



**O**ptions  
for  
**M**enstrual  
**M**anagement

**Resources and  
Information  
for Staff and Carers  
of Women  
with an  
Intellectual Disability**

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# **OPTIONS FOR MENSTRUAL MANAGEMENT**

## **Resources and Information for Staff and Carers of Women with an Intellectual Disability**

Women with an intellectual disability have the same rights as other women in the community to access relevant resources to help them manage their menstruation. This booklet is designed as a resource for those working with women who have an intellectual disability. It does not provide specific or complete programs. Rather, it is intended to assist workers and carers to develop their own individualised menstrual management strategies and programs for the women with whom they work.



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Revised in 1999 and 2003

by

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**Menstruation is a normal, healthy process for women. Women with an intellectual disability are usually able to manage their menstruation either by themselves or with varying degrees of assistance from others.**

### ***What is menstrual management?***

Menstrual management refers to a range of strategies that a woman might use during her menstrual cycle.

The aim of menstrual management for a woman with intellectual disability is:

- for her to experience her normal menstrual cycle
- for her to be comfortable with her menstrual fluid
- for her to manage her menstruation hygienically, with dignity and privacy
- to meet the individual needs of each woman.

A woman with an intellectual disability will generally have the same menstrual hygiene needs as all other women – that is, to manage her menstruation as independently as possible, meeting her needs for both good hygiene and appropriate privacy.

### ***Is menstruation any different in women with disability?***

- Most girls who have an intellectual disability begin menstruating at the usual time and go on to menstruate with the same regularity as their peers who do not have a disability.

- Women with intellectual disabilities have the same right to the full range of menstrual management options as any other women.
- Regardless of disability, the management of any menstrual problem is the same for all women.
- Treatment options recommended should be the least restrictive and always in the woman's best interest

## **Important Considerations**

When considering menstrual management options for a woman with an intellectual disability, all facets of a woman's life which may relate to her menstruation must be taken into account.

These include:

**Age:** Most women experience variations in their menstruation during different stages of their life.

The first few years of a young woman's menstruation often bear little resemblance to what will become her long-term pattern.

The older woman may be approaching menopause, when the possibility of heavy or irregular periods increases.

**Ability/Functional Capacity:** This will impact on a woman's ability to understand her menstrual cycle and how to manage it. Menstrual education programs may need to be modified to suit the individual needs of each woman.

**Associated Disabilities:** Some women will have other disabilities, such as visual impairment or cerebral palsy, which may make menstrual management more difficult. Individual programs will need to be adjusted to suit each woman's needs.

**Personal Hygiene Skills:** The extent to which a woman can manage her toileting will probably reflect her ability to manage her menstrual period.

- If a woman toilets independently then it would be reasonable to assume that, given appropriate education and time, she could manage her menses.
- If a woman needs assistance with toileting then menstrual pads/tampons can be checked and changed at that time.
- If a woman is being taken to the toilet at specific times (toilet timing) menstrual pads/tampons can be checked and changed at those times.
- If a woman has difficulty handling soiled pads or if she spreads menstrual blood, she might find it preferable to learn to use tampons. Many women choose tampons as a matter of personal preference.
- Alternative hygiene products (Appendix 2) may be necessary if a woman is incontinent of urine and/or faeces, or is unable to tolerate disposable pads.
- The usual infection control procedures must be observed to prevent infections such as Hepatitis B, Hepatitis C and HIV/AIDS, although transmission through menstrual fluid has never been documented.



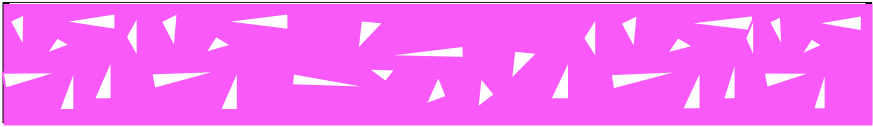
## *Where to start?*

**Most women with intellectual disabilities should be able to manage their menstruation either by themselves or with some assistance from staff or a carer.**

If a woman has high support needs and requires assistance to manage her menstruation, it is important to remember:

- Staff and carers play a significant role in the success of menstrual management programs. Positive attitudes towards menstrual care will usually generate positive outcomes.
- When implementing individual programs and strategies, the staff member involved should be someone with whom the woman feels comfortable and who is able to assist her consistently with her routine.

If staff and carers require further information, the woman's medical practitioner or agencies such as the Centre for Developmental Disability Health and Family Planning Victoria may be able to provide additional assistance (Appendix 1).



## *What makes a successful program?*

### **1. Simplicity**

- Programs should be as simple as possible and appropriate to the individuals' needs.
- Do not reinvent the wheel. Use existing programs and resources and adapt them for individual needs.
- Above all, use common sense.

### **2. Choice of carer**

- The availability of a carer who is acceptable to the woman is important if she requires assistance with management of her menses.
- Whenever possible this carer should be:
  - ◆ female
  - ◆ should be chosen by the woman.

### **3. Consistency**

Any program decided upon should be followed consistently by everyone involved ie:

- the same educational aids should be used by all support persons.

#### **4. Dignity**

- Use the rule of thumb “What if it was me/or my daughter?”, and afford that same degree of respect, privacy and dignity to the woman concerned.

#### **5. Environment**

- The aim should be for every woman to be given the opportunity to develop her personal hygiene skills to her full potential.
- Privacy, access to personal hygiene aids and convenient facilities for disposal of sanitary products are all important aspects of an appropriate environment.
- Infection control guidelines must be followed.

#### **6. Comfort/Protection**

- Specialised products and hygiene aids (Appendix 2) should be made available if necessary, so that a woman with an intellectual disability can be as independent as possible in the management of her menstruation.
- Most women will experiment with different pads and tampons to find the ones they prefer. It is important for women with disabilities to have the same opportunities to choose what they feel is most comfortable and appropriate.

## **7. Skill development**

- Use existing skills and build on them. For example, if a woman can change her underpants herself, her carer could fit adhesive pads into the pants so the woman only needs to change her underpants when the pad becomes soiled. Later in the program she may learn to fit pads into her underpants independently. If after an adequate trial a particular program is found to have been unsuccessful, a new approach should be considered.

## **8. Personal beliefs and attitudes**

*When assisting a woman with her menstruation carers may approach the task with their own values, myths and misunderstandings. It is important not to impose your own feelings about menstruation on the woman you are supporting.*

- Menstruation should be viewed as a normal physiological function.
- You may need to recognise and acknowledge the ethnic and cultural context within which a woman views her menstrual cycle.



## *What if menstrual problems arise?*

Recognition and treatment of menstrual cycle symptoms is an important aspect of menstrual management in women with intellectual disabilities.

**Menstruation is a simple and comfortable process for most women. There are occasions, however, when moods and sensations related to the cycle can be distressing.**

If a woman who has an intellectual disability is to deal with these feelings in a positive fashion, it helps if she is able to recognise them for what they are. In some situations, staff and carers will have to recognise these symptoms and provide reassurance for the woman.

*When menstrual management is not being successfully implemented, or when other related symptoms (discussed below) are causing concern, medical advice should be sought.*

If a doctor is consulted they will need to know:

- frequency of periods
- duration of menstruation
- associated symptoms - eg cramps, clots, flooding, mood changes or seizures - and the days on which they occur.

*A menstrual chart which records degree of blood loss and the presence of associated features eg pain, mood changes or seizure activity is very helpful in the documentation of menstrual problems (Appendix 3).*

The Department of Human Services (DHS) policy on Confidentiality and Privacy states that collection and exchange of all personal information should be in the best interests of the client and should only be on a “need to know” basis relevant to the particular circumstances. This is a common sense approach. For example, records of a woman’s menstrual cycle should be stored securely and not displayed on a pin board.

When a medical assessment is required, the doctor may need to examine the woman. The examination will probably include:

- a full physical examination
- a breast examination
- an internal examination of her pelvis.

*It is usually appropriate for a carer with whom the woman feels particularly comfortable to stay with her throughout the examination.*

**Some problems which can occur during menstruation are:**

### **Painful periods (Dysmenorrhoea):**

Most women will feel some level of discomfort, ranging from mild cramping to severe debilitating pain, during their periods. Other symptoms may include nausea, vomiting and diarrhoea.

Techniques such as relaxation, local warmth, exercises and massage may help relieve such symptoms.

If these are unsuccessful, ‘over the counter’ period pain relief tablets may be necessary eg Naprogesic or Ponstan. Before these can be administered carers must first check with the woman’s doctor for allergies and other contra-indications. DHS staff must seek their supervisor’s permission and document the permission and administration on the appropriate recording sheet.

## Heavy periods (Menorrhagia)

- It is difficult to estimate the volume of blood lost during a menstrual cycle.
- Women's cycles may vary in the amount of blood lost each month.
- Prolonged episodes of heavy menstrual bleeding can result in anemia due to loss of iron. A diet that is high in iron or the use of iron supplements may be necessary.

*When deciding whether to adopt a more restrictive approach to the management of heavy periods, the effect that the period has on the woman's quality of life is more important than the absolute volume of blood lost.*

A woman may manage her heavy menstrual bleeding by:

- changing her pads/tampons more frequently
- changing the style of sanitary products used.
- taking 'over the counter' period pain relief medications, such as Naprogesic and Ponstan, which may also reduce the amount of blood loss each month.

## Premenstrual Syndrome (PMS)

PMS is the term used to describe a range of symptoms experienced by a woman prior to her period.

Women may experience premenstrual symptoms including:

- breast discomfort
- mood swings, irritability and / or depression
- headaches, food cravings, acne, weight gain, bloating and fluid retention.

These symptoms are due to hormonal fluctuations and usually go away when the period starts.

There are a variety of approaches to the management of PMS. These may include:

- a calm supportive environment.
- information about the feelings women may have at different times of her cycle, and the hormonal basis for these feelings.
- a friendly, reassuring discussion with the woman about what she is experiencing and encouraging her to keep a menstrual diary is a good way to help her to understand her feelings.
- a simple high fibre, low fat and low salt diet, containing plenty of fresh fruit and vegetables, whilst avoiding highly refined and rich foods.
- a gentle exercise regimen and a good sleep pattern to enhance the woman's feelings of well being. Relaxation exercises can be of great benefit.
- vitamin and herbal preparations, including vitamin B6 and evening primrose oil. While it may be worthwhile assisting women with disabilities to experiment with these preparations, consideration needs to be given to their relative benefit and cost of treatment.

If symptoms continue to cause distress in spite of all these measures, consultation with a medical practitioner is advised.

## **No period (Amenorrhoea)**

If a woman who usually menstruates regularly misses a period, medical advice should be sought to exclude:

- pregnancy
- menopause
- other medical conditions.

## **Irregular periods (Polymenorrhoea):**

Irregular cycles are normal and acceptable for some women. If periods become irregular or variable in strength it may be necessary to:

- carefully chart and document length of cycle
- consult a doctor for further assessment and treatment. This consultation may include:
  - a careful history taken to establish period irregularity and amount of blood loss and other relevant symptoms
  - a general gynaecological examination and investigations to exclude organic disease
  - a Pap test
  - a discussion of treatment options. Hormonal medications such as the oral contraceptive pill or injectable preparations may be considered.

## **Epilepsy**

Many women with intellectual disabilities have epilepsy.

Some women with epilepsy have more seizures just before or during menstruation. This is called catamenial epilepsy.

A calendar showing any suspected association between periods and seizures is an important aid in diagnosis of this recognised medical condition (Appendix 3). Medical consultation is warranted if such an association is suspected.



## *When is menstrual suppression necessary?*

There will be some circumstances when adequate trials of less restrictive treatments fail and menstrual suppression may need to be considered in the best interests of the woman.

Menstrual suppression should only be recommended for:

- Gynaecological conditions eg menorrhagia, endometriosis or severe pre-menstrual syndrome where less restrictive measures have failed.
- Medical conditions which cause significant problems as a result of the menstrual cycle eg certain types of epilepsy.
- Situations where a woman makes an informed decision to suppress her menstruation.

Menstrual suppression can be temporary or permanent.

**The temporary suppression of menstruation can be accomplished by the use of certain medications**, such as the oral contraceptive pill and Depo Provera. These should only be administered after a thorough medical assessment.

### **Consent**

- When a woman cannot give informed consent to pharmacological menstrual suppression the decision should be made by the doctor and the ‘person responsible’ (as defined in the Guardianship and Administration Act 1986) in consultation with the woman herself.
- The insertion of hormonal implants, or a hormonally impregnated IUD are procedures for which the ‘person

responsible' MUST give informed consent if the woman herself cannot do so.

### **Permanent suppression of menstruation can be achieved by surgical intervention.**

Surgical interventions which result in permanent suppression of menstruation include :

- Endometrial ablation which is the permanent destruction of the lining of the uterus (this does not guarantee reduced menstrual flow or amenorrhoea).
- Hysterectomy refers to the surgical removal of the uterus.

This surgery will not alter a woman's hormonal status and thus will not affect conditions such as pre-menstrual syndrome or catamenial epilepsy.

Medical conditions which require hysterectomy to be accompanied by surgical removal of both ovaries, (bilateral oophorectomy) will result in cessation of both menstruation and the hormonal fluctuations which accompany it, unless cyclical hormonal replacement therapy is instituted.

**These surgical interventions result in infertility, and are considered to be special medical procedures. If the woman herself is unable to give informed consent then application MUST be made to the Guardianship List, Victorian Civil and Administrative Tribunal (for women 18 or over) or the Family Court of Australia (for children).**

***Is menstrual suppression acceptable as a behaviour management intervention?***

There may be a few situations where menstrual or pre-menstrual conditions cause a woman to injure herself or others or to persistently destroy property.

Menstrual suppression for behaviour management can only be considered in these cases if less restrictive approaches have been tried for an adequate time, and have been shown to be unsuccessful.

**Menstrual suppression by medication for the purposes of behaviour management is considered to be a chemical restraint and can only be used in accordance with Section 44(3) of the Intellectually Disabled Person's Act 1986 which states:**

*“Chemical means of bodily restraint of an eligible person can only be applied if that restraint is necessary:*

- To prevent a person from causing injury to herself or any other person*
- To prevent a person from persistently destroying property”.*

Spreading of blood, distress at bleeding, incontinence, hygiene problems or infection control eg hepatitis B or C cannot by themselves justify hormonal or surgical intervention.



## **A Final Comment**

It is important to remember that, while there is a wide range of menstrual hygiene products and educational materials available, the success of any menstrual management program will depend largely upon adequate communication and co-operation. Ultimately, it will be the enthusiasm and initiative of the women, staff and carers that will determine the outcome.



## **Teaching Resources**

**Resources helpful in preparing women with an intellectual disability for menstrual management include:**

### **Managing Menstruation**

3rd Edition Brisbane Department of Social Work and Social Policy University of Qld in conjunction with the Division of Intellectual Disability Services Qld Department of Family Services and Aboriginal and Islander Affairs. Taylor, M., Carlson, G., Griffin, J., & Wilson, J.

### **Janet's Got Her Period**

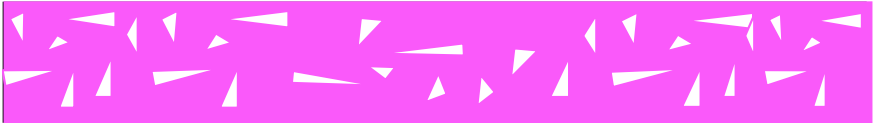
Self Care in Menstruation for Girls and Young Women with Special Learning Needs: a video based teaching package aimed to assist women with intellectual disabilities learn the skills necessary to be independent in managing their menstruation. Available from Family Planning Victoria.

### **Paps I Should**

Video about Pap smears. Available from Family Planning Victoria.

### **The Menstrual Preparation and Management Kit**

Produced by Intellectual Disability Services, Department of Family Services and Aboriginal and Islander Affairs in conjunction with the Department of Social Work and Social Policy, University of Qld.



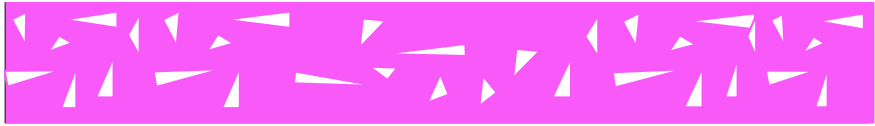
## Reading Resources

Medical/dental treatment for patients who cannot consent; Publications, Office of the Public Advocate, 2001.  
<http://www.publicadvocate.vic.gov.au>

Department of Human Services *Menstrual Management Policy* 1997  
[http://hnb.dhs.vic.gov.au/ds/disabilityimages.nsf/Downloads/menman/\\$file/menman.pdf](http://hnb.dhs.vic.gov.au/ds/disabilityimages.nsf/Downloads/menman/$file/menman.pdf)

Management Guidelines: People with Developmental and Intellectual Disabilities. Melbourne: Therapeutic Guidelines Limited, 1999. Chapters on Management of an Adolescent with an Intellectual Disability, Sexuality and Women's Health.

From Girl To Woman – Wesley Mission, Brisbane  
<http://www.fromgirltowoman.wmb.org.au>



## **Appendix 1**

### **Resource Agencies**

**(which may be able to provide additional assistance and information):**

#### **Centre for Developmental Disability Health Victoria**

Suite 202

3 Chester Street

OAKLEIGH VIC 3166

Tel: (03) 9564 7511

E-mail: [cddh@med.monash.edu.au](mailto:cddh@med.monash.edu.au)

<http://cddh.med.monash.edu.au>

The Centre for Developmental Disability Health Victoria works to improve health outcomes for adults with developmental disabilities in Victoria by enhancing the capacity of generic health systems.

Staff at the CDDHV are engaged in a range of activities directed at meeting this goal including:

- ◆ Undergraduate and postgraduate educational activities.
- ◆ Research projects and publications.
- ◆ A secondary and tertiary consultation service supporting Victorian GP to care for their own patients with a developmental disability.

## **Family Planning Victoria**

901 Whitehorse Road  
BOX HILL VIC 3128  
Tel: (03) 9899 4477  
[www.fpv.org.au](http://www.fpv.org.au)

Family Planning Victoria provides a range of clinical and educational services. The clinic provides experienced doctors and counsellors who can assess and, if necessary, treat women with menstrual management difficulties.

The educational and training unit provides information to both staff and women with disabilities in the area of menstrual management. This unit also has an extensive audio visual and resource collection.

The Options Bookshop and Library has a large range of literature relating to menstrual management and human relations issues.

## **Guardianship List**

Victorian Civil and Administrative Tribunal  
55 King Street  
MELBOURNE VIC 3000  
Tel: (03) 9628 9911  
[www.vcat.gov.au/vcatguardianshiplist.html](http://www.vcat.gov.au/vcatguardianshiplist.html)

The Guardianship List is one of two Lists making up the Human Rights Division of VCAT. The other List is the Anti-Discrimination List. On 1st July 1998 the List took over the jurisdiction of the former Guardianship and Administration Board.

The role of the Guardianship List is to protect persons aged 18 years or over who, as result of a disability, are unable to make reasonable decisions about their person or circumstances or their financial and legal affairs.

## **Office of the Public Advocate**

5<sup>th</sup> Floor

436 Lonsdale Street

MELBOURNE VIC 3000

Tel: (03) 9603 9500

[www.publicadvocate.vic.gov.au](http://www.publicadvocate.vic.gov.au)

The Office of the Public Advocate is an independent statutory office, working to promote the interests, rights and dignity of Victorians with disability.

The Office of the Public Advocate provides:

- \* advocacy, guardianship and investigative services, particularly in cases of abuse or exploitation of people with disability
- \* an advice service
- \* training and support for volunteers
- \* speakers and publications.
- \* policy & research on law reform and systemic issues relevant to people with disability

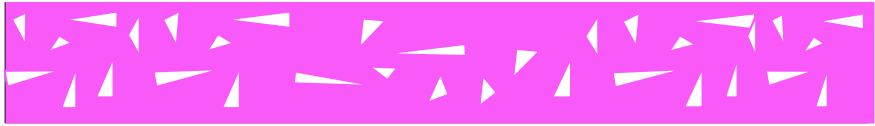
## **Intellectual Disability Review Panel**

Level 30, 570 Bourke Street

MELBOURNE Vic 3000

Tel: (03) 8601 5244; 1800 641 038 (toll free)

e-mail: [idrp@dhs.vic.gov.au](mailto:idrp@dhs.vic.gov.au)



## Appendix 2

### **Alternative Hygiene Products**

There are a wide range of hygiene products available in the community. While some of these are not specifically designed to be used during menstruation they are easily adaptable and may be a useful alternative for some women, especially if they are also incontinent of urine or faeces or unable to tolerate disposable pads.

- **Kanga pants**  
Includes pouch for disposable pad - widely available in chemists.
- **Kylie pants**  
Built in pad, re-usable - available from chemists.
- **Buddies Rozelle brief**  
Built in pad - available from “Buddies”; 9 Corr Street, MOORABBIN VIC 3189.
- **Huggies Girls Extra Large**  
Disposable - available from chemists and supermarkets.
- **Night’N’Day Comfort Pads**  
This company have a wide range of disposable and reusable products and are also willing to design and produce products to suit individual needs. (02) 9531 2011.

Further advice on individual needs and products can also be obtained from the following places:

**Continence Foundation of Australia**

59 Victoria Parade

COLLINGWOOD VIC 3066

Tel: (03) 9419 2496

**Independent Living Centre**

705 Geelong Road

BROOKLYN VIC 3025

Tel: (03) 9362 6111

**ParaQuad Victoria**

208 Wellington Street

COLLINGWOOD VIC 3066

Tel: (03) 9417 7400



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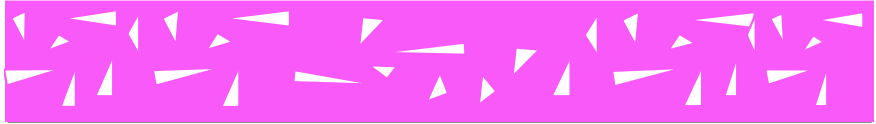
**P** = PERIOD/BLEEDING: + = light    ++ = medium    +++ = heavy

**C** = CRAMPS

**S** = SEIZURES

**H** = HAPPY ☺

**A** = ANGRY ☹



## **Acknowledgements**

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