Supporting Women

Information and resources for carers supporting women with intellectual disabilities to manage their menstruation
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Information and resources for carers supporting women with intellectual disabilities to manage their menstruation and assorted menstrual disorders.

Some women with intellectual disabilities require support to manage their menstruation and associated menstrual disorders. This booklet is designed as a resource for those who support women with intellectual disabilities in order to assist them to develop individualised menstrual management strategies for the women with whom they work.

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Menstruation and Disability

Menstruation is a normal, healthy process for women. Women with intellectual disabilities are usually able to manage their menstruation either by themselves or with some assistance from others.

Supporting a woman to manage her own menstruation

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

- be comfortable with her menstrual flow;
- manage her menstruation, independently or with assistance, hygienically and with dignity and privacy.

Is menstruation any different in women with intellectual disabilities?

Girls with intellectual disabilities usually begin menstruating at the same time and with the same regularity as their age peers.

Women with intellectual disabilities have the right to the same range of options to manage their menstruation as all other women.

Management options for treating menstrual disturbances are the same for all women, whether or not the woman has an intellectual disability.

Treatment options recommended should be the least restrictive and always in the woman’s best interests.
Developing Strategies for Managing Menstruation

When considering menstrual management options with and for women with intellectual disabilities, all aspects 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 menstrual pattern at different stages of their life. For instance, girls whose periods have just begun or women approaching menopause may experience heavy or irregular periods for a time.

**Level of Ability/Functional Capacity**
A woman’s cognitive capacity will influence her ability to understand her menstrual cycle and how to manage it. Menstrual education programs need to be adapted to suit the individual needs of each woman.

**Associated Disabilities**
Some women will have other disabilities, such as visual or motor impairments, which may make it more difficult for them to manage their periods. Programs must therefore be individually designed to suit each woman’s needs and abilities.

**Personal Hygiene Skills**
The extent to which a woman is independent in using the toilet usually reflects her ability to manage her menstrual period.

If a woman is able to use the toilet independently then it is reasonable to assume that, given appropriate education and time, she can learn to check and change her pads herself.

If a woman uses continence products for bladder and/or bowel function, these will also serve for menstrual hygiene.

If a woman is being taken to the toilet at specific times (toilet timing), menstrual pads can be checked and changed at those times.
Standard infection control procedures must be observed to prevent blood-borne infections such as Hepatitis B, Hepatitis C and HIV/AIDS, although transmission even though menstrual fluid has never been documented.
Providing Support for Women

Some women with disabilities may need the support and assistance of others in their daily lives. Those providing support may be family members, friends, volunteers or paid staff. We have chosen the word ‘carer’ to encompass all those providing this care.

Most women with intellectual disabilities can manage their menstruation either by themselves or with some assistance from a carer.

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

- **Carers** play a significant role in the success of menstrual management programs. Positive attitudes towards menstruation will usually generate positive outcomes.

- When implementing individual programs and strategies, the carer should be someone with whom the woman feels comfortable and who is consistently available to assist her with her routine. Often a mother, sister or regular staff member within the household is in the best position to provide this support.

If carers require further information, the woman’s medical practitioner, Women’s health clinics, or agencies such as Family Planning Association or the Centre for Developmental Disability Health Victoria may be able to provide advice and assistance (see Appendix 1).
Keys to Successful Strategies

What makes a successful strategy or program to support a woman to learn to manage her menstruation?

1. Simplicity

Programs should be as simple as possible and appropriate to the individual’s needs and abilities.

Use existing programs and resources and adapt them as required - i.e. do not reinvent the wheel.

2. Carer

If a woman requires assistance in managing her periods this should be provided by carers with whom the woman feels comfortable, and who themselves feel comfortable providing that support.

Whenever possible these carers should be chosen by the woman.

3. Consistency

When particular programs or strategies are decided upon, it is important that they are applied consistently by everyone involved in order to facilitate learning.

Wherever possible the same support person/s should be available.

The same language, phrases and actions should be used consistently by all those involved.

The same educational resources and aids should be used consistently by all those involved.

4. Dignity

Managing menstruation is an intimate and private matter. Those supporting women should afford the same degree of respect, privacy and dignity to the woman concerned as they would want for themselves, their daughter or mother.

5. Environment

Every woman should be given the opportunity to develop her personal care skills to the full potential of her ability, and to optimize her independence at home, work and within the community.
Privacy, access to personal hygiene aids and convenient facilities for disposal of sanitary products are all important aspects of an appropriate environment that promotes independence.

**Note:** *Standard infection control must always be followed by those assisting women with their menstrual hygiene.*

### 6. Comfort/Protection

Specialised products and hygiene aids (see 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 experiment with different pads and tampons to find the ones they prefer. It is important for woman with a disability to have the same opportunity to try different products and choose the one she prefers.

### 7. Skill Development

Use existing abilities and build on these, one step at a time, to develop the new skills required. For example, if a woman can change her underpants herself, her carer could fit adhesive pads into the pants so the woman needs only to change her underpants when the pad becomes soiled. Later in the program she may learn to fit pads to her underpants independently.

If, after an adequate trial, a particular strategy or program is found to have been unsuccessful, a new approach should be considered and trialed. A range of strategies may need to be explored before the ones that suit a particular woman are found.

### 8. Personal Beliefs and Attitudes

- Menstruation is a normal physiological function.
- Acknowledge and learn about the ethnic and cultural context within which a woman views her menstrual cycle. Attitudes and beliefs will generally come from the family in which she grew up, and other influential people in her life.
- When assisting a woman with her menstruation, carers approach the task with their own set of values, myths and understandings.

**Note:** *It is very important for carers not to convey any personal negative feelings they may have about menstruation to the woman being supported.*
Disorders of the Menstrual Cycle

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

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

If a woman with an intellectual disability is to deal with these menstrual cycle symptoms 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 identify these symptoms and provide explanation and reassurance for the woman.

When concerns arise with respect to the management of menstruation or when other related symptoms (such as those below) are causing concern, medical advice should be sought.

Medical Assessment

If a doctor is consulted s/he will need to know:

- When the woman’s periods first started
- Frequency of periods, i.e. how often periods occur.
- Duration of menstruation, i.e. how long periods last.
- Degree of blood loss, i.e. how heavy periods are (e.g. number of packets of pads used).
- Associated symptoms - e.g. cramps, clots, flooding, mood changes or seizures - and the days within the cycle on which they occur.
- Many women with intellectual disabilities will need the support and assistance of a carer to accurately and comprehensively provide all the information the doctor requires for a complete assessment.
- The use of a menstrual cycle chart is an essential tool in providing the doctor with details of symptoms associated with the menstrual cycle.
Menstrual Cycle Chart

A calendar-based menstrual cycle chart (see Appendix 2) recording the degree of blood loss and the presence of associated features (e.g. pain, mood changes or seizure activity) is essential in the documentation of menstrual problems and monitoring the effectiveness of interventions.

Note: A menstruation cycle chart can also be printed from the CDDHV website: www.cddh.monash.org/products/phr/specialpages

Dignity and Privacy

The collection and exchange of a woman’s personal and private information (including details of her menstruation) should always be done in such a way that is in the best interests of the client and should only be shared with others on a ‘need to know’ basis, relevant to the particular circumstances. This is a respectful common sense approach. For example, records of a woman’s menstrual cycle should be stored securely and not displayed in a common or public area of her home.

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

• a general physical examination;
• a breast examination;
• an abdominal examination.

An internal examination of the pelvis may also be required in some situations and/or a pelvic ultrasound may be needed.

Note: It is usually appropriate for a carer with whom the woman feels comfortable to stay in the room with her throughout the examination.
Menstrual Disorders

Painful Periods (dysmenorrhoea)

Some women experience discomfort during their period, ranging from mild cramping to severe debilitating pain. Other symptoms may include nausea, vomiting, diarrhoea and irritability.

Techniques such as relaxation, local warmth, exercises and massage may help relieve symptoms. If these are unsuccessful, ‘over the counter’ period pain relief tablets may be required e.g. naproxen or mefenamic acid. However, before these can be administered, carers must first check with the woman’s doctor for allergies and other contra-indications.

**Note:** Support staff must seek their supervisor’s permission and document the permission and administration of any medication (including over the counter or herbal remedies) on the appropriate recording sheet.

Heavy Periods (menorrhagia)

Women’s cycles may vary in the amount of bleeding each month and it can be difficult to estimate the volume of blood lost during a menstrual cycle. Estimates can be given by the number of pads used and how much blood is on each pad.

Prolonged episodes of heavy menstrual bleeding can result in anaemia due to loss of iron. A diet that is high in iron or the use of iron supplements may sometimes 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.*

Women can manage heavy menstrual bleeding by:

- Changing pads/tampons more frequently.
- Changing the style of sanitary products used.
- Taking ‘over the counter’ period pain relief medications, such as naproxen or mefenamic acid, which may also reduce the amount of blood loss each month.
• Taking prescription medication, including hormonal preparations such as the oral contraceptive pill, which tends to reduce blood loss.

• Using depot hormonal preparations such as Implanon implants, DepoProvera injections or a Mirena IUD, all of which tend to reduce blood loss.

Premenstrual Syndrome (PMS)

PMS is the term used to describe a range of symptoms that may be experienced by a woman in the days prior to her period.

Premenstrual symptoms may include:

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

If these symptoms are due to Premenstual Syndrome, and therefore related to hormonal fluctuations, they usually lessen when the period starts.

There are a variety of approaches to the management of PMS.

These may include:

• A calm supportive environment.

• Providing information about the feelings a woman may have at different times of her cycle, the hormonal basis for these feelings and reassurance that they are a natural part of the menstrual cycle.

• A friendly, reassuring discussion with the woman about what she is experiencing. Encouraging her to keep a menstrual diary is a good way to help her to understand her feelings and when they tend to occur.

• A simple high fibre, low fat and low salt diet, containing plenty of fresh fruit and vegetables, and 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 some women with disabilities may wish to try these preparations, careful consideration needs to be given to the financial cost of treatment and the potential benefit - and how any beneficial or adverse effects will be detected and monitored.

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

No Period (amenorrhoea)

Medical advice should be sought if a young woman has not started to menstruate by age 15, as there may be medical, genetic, hormonal or other reasons for the late start of menstruation.

If a woman who usually menstruates regularly misses a period, medical advice should be sought to exclude:
- pregnancy
- menopause
- other medical conditions

Irregular Periods (including frequent periods - polymenorrhoea)

Irregular cycles are normal and acceptable for some women. If periods become more irregular, or bleeding at other times of the month is noted, it may be necessary to:
• Carefully chart and document length of each cycle, any other bleeding and associated symptoms (see Appendix 2).
• Consult a doctor for further assessment and treatment. This consultation may include:
  - taking a thorough history to establish period irregularity and amount of blood loss and other relevant symptoms
  - general and gynaecological examinations and other investigations to exclude organic disease
  - a Pap Test (if indicated)
  - a discussion of treatment options.
Epilepsy

Many women with intellectual disabilities have epilepsy. Some women with epilepsy tend to have more seizures just before or during menstruation. This is called catamenial epilepsy. Medical consultation is warranted if such an association is suspected.

A calendar-based menstrual cycle chart (Appendix 2), to document any suspected association between the menstrual cycle and seizures is an essential aid in diagnosis of this medical condition.
Menstrual Suppression

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.

When is menstrual suppression necessary?

Menstrual suppression should only be considered for:

- Gynaecological conditions, e.g. menorrhagia, endometriosis or severe Pre-Menstrual Syndrome where less restrictive measures have failed.
- Medical conditions that relate to the menstrual cycle, e.g. certain types of epilepsy that are associated with the menstrual cycle.
- Situations where a woman makes an informed decision to suppress her menstruation.

Menstrual suppression can be temporary or permanent.

Temporary Suppression of Menstruation

The temporary suppression of menstruation can be accomplished by the use of certain medications, such as the oral contraceptive pill or implantable or injectable hormonal preparations, e.g. Implanon, Depo Provera, Mirena IUD. However, these should only be administered after a thorough medical assessment.
Permanent Suppression of Menstruation

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 (note: this does not guarantee reduced menstrual flow or amenorrhea).

- **Hysterectomy** - the surgical removal of the uterus.

Hysterectomy does not usually include removal of the ovaries and will therefore not alter a woman’s hormonal cycle and so will not affect conditions such as pre-menstrual syndrome or catamenial epilepsy that relate to changing hormone levels.

When hysterectomy is associated with surgical removal of both ovaries, cessation of both menstruation and the hormonal variations which accompany it will occur. Hormonal replacement therapy is often instituted after removal of the ovaries to prevent sudden onset of menopausal symptoms and maintain the health of body tissues, including bones.

Is menstrual suppression acceptable as a management intervention for behaviours of concern?

In general, the answer is **no**. Appropriate interventions for behaviours of concern will depend on the cause and function of the behaviour and this must be determined through a thorough and comprehensive behavioural assessment.

There may be some **rare** situations where menstrual or pre-menstrual conditions cause a woman to injure herself or others, but in general, this intervention is not indicated.
Menstrual suppression for the management of behaviours of concern can only be considered in these cases if:

- The link has been clearly demonstrated between the menstrual cycle and behaviours of concern through the careful recording of calendar-based menstrual and behavioural charts over a number of cycles (see Appendix 3)
- Less restrictive approaches have been tried for an adequate time, and have been shown to be unsuccessful.

**It is not appropriate to consider menstrual suppression for:**

- The spreading of blood and other bodily fluids, distress at bleeding, incontinence, hygiene problems or infection control, e.g. Hepatitis B. These require behavioural interventions and infection control procedures and cannot, in themselves, justify hormonal or surgical intervention.
- Fear of sexual assault, unwanted pregnancy or concerns regarding sexual vulnerability. These concerns demand education of the woman in protective behaviours, and the provision of a safe environment for her. The risk of sexual assault should be dealt with in its own right, and should never be considered to be a reason for menstrual suppression.
- Menstrual suppression should never be considered for the sole purpose of the convenience of staff or carers.

**Note:** Menstrual suppression by medication for the management of behaviours of concern is considered to be a chemical restraint and can only be used in accordance with Section 140 of the Disability Act 2006 which states that restraint and seclusion can only be used:

- To prevent the person from causing physical harm to themselves or any other person;
- To prevent the person from destroying property where to do so could involve the risk of harm to themselves or any other person.
Legal Issues

Temporary Menstrual Suppression

A woman can give consent if she is able to understand the implications of having both an intervention designed to temporarily suppress her menstruation, not having the intervention being considered, and the possible consequences (both beneficial and adverse) of each course of action.

When a woman cannot give informed consent to pharmacological menstrual suppression as recommended by her doctor, consent may be obtained from 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 cannot do so herself.

Permanent Menstrual Suppression

Surgical interventions resulting in infertility are considered to be special medical procedures as defined under the Guardianship and Administration Act (1986). 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) before these interventions are carried out on women or children with intellectual disabilities.
Resources for Women and Carers

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

State Family Planning Associations resources

- **Family Planning Victoria** have a wide range of educational materials and resources:
  www.fpv.org.au/pdfs/ISES

- **Managing Menstrual Care**
  www.sa.gov.au

- **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:
  www.fpv.org.au

- **Let’s Talk about Periods** – a booklet about growing up for girls who have Down’s syndrome Produced by Down’s Syndrome Association of Scotland and available from:
  www.dsscotland.org.uk
Further Reading

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


• From Girl To Woman – Wesley Mission, Brisbane www.fromgirltowoman.wmb.org.au
Hygiene Products

There are a wide range of hygiene products available in the community.

Most women with intellectual disabilities will learn to use the same range of hygiene products as other women in the community.

Some women, including those who are incontinent of urine and/or faeces, or are not able to tolerate/use standard disposable pads/tampons, may benefit from using other continence products, such as those below. 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, faeces or unable to tolerate disposable pads.

Products include:

- **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 Australia’, 9 Corr Street, MOORABBIN VIC.

- **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.
Advice on individual needs and products can also be obtained from the following places:

• National Continence Management Strategy
  www.bladderbowel.gov.au

• Directory of Australian Continence Services

• Continence Aids Assistance Scheme (CAAS)

• Continence Foundation of Australia
  www.continence.org.au

• Independent Living Centres
  www.ilcaustralia.org

A Final Comment

It is important to remember that, while there are a wide range of menstrual hygiene products and educational materials available, the success of any menstrual management program will depend largely upon rapport between the woman concerned and those supporting her. Good communication and collaboration between all involved is therefore essential. Ultimately, it is the interest, enthusiasm and commitment of the woman, staff and carers that will determine the outcome.
Appendix 1- Resource Agencies

Centre for Developmental Disability Health Victoria (CDDHV)
Building 1, 270 Ferntree Gully Rd
NOTTING HILL VIC 3168
Tel: (03) 9501 2400
www.cddh.monash.org

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.
• Secondary and tertiary consultation service supporting Victorian GPs to care for their patients with an intellectual or other developmental disability.

Family Planning Victoria
901 Whitehorse Road
BOX HILL VIC 3128
Tel: (03) 9257 0100
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

The Guardianship List is one of the two Lists making up the Human Rights Division of VCAT. The other List is the Anti-Discrimination List.

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
5th Floor, 436 Lonsdale Street
MELBOURNE VIC 3000
Tel: 1300 309 337
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
Office of the Senior Practitioner

The Senior Practitioner is generally responsible for ensuring that the rights of people who are subject to restrictive interventions and compulsory treatment are protected, and that appropriate standards in relation to restrictive interventions and compulsory treatment are complied with.


Disability Services Commissioner

The Commissioner has been created to work with people with a disability and disability service providers to resolve complaints. The Commissioner commenced on 1 July 2007 under the Disability Act 2006 to improve services for people with a disability in Victoria. The Commissioner is independent of government, the Department of Human Services and disability service providers and provides a free confidential and supportive complaints resolution process.

www.odsc.vic.gov.au
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**CODE**

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

- **C** = CRAMPS
- **S** = SEIZURES
- **H** = HAPPY
- **A** = ANGRY
- **B** = BEHAVIOUR (Detailed description of specific behaviour being recorded must be provided)