgeable parents. This education would indirectly remove the age-old wrong ideas and make her feel free to discuss menstrual matters including cleaner practices without any hesitation. All mothers irrespective of their educational status should be taught to break their inhibitions about discussing with their daughters regarding menstruation much before the age of menarche.

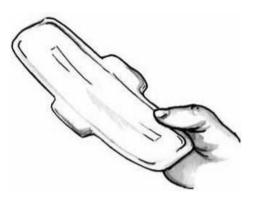
Menstrual hygiene and management can be essential in ensuring that everyday life is not interrupted by menstruation. It ensures that she can continue with her daily routine such as going to school, going to work or doing household chores. It can also prevent embarrassments and make her feel confident about herself and her body. Maintaining proper menstrual hygiene is important for wellbeing and development.

# Methods of sanitation

There are various ways like sanitary napkins, tampons and menstrual cups to stay clean.

Sanitary pad It is also known as sanitary towel, menstrual pad or maxi pad. It is an absorbent item worn by a woman or a girl while she is menstruating, while recovering from vaginal surgery, for post birth bleeding, after an abortion, or in any other situation where it is

necessary to absorb a flow of blood from her vagina. These pads are not to be confused with generally higher absorbency incontinence pads, which are worn by men or women who have urinary incontinence problems or experience stress incontinence.





Most unmarried girls in India prefer to use sanitary pads. The best tip here is to try and use one brand for one type of protection as frequent switching between brands can make one feel uncomfortable. Most women use napkins (a soft cloth), disposable sanitary pads (that can be placed inside your panties).

#### Tampons

They are designed to be easily inserted into the vagina during menstruation and absorb the user's menstrual flow. The hymen is a thin, flexible layer that partially covers the opening of the vagina. It does not completely cover the opening, as there is a small gap to let menstrual fluid



Figure 4

out. The tampon can easily slip through this gap without breaking the hymen. It is important to know that a girl will NOT lose her virginity by wearing tampons made by good companies.

**Menstrual Cup** A menstrual cup is a reusable device, around two inches long and made from soft medical grade silicone. It is worn internally a lot lower than a tampon but, while tampons and pads absorb menstrual fluid, the menstrual cup



Figure 5

collects it. A light seal is formed with the vaginal walls, allowing menstrual fluid to pass into the cup without leakage or odour. This seal is released for removal, allowing you to empty the contents, rinse or wipe and reinsert.

These products have been on the market for some time, so why don't more Indian women use feminine hygiene products? This is because of:

- Lack of availability
- Cost
- Embarrassment about sexual health
- Lack of awareness about human anatomy
- Myths about menstruation

Some girls and women prefer pads or napkins because you don't need to put anything inside yourself, and a napkin can be washed and reused. Others prefer tampons because they feel like it is cleaner (it catches the blood inside your vagina), there is no menstrual odour and can be disposed of easily. But 95% of female population in India don't know about tampons and menstrual cups or how to use them. There is a myth associated with them that those who use might lose their virginity.

For choosing the products by women with disabilities who have incontinence problems some factors that must be considered include: absorbency needed, the woman's comfort, ease of use, cost per year, sizes available, ease of washing (for reusable products), and impact on the environment. A woman with disabilities who does not have problem of incontinence, it must be ensured that she has firm-fitting briefs (full briefs are better than bikini styles); close fit will assist her pads to remain in place, and will reduce the chance of menstrual odour. Cotton blends may be better in warm weather or if she is prone to vaginal infections/rashes.

### Estimated Cost

Average cost per sanitary pad is Rs 5 to Rs 8. Duration of menstrual cycle on an average is 5 days. 3 pads a day=4\*2=8pads

Total= Rs 50 to Rs 70

Regular tampons (pack of 20) = Rs.175

Super tampons for heavy flow (pack of 10) Rs. 110

(Assuming that one would need Super tampons on day 2 only)

Day 1 - 2 Regular tampons= Rs.17.5

Day 2- 2 Super tampons= Rs. 22

Day 3- 2 Regular tampons= Rs 17.5

Total= Rs 57

SheCup, an Indian manufactured menstrual cup, retails for Rs. 760, and can be re-used for up to 5 years!

www.crossthehurdles.org

### Hurdles for Women With Disabilities

There are simple steps involved while changing a pad or tampon. Following are the basic steps that are must:

- 1. Pull pants down or skirt up.
- 2. Pull panties down.
- 3. Position self.

4. Remove pad or tampon (the latter probably while seated on the toilet).

- 5. Dispose of the used material
- 6. Wipe and wash the perineal (area between vagina and anus) area.
- 7. Take and unwrap a new pad or tampon.
- 8. Place pad or tampon.
- 9. Get up from toilet.
- 10. Pull up panties and pants.

For women with disabilities all these seemingly simple steps can be difficult. Women with paraplegia, quadriplegia or multiple sclerosis who are wheelchair users or those with upper extremity strength or dexterity loss caused by cerebral palsy, multiple sclerosis or quadriplegia, bilateral upper extremity amputation, or rheumatoid arthritis are likely to face problems of management depending upon the severity of their disability. All this is because of various hurdles faced by them. Like:

#### Lack of sensation

Due to weakness or nerve damage some women may have problems with perineal (area around vagina) sensation. She may not know that menstruation has started, or when she needs a change. She may have problem in finding the vulva and in knowing if the tampon is inserted correctly or if the sanitary pad is at proper place. She may not even be aware if she is sitting uncomfortably on a pad, with the possibility of causing a pressure area.

#### Limited accessibility

WASH facilities (access to water, sanitation and hygiene) that provide privacy for women to wash their bodies, stained clothing and any cloths used for menstrual hygiene management are not available to them in underdeveloped regions or villages in India. A woman with disability may have problem in finding an accessible toilet, especially in rural areas. She may not be able to reach her perineum (area between vagina and anus) when seated on an ordinary unraised toilet.

#### Spasticity

The person with affected by involuntary jerky muscular contractions may have trouble in spreading her legs so that she can place a pad. Inserting a tampon may increase her spasticity.

### Strength and dexterity loss

A woman who has lack of strength in hands may have trouble getting her pants down, transferring to the toilet, or standing. She may also have difficulty opening the packaging of the pads or tampons. A woman may have particular difficulty in handling tampons and may bend or distort them.

### Tip

Women who have problems of hand must used pads rather than tampons.

# How To Manage

Women with disabilities, for whom menstruation is a challenge, must be taught adjustment to position and modification in panty, tampon or pads. If they are provided with aids, such as use of mirrors or knee spreaders so that changing pads or tampons becomes less troublesome for them. If they are able to manage menstruation themselves and take care of their hygiene in privacy or with little help life would completely become different for them.

### Using a sanitary pad

It is easiest to change the pad while sitting down with under garments around knees.

- Remove the wrappers or boxes from the pad.
- Try not to discard the wrapper as you can use it for disposing off the used up pad.
- Remove the strip to reveal the adhesive on the back of the sanitary napkin. If you are using a sanitary napkin with wings, there will be three strips--the main one and one on each wing.
- Press the sanitary napkin, adhesive side

Figure 6



Figure 7

down, onto the middle of your underwear.

- Fold the wings around the sides of the crotch of your underwear and press them against the underneath of your panties.
- Check your sanitary napkin every two hours to see if it needs to be changed. If the sanitary napkin is wet on the surface and no longer absorbs menstrual fluids, it is time to change it.

#### Using a tampon

 Wash your hands with soap and water. With dry hands, unwrap the tampon. If you drop the tampon on the floor, throw it away and begin again with a new tampon.

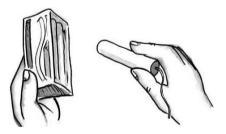


Figure 8

 Sit or stand in a comfortable position. After you find a position that is most comfortable for you, hold the tampon with the fingers that you write with. Hold the middle of the tampon, at the spot where the smaller, inner tube inserts into the larger, outer tube.

- Make sure the string is visible and pointing away from your body.
- With your other hand, open the labia (the folds of skin around the vaginal opening) and position the tampon in it.
- Gently push the tampon into the opening, aiming for the small of your back. Stop when your fingers touch your body and the applicator, or outer tube, is completely inside the vagina.



Figure 9



Figure 10

- Once the outer tube is inside your righter of vagina, use your index or "pointer" finger to push the inner tube.
  This pushes the tampon into the vagina.
- When you are ready to remove the tampon, hold the string and gently pull it downward until the entire tampon is out.
- Remember to wash your hands before and after you insert and remove a tampon.

### Using a menstrual cup

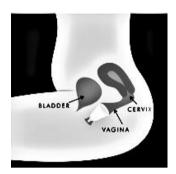
- Press the sides of the cup together and then fold it in half again forming a tight "U" shape.
- Place a finger on the top rim of the cup and press it down into the centre of the inside base to form a triangle. This makes the top rim much smaller to insert.
- Hold the folded sides firmly in place between your thumb and forefinger so that the curved edge is facing away from your palm (or so that the stem is facing your palm).
- Be in a comfortable position and with Figure 12
  your vaginal muscles relaxed, gently
  separate the labia (the folds of skin around the vaginal opening)
  with your free hand and then push the curved edge of the folded
  cup horizontally into the vaginal opening so that the tip of the
  stem is no further than a 1/2 inch (1.27 cm) into the vagina.
- Grip the base of the cup (not the stem) and turn the cup one full rotation (360 degrees) in either direction or insert the cup about



Figure 11



half way, turn the cup one full rotation and then push it horizontally in the rest of the way. The cup must rotate easily as this ensures that it is fully open and that it is positioned horizontally towards your tailbone.



• To remove, pull gently on the stem of the cup until you can reach the base of

Figure 13

the cup. Pinch the base of the cup to release the seal and continue to pull down to remove it. After the cup has been removed, empty the contents in toilet and wash.

## How to clean a menstrual cup?

During periods, the cup only needs to be emptied 2-3 times a day, and can be left in all night. You can empty the contents into the toilet, rinse with plain water and immediately reinsert. Since medical grade silicone is used, it inhibits the growth of bacteria, ensuring the cup is always safe and hygienic. If water is not available you can just wipe with toilet paper and reinsert immediately! Be careful not to use soap or disinfectant, as this can cause irritation.

### Changes in positions

While using these methods of sanitation women with disabilities can confront many problems. These difficulties can be lessened by changes in positions. Some changes in positions that can be taught or tried while changing pads or tampons can be:

 A women sitting on a wheelchair may be able to use tampons independently if she can pull her pants down. She then must sit right on the front edge of her seat. Good practice is required to manage tampons in this position.

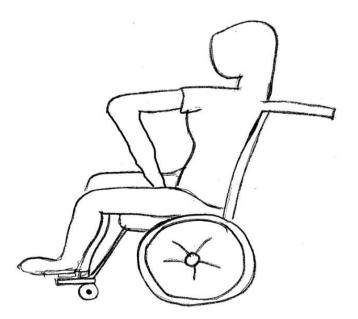


Figure 14

- 2. As far as using pads is concerned it may be difficult to get pads far enough back. Pads must be placed well underneath because the menstrual flow is inclined to run to the back both in a standing and a seated woman, especially in a wheelchair with its backward tilt.
- 3. A woman, who cannot lean over to reach her perineum, may need a raised toilet seat so that she can place a pad or a tampon. If she lacks sensation, she may also require a mirror angled so that she can see underneath, and if she has spasticity, she may require a knee spreader to keep her legs abducted. If her spasticity is severe, it is probable that inserting a tampon will increase her spasticity. She can be taught to lean sideways using a raised toilet seat



Figure 15

4. If a woman's balance is poor and she is unable to reach forwards, or if she is unable to get up again if she rests her trunk on her knees, she may need to lean sideways, and perhaps hold on to a bar or her wheelchair at the side. Both of these positions allow tampons to be used. Both of these positions also require transfers from wheelchair to toilet, and of course the problem remains of pulling down pants, and pulling them up again. This would not be very easy for a paraplegic as it would require the ability to lean far over from one side to the other.



Figure 16

5. Some women cannot balance well enough on a toilet, and may require use of both the hands due to problems in dexterity. For such women it would be easier to transfer to a bed to change pads or tampons rather than doing it on wheelchair or toilet seat. Those with dexterity problems can find use of pads more comfortable rather than tampons.



Figure 17

6. Women who have problems of coordination such as those with cerebral palsy can kneel so that they can stabilize themselves sufficiently to cope. This position can be two-point or three-point kneeling since one hand must be free. But if public facilities are used, this can be very unpleasant if they are unclean or littered. This may also be very embarrassing if the cubicles have wide gaps underneath.

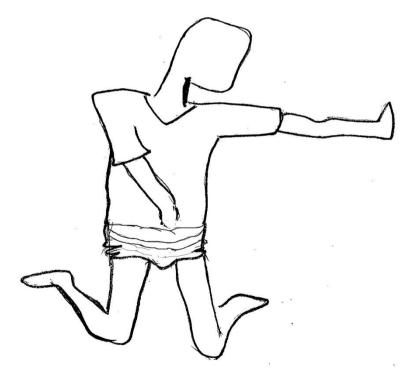


Figure 18

7. A woman with spasticity or loss of balance may be able to stand with the help of a grab bar, and if she can hold on with one hand only, she would be able to manage pads or tampons. Some method of retrieving pants may be required, unless the woman can reach down for them. Skirts can be equally difficult because they have to be held up, usually with the teeth, and also obscure vision.

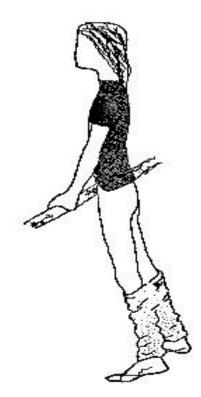


Figure 19

8. Women with cerebral palsy, multiple sclerosis, or spinal cord injury with sparing or controllable spasticity may be able to raise their buttocks from the wheelchair, but since this usually requires two hands, it is convenient only for a helper.

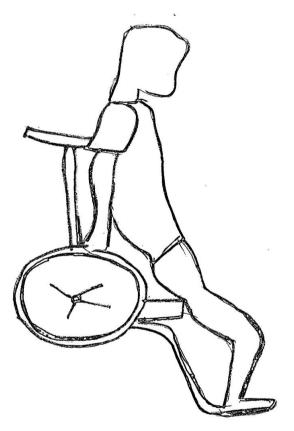


Figure 20

### Adaptive Clothing

Getting help in this area may be too embarrassing for a girl or woman. It seems infringement on their privacy. So if little thought can be placed on making panties or undergarment adaptive, it may solve lot of problems. Getting panties up and down is one of the major problems for many people. There are not many solutions to this. One solution of course, is to go without, and use tampons, or sit on pads. This however is unacceptable to many women; those who cannot use panties usually cannot cope with tampons, and if pads are used, panties are required to keep them in place, particularly during transfers.

Pampers with a crotch flap with velcro fastening and loops can save taking panties on and off each time. This can be used either sitting on a wheelchair, on the toilet seat or on the bed. This flap can be used with tampons, stick-on pads, or even large pads such as disposable diapers.

Loops can be used to pull up panties and pants if the woman has lack of hand dexterity.

Many types of panties can be pulled aside for urinating or using a tampon or pad.

Women who have problems of incontinence along with her menstruation need to change frequently. In that case they must avoid waterproof incontinence pants if possible, as these are not good for the skin.

#### Other Aids

An aid which may be required is a knee spreader designed to keep the thighs apart without damaging pressure on the skin. The knee spreader may be a simple bar with padded horseshoe shaped ends to fit the

thighs, or it may have a lever mechanism to help to part the knees. A simple knee spreader may be made from a wooden board with the concave curves at the ends well padded, and fitting the curve of the legs. The board





has the advantage that a mirror can be attached easily to the centre but it is not as easy to insert as the mechanical type if spasticity is severe. Mirrors may be useful for those with lack of sensation, particularly while learning or relearning to insert a tampon. A mirror may be fastened to a knee spreader, may be placed on a bed or on a stand by the toilet. A magnifying mirror or a mirror with a light can be useful. Generally an adjustable mirror is more useful, but if stability is required a correctly angled mirror which can be accurately placed each time may be indicated.

# Steps to hygiene

Good menstrual hygiene for WwDs requires:

- Access to accurate and pragmatic information
- Access to affordable menstrual hygiene materials
- Access to facilities that provide privacy for changing and washing
- Access to water and soap
- Access to disposal facilities

The normal general hygiene routine is helpful in ensuring good health for the girl. These coupled with specific menstrual hygiene measures are necessary to be clean and feel it too.

## Do not wear synthetic

Ensure that undergarments and sweat drenched clothes are changed regularly. Cotton panties are preferable to synthetic ones as synthetic ones do not absorb moisture and heat, making it a breeding ground for bacteria.



Figure 22

## Change regularly

As soon as the menstrual blood leaves the body it gets contaminated even if one is not bleeding much. If the pad is damp it will have organisms from the vagina, sweat from genitals, etc. Organisms tend to multiply fast when they remain in a warm



Figure 23

and moist place for a long time and can lead to urinary tract infection, vaginal infections and skin rashes. Sanitary pads should be changed once in six hours and a tampon should be changed once in two hours. One may change the changing schedule according to needs. Those with a heavy flow and would need to change more often.

## **Clean regularly**

During menstruation the blood tends to enter tiny spaces like the skin around the opening of the vagina. This excess blood should be washed away before the pad is changed. This would beat bad odour from the region. This is can be difficult for wheelchair users. If they are unable to



Figure 24

wash they can wipe off with tissues or toilet paper.

### Keep the area dry

The region around groin and underside of thighs must be kept dry in order to prevent from fungal and bacterial infections. After washing the area always dry it with a cotton towel or tissue paper.



Figure 25

## Do not use soaps or cleaning agents

The vagina has its own cleaning mechanism and it has a very fine balance of good and bad bacteria. Washing it with soap can kill the good bacteria. This may lead to infections. So

it is important to wash oneself regularly

X

Figure 26

during this time. Use only some warm water. Soap can be used on the external parts but not inside your vagina.

### The right washing technique

Always wash or clean the area in a motion that is from the vagina to the anus. Never wash in the opposite direction. Otherwise it can transfer bacteria from the anus to the vagina and urethral opening, leading to infections.



Figure 27

## Discard used sanitary product properly

It is necessary to discard used napkins or tampons properly because they can spread infections. They must be wrapped well before they are discarded. One should not to flush the pad or tampon down the toilet as they can block the toilet drains. Wash your hands well

after you discard your used napkin and if it is difficult you can use hand sanitizers.

## Beware of a pad rash

One may develop a pad rash during a period of heavy flow or when the pad has been wet for a long time and rubs along the thighs causing it to chaff. Try to stay dry during periods. In case of a rash, change your pads regularly and stay dry. Apply an antiseptic ointment, after a bath and before bed. Visit a doctor in case of severe rashes.

## One method of sanitation at a time

Those who have heavy flow during their periods sometimes tend to use either two sanitary pads or a tampon and sanitary pad or a sanitary pad along with a piece of cloth. But actually it is not good. Best way is to change regularly. Using two pads or a tampon and a sanitary pad is bad because this can lead to rashes, infections. A cloth may not be the cleanest thing to put next to your private parts.

## Have a bath regularly

In some cultures it is believed that a bathe during woman should not her periods. Bathing not only cleanses the body but also gives a chance to clean the private parts well. It also helps relieve menstrual cramps. backaches. helps improve the mood and makes one feel less То bloated. relief from qet some backaches and menstrual cramps, just



Figure 28

stand under a shower of warm water that is targeted towards back or abdomen.

#### **Kit For Your Periods**

When you have your periods it is important to be ready. It is important to have extra sanitary pads or tampons properly stored in a clean pouch or paper bag, a soft towel, some paper tissues or towels, hand sanitizer etc. a tube of antiseptic medication (if you are using one).

Changing your pads/ tampons regularly is essential, so you will need extra. More importantly you must store them properly so that they don't get contaminated. It is as important as changing. Pads or tampons that remain in your bag without a clean

pouch to protect it can also lead to infections like UTI (urinary tract infection)





or vaginal infections. The soft towel can be used to wipe your hands or face if you wash them. Paper towels are the important to wipe off the excess water after you wash your private parts. It is best you don't use toilet paper for this as it tends to shred and tear when it touches water. Your hand sanitizer is a very important factor here. You will need it to clean your hands and you can use it to clean the flush knob and tap faucet as well.

# Tip

A long shower hose may allow a quick rinse between the legs.

# What is Premenstrual Syndrome

Girls with physical and learning disabilities are more likely to suffer from period problems than their peers without disabilities. PMS refers to the mental and emotional symptoms which women may physical. experience during their menstrual cycle. Most women experience some symptoms of PMS at intervals throughout their life. Many women may have a headache, nausea (sometimes with vomiting), and constipation or diarrhoea. They may need to urinate frequently. Symptoms of premenstrual syndrome may persist during part or all of the menstrual period. Sometimes menstrual blood contains clots. The clots, which may appear bright red or dark, may contain tissue and fluid from the lining of the uterus, as well as blood. Some may have severe pain in the lowest part of the pelvis a few days before, during, or after a menstrual period. The pain tends to be most intense about 24 hours after periods begin and to reduce after 2 to 3 days. The pain is usually sharp and comes and goes. It may also be a dull and constant. It sometimes extends to the lower back and legs. Symptoms tend to be more severe if:

- Menstrual periods started at an early age.
- Periods are long or heavy.

However some women experience PMS every month. Symptoms can include mood swings, anger, depression, abdominal cramps, tender breasts, nausea and a flare-up of acne, binge eating or change in appetite. PMS and Down syndrome are a deadly duo.

### General Self-care Steps

- Take ibuprofen or a pain killer (as advised by your physician) if you have headaches, backaches, cramps, or breast tenderness.
- Limit salt and drink plenty of fluids.
- Avoid caffeine and alcohol.
- Try eating smaller, more frequent meals to reduce bloating.
- Try to exercise (only those which your body can tolerate or your doctor recommends you)
- Get enough sleep.
- Look for ways to manage your stress.
- Eat plenty of fruits, vegetables, pasta, and whole-grain breads and cereals.
- Take a daily multivitamin that includes 400 mcg of folic acid.
- Choose low-fat or non fat dairy products

## Strategies For Women With Epilepsy

There is an increased incidence of seizures at the time of ovulation and the premenstrual phase. Studies reveal that it may be because of increase in the ratio of estrogen to progesterone. Hormones may not be the exact cause behind seizures but they do influence the occurrence of seizures.

- Identify the role that your hormones play in your seizure patterns. This can help in your treatment. Keep a calendar of your menstrual cycle, and the days that you have seizures.
- Take your medication on time during menstruation and ovulation.
- Adjust the dose of a seizure medication before the time of increased seizures. This should only be done only with advice of your doctor.
- It is important to maintain good sleep
- Avoid alcohol and less than two beverages per day during periods.
- Reduce the water retention that occurs in the premenstrual period.

# Period As A Vital Sign

Menstrual problems are common in young women. Mild irregularities are normal, especially in the first few years of menstruation. Girls should be taught to pay attention to vaginal secretions. This would helps girl to understand their bodies. For example, yellow or strongsmelling secretions are not normal. These kinds of secretions are often a sign of infection.

Some situations may also require medical evaluation like. Menstrual irregularities can be a sign of a medical problem, including hypothyroidism and obesity. Excessive bleeding can also cause problems, including anaemia (low blood) and social difficulties with managing the flow.

## When should you see a doctor about your period?

See your doctor about your period if:

- You have not started menstruating by the age of 15.
- You have not started menstruating within 3 years after breast growth began, or if breasts haven't started to grow by age 13.
- Your period suddenly stops for more than 90 days.
- Your periods become very irregular after having had regular, monthly cycles.

- Your period occurs more often than every 21 days or less often than every 35 days.
- You are bleeding for more than 7 days.
- You are bleeding more heavily than usual or using more than 1 pad or tampon every 1 to 2 hours.
- You bleed between periods.
- You have severe pain during your period.
- You suddenly get a fever and feel sick after using tampons.

# Tip

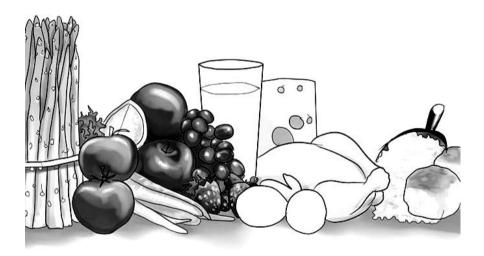
It's a good idea to use the "slender" size tampon when you are learning how to use tampons for the first time. It's also easier to insert it when your menstrual flow is moderate to heavy as this allows the tampon to glide in more easily. Remember, the more you relax, the easier the insertion will be. When you are nervous, your muscles tense up, which can make inserting the tampon more difficult.

# **Nutritional Requirements**

During menstruation, girls suffer from loss of appetite. However, taking no food or less than normal diet weakens the body. It is also necessary to take iron rich food to compensate for the blood loss and prevent anaemia. A balanced diet with lots of fresh fruits and vegetables may ease some of the problems associated with menstruation:

- Cut down on salt during your period to reduce bloating and fluid retention.
- Eat foods that are high in calcium. Calcium has been shown to help reduce some of the symptoms associated with PMS
- Some women get low progesterone levels during this time, which can cause anxiety-depression, mood swings, and cramps. Progesterone is a natural hormone. Vitamin B6 allows your body to maintain normal levels of progesterone. Without this vitamin, body's production of progesterone could dramatically decrease. Foods that are rich in vitamin B6 include potatoes, beans, spinach, bananas, seafood, poultry, red meat, whole grains and walnut.
- Intake of vitamin C is also important. Taking 750mg of vitamin C daily for six months can increase the production of progesterone in the body.

- Food rich in zinc and magnesium are also important for increasing progesterone levels.
- Take citrus fruits or vegetables before taking iron rich food.
- Avoid caffeine and tannin which decreases iron absorption by the body.



# Some Useful Tips

- Be comfortable, relax, and take things slowly, take some time off to yourself and away from others.
- You're not alone. Other women will know what you're going through. You can ask your friends if you need help or advice.
- Take your mind off of things and try to do what interests you the most.
- Exercise to let energy out. It doesn't have to be intense it can be something simple like a few push-ups three times a day.
   Exercise releases endorphins to make you happy, and increases blood flow around the body, which can help relieve cramps.
- Talk to an older person (like your mom) if you don't feel comfortable.
- Fatigue is also normal, so try to rest more and do something that takes your mind off your period, like reading. Severe pain may come but try not to take pills, try to get your mind off it.

# Charting

Charting is important to remember that every cycle is different. Some women have 4 day periods while other will have 7. Some may experience irritability and cramping, while others, menstrual migraines or both. Women may also experience food cravings, boosts of energy or positivity and moments of creativity throughout the month. Although not every symptom of our menstrual cycles are enjoyable, each symptom shows characteristics that are unique to your cycle. Tracking menstrual cycle doesn't require much. Simply record the symptoms that you experiences and after a few months you will notice some common trends.

**Caters to individual needs.** For example, for a woman who currently needs assistance at meal times, or while using the toilet, try rubber or self-inking stamp and a large calendar; for a woman with very poor vision, a method which relies more on touch and less on visual information may be more helpful (e.g. A wall chart with Velcro-attached objects or shapes); for the most dependent women, for whom charting will be done by others, the whole-year chart at the end of this chapter is the most suitable. The woman should still be present during charting and receive basic explanations of the process.

**Chart every day.** Regular charting will help people to be aware of both physical and psychological changes which accompany menstrual cycles. Patterns will probably emerge. The women and those assisting them will become more able to predict and respond appropriately.

**Establish a routine.** Choose a time of day which seems suitable to chart. Some people like to chart towards the end of the day or night. Others do it twice-daily: this applies particularly to settings where women are assisted by different people at different times of the day, such as in residential services.

**Record relevant information.** Women experience different kind of changes during her menstrual cycle. Like sore breasts, abdominal swelling, irritability, and fatigue, depression or some women may experience positive changes such as increased energy and enthusiasm. Each woman may have 3-4 types of information recorded. For some women, it will be important to record changes in mood and behaviour. The personal meaning of "happy" and "sad" stamps for each woman can be noted- either on her calendar or in her chart. Heaviness of flow may be an issue for some women. Using an Estimation of Menstrual Flow chart for several months will be helpful to clarify the type of flow a woman is experiencing. Women's involvement in their

own pad management can also be charted, to record achievements and progress.

Many years ago women used to track their cycles according to the phases of the moon. Moon having a cycle of its own, with different phases and a 29.5 day count, it made perfect sense for them to follow the moon's phases to track menstrual cycle

### **Types of Menstrual Charts**

There are several charting options for Menstrual Management of women with intellectual disability and high support needs. These include:

*The whole-year chart* enables all recorded information to be seen "at-aglance". This chart is suggested for use by people assisting the woman. Other menstrual charting systems are recommended for women who will be assisting with their charting.

*The twelve-month calendar* has a 4cm x 3.5cm recording space for each day. Using this calendar, women with high support needs may be able to assist with recording of information about their cyclic changes and periods. It is recommended that the calendar is used in conjunction with stamps.

The self-inking stamps were devised to assist with charting. Many women with high support needs are not able to use with pen and paper style recording. Stamps are much easier for them to use. Self-inking stamps may allow women with severe physical disability to do their menstrual charting. For that she would need place her hand or arm on the top of the stamp, and to press down. She can be helped with this. Other women may be able to use self-inking stamps independently. Stamp designs can be used to record key information.

Encourage girls and women with disabilities to take part in their menstrual charting.

<u>Period Tracker</u> A mobile app to predict your period's monthly due date. It doesn't base its projections on the standard, 28-day calendar as only a few women's bodies actually adhere to it. It calculates the average length of your last three cycles, so it can more accurately predict the date of your next periods. It is free on Android and iOS

## **Menstrual Chart**

\*\*While charting use appropriate symbols to show

- ✓ Spotting
- ✓ Light Bleeding
- ✓ Heavy Bleeding Cramps

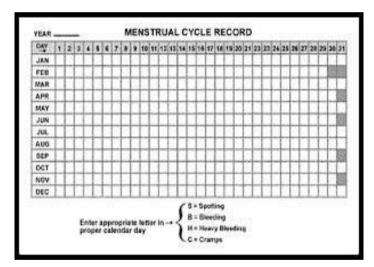


Figure 30

## Exercises

There are several exercises that can relieve menstrual discomfort. (For women with severe problems it would be better to take your health care provider into confidence before doing them). Whenever pain or discomfort is felt during any exercise it should be stopped immediately.

 Lie comfortably on your back with knees raised and feet on the ground. Relax. Breathe deeply and slowly. Put your hands on your stomach. As you breathe out, your hands will move down. As you breathe in, your hands will move up. Repeat this exercise four times. If you need assistance always ask for help.

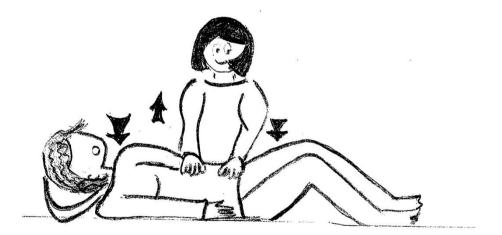
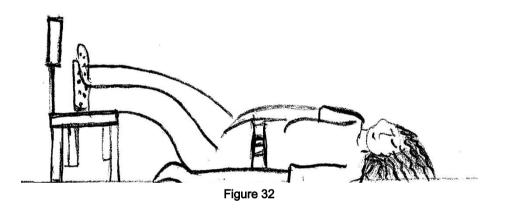


Figure 31

 Lie comfortably. Your assistant places your legs on a chair or foam cylinder. Your legs are supported from knee to heel. Lie comfortably for about ten minutes. If you feel any discomfort or pain in your back do it for a lesser time. Exercises are not meant to hurt you.



3. Lie comfortably on your back. Place a pillow under your head. Your assistant places one of their arms under your knees and their other one under your ankles. Your legs are moved in small circles. First in one direction and then in another. [For women who are unable to hold their knees together, more than one assistant may be needed].

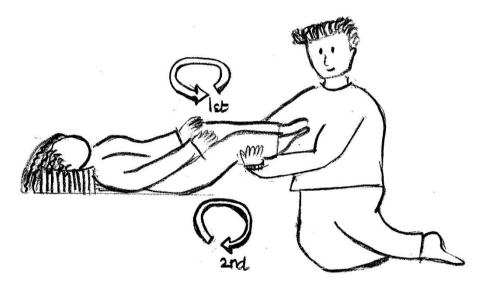


Figure 33

4. Lie comfortably on your back. Lift your bottom off the floor or of the bed (wherever you are lying down). Slide your hands underneath your bottom. Or use your hands on the floor/bed to push your bottom off the floor or bed. Hold for 5-10 seconds only. Repeat this 5 times. This exercise can be done by those whose hands are strong and pelvic region can be raised.

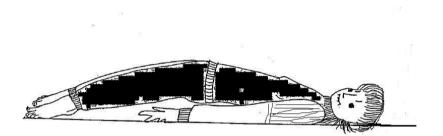


Figure 34

 Kneel down and hug a pillow, or beanbag or big covered foam cylinder. Your assistant places a warm pack on your lower back. You may be able to watch television or listen to some music while doing this.

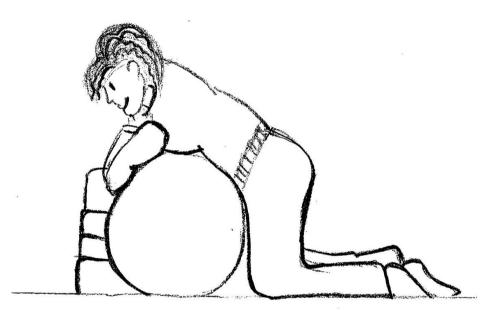


Figure 35

6. Kneel down with hands and knees on the floor or the bed. Your assistance helps you to comfortably arch your back like a cat, first upwards, then downwards. Repeat this four times each way. This exercise can be done by those women and girls who can kneel down easily putting pressure on their hands.



Figure 36

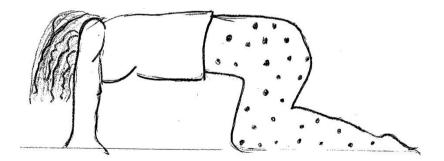


Figure 37



Those who have weak hands can be helped by their assistants.



7. For those who can stand up easily. Stand up with your arm elbow to palm against the wall, and the other hand on your hip.

Your assistant can help you in this exercise. With feet flat, try to touch your hip to the wall. Repeat this four times. Turn around and use your other hand and hip. Repeat the exercise on this side four times.

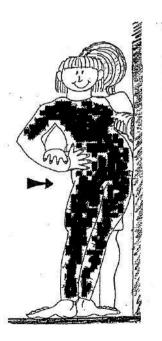


Figure 39

8. For those who can stand without any assistive devices but need assistance and support can do this exercise. Stand with hands on your hips. Your assistant helps to rotate your hips in a circle like a belly dancer. First one way, then another. Try to keep feet flat on the floor. Repeat this four times each direction.



Figure 40

 Lie comfortably on your back. Your assistant can place a warm pack on your lower abdomen on top of your clothing. Your assistant turns on some relaxing music. Close your eyes and



relax. Your assistant checks Figure 41 the warm pack every few minutes to make sure it is not too hot for you.

## For Mothers/ Caregivers

Attitudes of family members, care givers and friends towards menstruation can influence the reactions of a young woman who has a disability. Care givers of young women with the need of menstrual management may not know how to explain menstruation to her and how to train her in pad changing. The young woman may have grown and her weight may have increased. All this can add to difficulties for the people who assist her with bathing, toileting and changing menstrual pads. It is absolutely significant that those who provide personal assistance have a positive and supportive outlook towards menstruation. An individual plan would be required to take the needs, abilities and conditions of a young woman into consideration. For young women who are very dependent for self care, reassurance and acceptance of menstruation must be the main aim, rather than teaching of skills.

People assisting women with intellectual and other disabilities must to be aware of a range of methods of communicating, to increase the woman's ability to understand messages. One needs to consider the following points:

- When speaking about menstruation, the tone of voice, as well as the words used, should be very influential. If the person speaking is not comfortable, then the young woman is likely to sense this and react accordingly.
- 2. Television and magazine advertisements may help to illustrate some of this information.
- 3. It may be helpful to use "anatomically correct" dolls when providing explanations for some young women.
- Personalised books can be another useful approach. For those who are able to respond well, photographs and/or familiar communication symbols could be used to assist with learning.

There is a phenomenon, called "synchrony". Synchrony occurs when women who share living or working space experience their menstrual cycles at the same time; that is, they begin their periods on the same day in each cycle. Mothers and daughters living in the same house may experience synchrony. But premenstrual changes are not experienced in the same ways by women in the same family. Mothers and others who assist the young woman may need to remember to take care, or seek care for themselves in relation to their own menstrual cycles.

- Not reinforcing negative reactions to the sight of blood. Modelling of calm responses to menstruation by care providers can prove to be useful.
- Encouraging appropriately modest behaviour while bathing, dressing and toileting.
- 7. Encouraging affection behaviour which is appropriate to her age.
- Encouraging interactions with the young woman that recognise her approaching adolescence and maturity.
- 9. Encouraging appropriate (that is, in private) masturbation behaviour if it is occurring.
- 10. Ensuring consistency of approach in menstrual management for the woman both between people who assist her and across environment.
- 11. If your daughter has visual disability then you must try covering your eyes and do the things you're teaching your daughter. This may give you ideas for suggestions or adaptations that will be useful to her. Encourage her to ask a friend or her teacher if she's unsure whether or not she has a stain that's visible to others.
- 12. A visually impaired girl may be less likely than other girls her age to notice the changes in physical development that she and others are beginning to undergo, and she may need some more

detailed explanations if she can't see the pictures and diagrams in the typical books for teens and preteens.

- 13. For girls with autism carers might need to tell her whom to go to at school if her periods start there. Children with ASD often need longer to adjust to and understand changes in their lives than typically developing children do. And because you can't know exactly when your daughter will get her first period, it's a good idea to start talking about it early. Teaching simple phrases like 'You will bleed every month' and 'Blood is not dirty or 'It is clean' can be an effective way to break down more complicated ideas.
- 14. If your child uses visual supports, a visual schedule that shows the steps involved in changing a reusable cloth, pad or tampon can be useful. It will also help if you show your child where to attach the cloth or sanitary pad – you could mark her underwear to show where it goes.
- 15. Once your child's periods have started, you could teach how to use a calendar or an app to plan when her period is due.
- 16. Self care is the most important thing to focus on at this age. One lesson plan must focus on preparing the girl for menstruation by teaching her how to change her own sanitary napkin. This must be started when she is still small because rate of acquisition is very slow in developmental and intellectual disabilities.

- 17.Keep a list of activities or objects which each woman enjoys. Some of these can be planned for when the woman has her period. This may help her to associate periods with pleasant experiences.
- 18. Enjoyable activities may also direct attention away from discomfort, or inappropriate menstrual behaviours.
- 19. It may be appropriate to assist the woman to start using pads a few days before her period is due. This may help to communicate to some women that menstruation will soon begin.
- 20. Changes to the environment can signal to a woman that her period is due. Playing distinctive soothing music, burning a relaxing essential oil, giving her a daily massage in the days before and during a woman's period, may communicate to her in a pleasant way that her period is due.
- 21.Before helping a woman to change her pad, tell her what you are going to do and give her the object or tangible symbol that has been chosen to symbolise "change of pad" for her. Try to do so in a similar private place.
- 22. Show her a full packet of pads at the start of her period. Each time that her pad is changed, show her how to packet is becoming less full. On the last day of her period, show the

woman the almost-empty packet. When the packet is empty, she may be able to help dispose of it in the bin.

- 23. Every step of the process has to broken down into its simplest elements. This can be done many times a day for practice. Try that she is not scared. For e.g.
  - ✓ putting the sanitary napkin in a purse
  - ✓ bringing the purse to the bathroom,
  - $\checkmark$  sitting on the toilet
  - ✓ removing the paper from the back of the pad
- 24. Use positive language around menstruation. Never use negative connotations like "the curse". Your own attitudes around menstruation can influence how your girl feels about it too.
- 25. Children with ASD often fear change and unpredictability so it is important to make menstruation part of our dialogue with your children. Preparation process is key to reduce anxiety
- 26. Introduce the 28-day cycle calendar after menstruation starts to build in awareness and predictability of when menstruation will happen. People with Autism Spectrum Disorder like predictability and no surprises. They may take a few cycles to adjust. Calendar will provide a place to start. Colour days 1 – 5 in red to represent the menstrual bleeding. If the girl is aware of ovulation

you may also want to mark in ovulation on Day 14 as there is an alteration in discharge at that time.

- 27. If a woman has trouble communicating or finds it hard to regulate her emotions, her emotional symptoms might lead to challenging behaviour. You need to be careful of that.
- 28. Help your daughter to manage the emotional symptoms of PMS by letting her know how she might feel:
  - ✓ cross and cranky
  - ✓ trouble with concentration
  - ✓ depressed
  - ✓ sleepy

Pictures to illustrate these feelings might be useful.

- 29. If your daughter understands the reasons of these symptoms and their length it may be useful for her to be in control of her changing body. For example, *'You are looking uncomfortable today. I wonder if your period is coming soon'*.
- 30. Pads are cheaper than diapers. If your daughter wears a diaper, put a pad inside the diaper. Change the pad when it is soiled so you do not have to change the diaper as often.
- 31. Shaving pubic hair is not necessary for hygiene reasons. Some parents have their daughter's pubic hair shaved for religious or

cultural reasons. This is fine, but it is just as clean to leave the area unshaved.

- 32. It's fine to talk about menstruation, but teach her that there is a time and place. Teach those boundaries early.
- 33. Establish appropriate social etiquette.

Explanation of the natural course of development and menstruation is important. Education of the adolescent girl will need to be individualized to her level of understanding and explicit explanation of hygiene issues and acceptable behaviour may be needed. Families may find additional support from other carers in similar situations or health care professionals experienced in the day-to-day care of adolescent girls with learning disabilities helpful.

Help is sometimes sought while the girl is still premenarchal and it is important to emphasise that girls must be allowed to enter puberty normally before any therapeutic intervention can be considered. An explanation of the necessity of oestrogen exposure to promote skeletal and cardiovascular health needs to be given.

# **Sex During Menstruation**

It is absolutely safe to have sex during periods. Symptoms of PMS can be eased if one has sex during the time of menstruation. Orgasms can ease cramps and the orgasmic contractions of the uterus and offer a soothing internal massage. Orgasms release endorphins which are a kind of natural painkillers and mood enhancers. These can help to soothe the cramps, headaches, mild depression, and irritability sometimes associated with periods.

Safe sex is even more crucial during your period. Your risks of sexually transmitted diseases and infections are higher than normal during this time because the cervix opens to allow blood to pass through. Unfortunately, this creates the perfect pathway for bacteria to travel deep inside the pelvic cavity. You are also more likely to pass on blood-borne diseases like HIV and hepatitis to a partner during your period and more likely to develop yeast or bacterial infections because the vagina's pH during menstruation is less acidic. Finally, there is still a chance that you could get pregnant during your period (unless one is on the pill). So don't assume it's safe to forgo contraception.

## Social Taboo Around Menstruation

Menstruation is a normal human process. But it is still treated as a taboo in many cultures and societies across the world. A profound silence around the topic combined with a lack of access to information results in girls and women possessing very little understanding of their own bodies. Many are left to manage their periods in an unsafe manner, using old rags or other unhygienic and ineffective materials. The problem increases by limited access to hygienic products, safe and private sanitation facilities, and inconsistent supplies of water for personal hygiene, and inadequate disposal options. As a result, menstruating girls and women often feel ashamed and embarrassed about themselves. Facing health problems and socio-cultural taboos surrounding their periods, they become isolated from family, school, and their communities. Women and girls miss school and productive work days, thus falling behind their male counterparts. Many people are not comfortable about discussing menstruation. There is a paucity of literature about menstruation management for the disabled which also may be due to this embarrassment.

The taboo is woven into very complex web of issues. It begins initially with an extremely patriarchal, hierarchical society which is responsible for an uneasy reticence around menstruation. The whole situation is paradoxically related. Without menstruation pregnancy is not possible. But in our culture and society while menstruation and a menstruating woman are stigmatised, pregnancy becomes the time to celebrate.

There is a need for an open advocacy platform around Menstrual Hygiene and Management that would bring together organizations from the diverse sectors working in the area, including WASH, education, gender, and reproductive health especially for the Women with Disabilities.

The need is to have a single celebration from puberty to motherhood; "A complete celebration of womanhood". This issue should become an issue of pride rather than shame. Once this happens all the psychological burden and the trauma associated with the silence will slowly start chipping away and will in time die away.

So let us teach the world that shedding endometrium is not dangerous but NOT shedding of myths and negative attitudes about menstruation is dangerous!

#### References

- Overview of Menstrual Management for Disabled Women, by Bridget Duckworth
- The Management of Menstrual flow in Disabled Women. Nursing Times, 76, 409-411, McCarthy, B.P. (1980).
- Disabled Eve: Aids in menstruation. London: Disabled Living Foundation, McCarthy, B.P. (1981).
- Guide to having a period, FAIR in association with Community Nurses for People with Learning Disabilities, NHS Lothian.
   (www.fairadvice.org.uk)
- OPTIONS FOR MENSTRUAL MANAGEMENT; Resources and Information for Staff and Carers of Women with an Intellectual Disability; Dr Harjeet Kaur, Ms Jenny Butler & Dr Stephen Trumble Developmental Disability Unit Department of Community Medicine & General Practice Monash University.
- Managing Menstruation; The Menstrual Preparation and Management Kit, by Miriam Taylor, Glenys Carlson, Jeni Griffin, Jill Wilson, March 1994; Developed by Department of Social Work and Social Policy at the University of Queensland and the Division of Intellectual Disability Services in the Queensland Department of Family Services and Aboriginal and Islander Affairs

- Menstrual Issues in Adolescents with Physical and Developmental Disabilities by ELISABETH H. QUINT; Department of Obstetrics and Gynecology, Division of Gynecology, University of Michigan Health System, Ann Arbor, Michigan, USA
- Menstrupedia



#### About the author

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