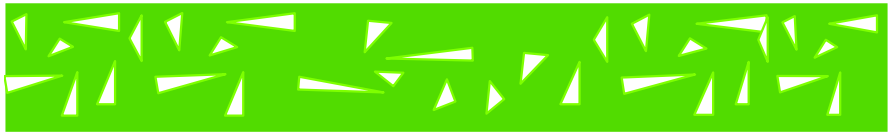


Menstrual

Management
and
Women
with an
Intellectual
Disability

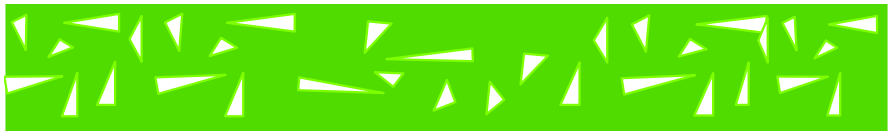
A Guide for GPs



MENSTRUAL MANAGEMENT AND WOMEN WITH AN INTELLECTUAL DISABILITY:

A GUIDE FOR VICTORIAN GPs

Women with an intellectual disability are a part of our community. Their primary medical care is provided by General Practitioners who may have had limited experience and training in the area of disability. This booklet aims to support GPs in assisting women with an intellectual disability to manage their menstruation.



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Developmental Disability Unit
Monash University**

Revised in 1999 and 2003

by

**Dr Mary Burbidge, Ms Jenny Butler and Dr Jane Tracy
Centre for Developmental Disability Health Victoria
Monash University**

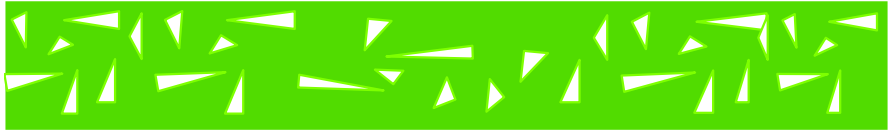
Disability and Menstruation:

- Most girls who have an intellectual disability experience menarche at the usual time and go on to menstruate with the same regularity as their peers without disabilities.
- Women with intellectual disabilities have the same right to the full range of management options as any other women.
- The management of menstrual problems is the same for all women - regardless of disability.
- Treatment options recommended should always be the least restrictive alternatives that are in the woman's best interests.

It is important to be clear about the issues needing to be addressed with the woman concerned and/or her carers.

- ◆ *Is there a menstrual disorder?*
- ◆ *Is there a request and /or need for menstrual suppression?*
- ◆ *Is there a need for further education or information about menstruation, sexual development, behaviour or health?*
- ◆ *Is there a need for contraceptive advice and/or contraception?*
- ◆ *Is there concern about or risk of sexual abuse or exploitation?*

Discussion of some of these issues is beyond the scope of this booklet but the resources listed in the appendix will be of assistance.



Is there a problem with menstrual management?

Menstrual management in women with an intellectual disability is basically no different than for other women. In order to ascertain that a problem exists it is important to:

Obtain a good history:

As far as possible, information should be obtained directly from the woman herself.

- Even if the woman appears to have very limited communication skills she should remain the focus of any discussion during the consultation.
- A gynaecological history including a menstrual chart recording relevant details such as timing and degree of blood flow, pain, mood changes, behavioural changes and seizure activity is invaluable.
- Relevant aspects of general medical history should be gathered in the usual way including systematic questioning about coexistent medical conditions.
- Relevant social and family history should also be sought.

Do a thorough examination:

As in all women with possible menstrual disturbances:

- It is important to establish trust and rapport prior to a general physical examination to put the woman at ease. The examination aims to detect possible causes for menstrual problems eg thyroid dysfunction.
- The woman may elect to have a support person of her choice with her during the examination.
- Ensure that the woman understands what the examination involves and that she consents to it.
- A gynaecological examination should be performed if clinically indicated to exclude organic disease such as fibroids or cervical pathology.
- A Pap test should be done if there is a history suggestive of sexual activity.
- The internal examination may have to be postponed to allow for adequate preparation and explanation of the procedure.
- Occasionally examination and investigation under anaesthesia is medically indicated. Appropriate consent will be required.

Order the necessary investigations:

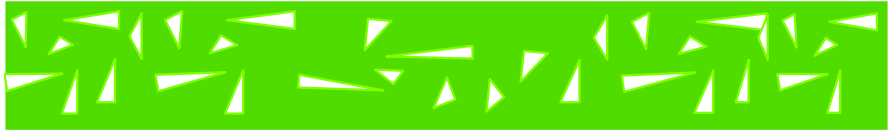
Investigation should not replace a thorough process of history taking and physical examination.

- Organic causes for menstrual disturbances should be considered before treatment is instituted.
- Diagnostic curettage and hysteroscopy are still the 'gold' standards in the diagnosis of menstrual disorders.
- Ultrasonography may be of benefit in the diagnosis of fibroids or endometrial polyps.
- Women with a diagnosis of menorrhagia may require investigation for anaemia and depleted iron stores.
- Systemic causes of menorrhagia such as bleeding disorders and thyroid disease should be excluded by appropriate investigation.

Managing menstruation:

- Most women with an intellectual disability can manage their own menstruation.
- Specific and appropriate education of the woman and her carers may be all that is required.
- Explanation of common symptoms and simple relief measures such as rest, the application of local warmth and perhaps the use of simple analgesics may be all that is required.
- Attention to general lifestyle factors such as diet, exercise, relaxation and smoking cessation may be beneficial in the treatment of menstrual disorders (eg PMS) – as well as improving general health and well-being.

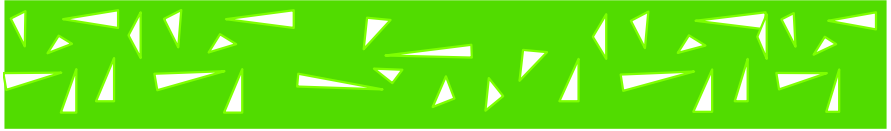
In some cases, presentations of suspected menorrhagia, polymenorrhoea, PMS etc will in fact be normal menstruation which has been misunderstood, misreported or inadequately managed.



Is there a menstrual disorder?

It is important to recognise and where necessary to treat disorders of the menstrual cycle in women with intellectual disabilities. Effective management depends on accurate diagnosis which in turn depends on accurate information. The use of a menstrual chart (see Appendix 3) is helpful in recording information and improving diagnostic accuracy. Disorders of the menstrual cycle may include:

- **Menorrhagia:** There may be a discrepancy between the perceptions of women and their carers in what constitutes a normal period. It is important to establish that the woman is actually menstruating heavily before taking any action.
- **Dysmenorrhoea:** Attention should be paid to establishing the severity and timing of the pain to ensure decision making is well informed.
- **Polymenorrhoea:** It is important to have accurate information about the woman's menstrual cycle, including timing and blood loss.
- **Premenstrual Syndrome:** Diagnosis must be based on adequate and accurate evidence. Symptoms are often more difficult to assess in women who have communication difficulties.
- **Catamenial Epilepsy:** A clear temporal link between menstruation and exacerbation of a seizure disorder must be obtained to make this diagnosis.



Management of menstrual disorders

Medical management:

The starting point for management decisions is “How would I treat this woman if she did not have a disability?”

A guiding principle of medical management is that the least restrictive option that meets the woman’s needs is the most appropriate.

- Anti-prostaglandin nonsteroidal anti-inflammatory drugs are of value for menorrhagia and dysmenorrhoea.
- Vitamin B6 or evening primrose oil may be helpful for some women with PMS. While it may be worthwhile suggesting women with disabilities experiment with these preparations, consideration needs to be given to their relative benefit and cost of treatment.

Hormonal Interventions:

- The oral contraceptive pill can be used to regulate menstrual flow, reduce menstrual blood loss and relieve dysmenorrhoea.
- Reducing the frequency of withdrawal bleeds may be appropriate for some women.
- Low dose monophasic pills are usually the first line option.
- A trial of at least three months is usually required to experience the full beneficial effect.

- If menorrhagia continues, a higher dose pill or a pill with a different progesterone can be trialled.
- Menstrual suppression with Depo-Provera may be considered appropriate for some women.
- Hormonally impregnated IUDs provide long-term management of menorrhagia in selected women.
- Specific treatments may be indicated for particular medical conditions, such as Danocrine for menorrhagia or pain associated with endometriosis.

Many women with an intellectual disability can be reliable pill takers when given clear specific information. Some will benefit from assistance in devising strategies to help them remember to take their pill, others may require the direct support of carers.

Surgical Management:

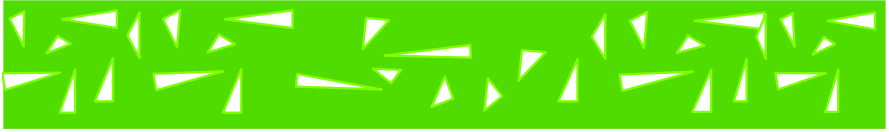
Surgery is invasive and irreversible and should only be considered if less restrictive medical options fail or if there are clear medical indications. Surgical options include:

- **Endometrial Ablation:** Involves the ablation of the endometrium by diathermy or laser. The procedure:
 - ◆ Is indicated only if no malignancy or other intra-uterine abnormality is present.
 - ◆ May avoid the need for hysterectomy.
 - ◆ Does not guarantee long term reduced menstrual flow or amenorrhoea
 - ◆ Cannot be relied on as a form of contraception.
- **Myomectomy:** Is indicated for large solitary fibroids.

- **Hysterectomy:** Involves the removal of the uterus and often also the fallopian tubes. This procedure:
 - ◆ Is a surgical procedure with the inherent risks associated with the procedure itself and the anaesthetic administered.
 - ◆ May be indicated in women with menorrhagia and uterine abnormalities eg fibroids.
 - ◆ Removes the need for continued medical treatment.
 - ◆ Results in permanent amenorrhoea and irreversible infertility.
 - ◆ Some questions have been raised about the long-term consequences on ovarian function due to loss of blood supply through the broad ligament.

Endometrial ablation and hysterectomy cause permanent infertility and are considered special medical procedures under the Guardianship & Administration Act (1986).

- ◆ If a woman is over eighteen and is unable to give informed consent, or if there is doubt about her ability to give informed consent, (whether or not a guardian has already been appointed), an application must be made to the Victorian Civil and Administrative Tribunal (VCAT) for consent to perform a special medical procedure.
- ◆ If she is under eighteen, consent must be given by the Family Court of Australia before the procedure can go ahead.
- ◆ Carrying out a special medical procedure without the appropriate consent may constitute the offence of assault and battery.



When is menstrual suppression appropriate?

Menstrual suppression is defined as:

“The temporary or permanent cessation of menstruation by the use of pharmacologically active substances or surgical intervention.”

The Place of Menstrual Suppression:

- ◆ There will be some circumstances when the suppression of menstruation is considered to be in the woman’s best interest.
- ◆ This should only be considered if adequate trials of less restrictive options have failed **or** if the woman is able to make an informed decision to choose this alternative.
- ◆ Consent for interventions to cause temporary menstrual suppression can be given by the woman concerned or by the ‘person responsible’ as defined in the Guardianship and Administration Act 1986.
- ◆ Consent for procedures leading to permanent menstrual suppression, and therefore infertility, **MUST** be obtained from the Victorian Civil and Administrative Tribunal (for women 18 years or older) or from the Family Court (for girls under 18 years). (*See Appendix 1*).

Menstrual suppression may be indicated for:

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

Temporary Menstrual Suppression:

- Pharmacological medications in common use include the combined oral contraceptives used continuously, medroxyprogesterone acetate or norethisterone.
- Hormonally impregnated IUDs are also used for this purpose but insertion of such a device is considered to be a medical procedure and requires consent by the 'person responsible' if the woman herself is not able to give informed consent.
- Should only be administered after a thorough assessment of the woman's health.
- Some breakthrough bleeding may occur with any of the above managements.

Surgical Menstrual Suppression:

- Surgical interventions which aim to permanently suppress menstruation include endometrial ablation (this does not guarantee total amenorrhoea) or hysterectomy.
- These interventions will not alter a woman's hormonal status and thus will not affect cyclical conditions such as pre-menstrual syndrome or catamenial epilepsy.

Endometrial ablation:

- ◆ This is a special medical procedure as it usually results in permanent infertility.
- ◆ Consent **must** be sought from the Victorian Civil and Administrative Tribunal (VCAT), see Appendix 1, if the woman is unable to give informed consent (or the Family Court if she is under 18).
- ◆ Relevant medical and social facts must be presented to VCAT (or Family Court) so that a decision can be made that is in the best interests of the woman.
- ◆ The Office of the Public Advocate may be asked to provide a report to VCAT (or the Family Court) outlining alternative strategies, and making recommendations before a decision with respect to consent is made.

Hysterectomy:

- ◆ This is also a special medical procedure therefore consent considerations are similar to endometrial ablation. (*See Appendix 1*).

Menstrual Suppression for Behaviour Management:

- 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 may be considered in these cases.
- The principle of management is to create a stable hormonal environment and therefore reduce the behaviours related to hormonal fluctuations.

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

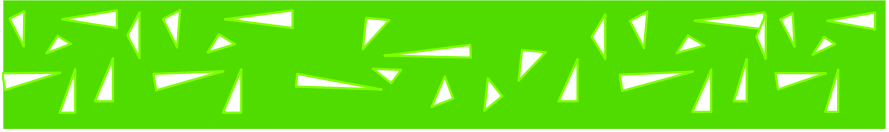
Menstrual suppression by medication for behaviour management purposes is considered to be a chemical restraint and can only be used in accordance with Section 44 (3) of the Victorian Intellectually Disabled Person’s Act 1986 which states:

- ◆ *To prevent a person from causing injury to herself or any other person*

Or

- ◆ *To prevent a person from persistently destroying property”.*

- Spreading of blood, distress at bleeding, hygiene problems or infection control issues, eg HepB or C, cannot by themselves justify hormonal or surgical intervention.
- However, one or more of the above problems combined with a menstrual disorder may justify menstrual suppression.

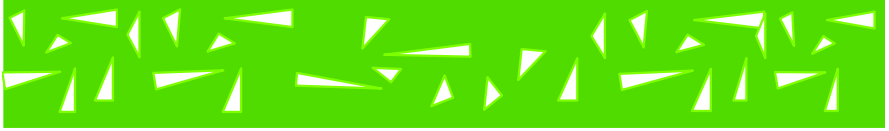


Some important legal issues

Sometimes decisions concerning the medical management of menstruation for a woman with an intellectual disability who is unable to give informed consent and has no formally appointed guardian, may require:

- consultation between the woman, the doctor and other concerned parties eg family members and/or carers. Usually the decision is then legally made by the doctor and the 'person responsible' (as defined by Victorian Guardianship and Administration Act) acting together.
- appointment of a medical guardian through application to the Guardianship List of Victorian Civil and Administrative Tribunal.

If there is doubt about the woman's capacity to consent or about guardianship then advice should be sought from the Office of the Public Advocate or from the Guardianship List of Victorian Civil and Administrative Tribunal.



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

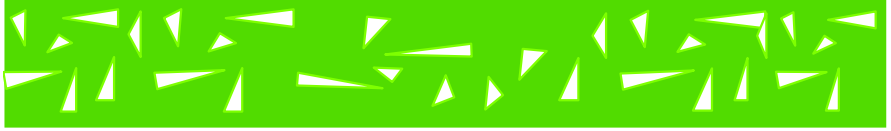
Self Care in Menstruation for Girls and Young Women with Special Learning Needs: a video based teaching package aimed to assist women with intellectual disabilities learn the skills necessary to be independent in managing their menstruation. Available from Family Planning Victoria.

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.



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**

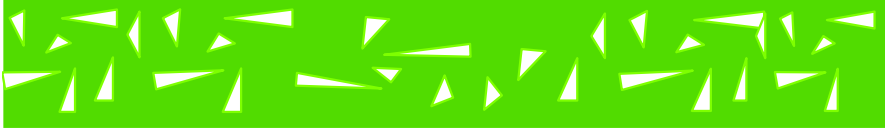
This company have a wide range of disposable and reusable products and are also willing to design and produce products to suit individual needs. (02) 9531 2011.

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

- **Continenence 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



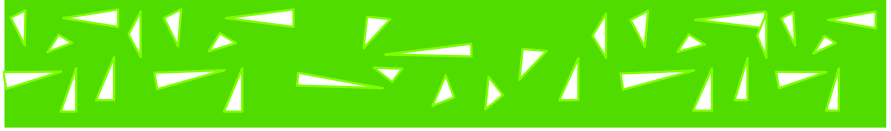
READING RESOURCES

Grover, S. *Menstrual and contraceptive management in women with an intellectual disability* MJA Feb 2002 176 3:108-110
http://www.mja.com.au/public/issues/176_03_040202/gro

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)

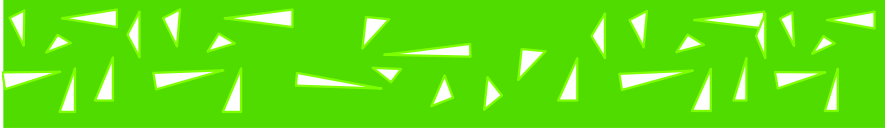
Management Guidelines: People with Developmental and Intellectual Disabilities. Melbourne: Therapeutic Guidelines Limited, 1999. Chapters on Management of an Adolescent with an Intellectual Disability, Sexuality and Women's Health



APPENDIX 1

The procedure for application to the Guardianship List of the Victorian Civil and Administrative Tribunal (VCAT) is:

- ◆ Discuss the issue with the client, family members and significant others to determine who is the most appropriate person to make the application.
- ◆ Where possible, appropriate family members should be encouraged to formalise informal guardianship arrangements.
- ◆ When an appropriate person is identified, provide the applicant with information about the application process. NOTE: Any person with a concern may apply without discussion with others.
- ◆ If there is no other appropriate person the GP can apply to the Office of the Public Advocate for an advocate to be appointed to make the application to the Guardianship List.
- ◆ All applications must be made on the prescribed forms provided by the Victorian Civil and Administrative Tribunal (<http://www.vcat.vic.gov.au/vcatguardianshiplist.htm>).
- ◆ The completed application form must be sent by post to the Guardianship List, VCAT.
- ◆ Queries related to applications can be discussed with the duty worker of the VCAT Guardianship List on (03) 9628 9700.



APPENDIX 2

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
<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

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.htm

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. 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**

5th Floor

436 Lonsdale Street

MELBOURNE VIC 3000

Tel: (03) 9603 9500

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

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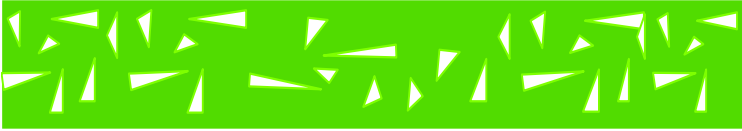
P = PERIOD/BLEEDING: + = light ++ = medium +++ = heavy

C = CRAMPS

S = SEIZURES

H = HAPPY ☺

A = ANGRY ☹



ACKNOWLEDGMENTS

A special acknowledgement to the late Dr Mary Westcott for her contribution to this project. Mary was always dedicated and committed to the practice of Women's Health and had an ongoing interest in women with disabilities.

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