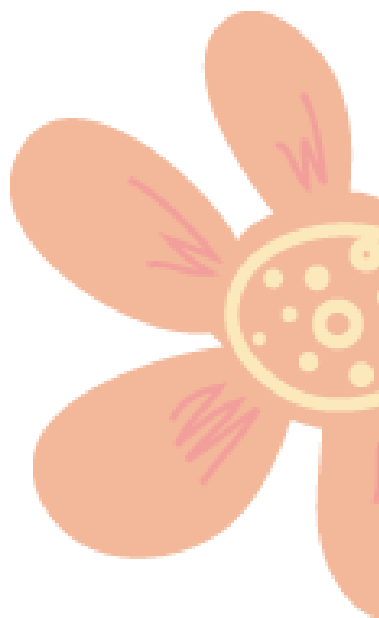


Supporting Women

Information and resources for **general practitioners** supporting women with intellectual disabilities to manage their menstruation





Supporting Women

Information and resources for General Practitioners supporting women with intellectual disabilities to manage their menstruation and associated menstrual disorders.

Women with an intellectual disability are a part of our community. Their primary medical care is provided by general practitioners. This booklet aims to assist GPs to support women with an intellectual disability manage their menstruation and associated menstrual disorders.

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Menstruation and Disability

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 **same right** to the full range of options to manage their menstruation as any other women.

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

Recommended treatment options should be the **least restrictive** and always in the **woman's best interests**.

The starting point for all management decisions is:

“How would I address these issues if this girl/woman did not have a disability?”

Menstruation and the Menstrual Cycle

Most women with intellectual disabilities can manage their own menstruation. If a woman can use the toilet independently she can usually learn to manage her own menstrual hygiene.

Specific and appropriate **education** of the woman and her carers may be all that is required to enable her to manage her menstrual hygiene independently. **Resources** including books, audiovisual aids and websites can be very helpful (see Teaching Resources p.17).

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 sufficient to address minor menstrual disorders.

Attention to general **lifestyle factors** such as diet, exercise, relaxation and smoking cessation are beneficial in the management of menstrual disorders – as well as improving general health and well-being.

Note: *Keeping a menstrual chart over several cycles is usually required to accurately document the presenting issues, and to clearly identify whether or not they do in fact relate to the menstrual cycle.*

Identifying Menstrual Issues

Menstrual management in women with intellectual disabilities is usually the same as for other women. In order to identify issues related to the menstrual cycle:

Obtain a good history

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

The woman should always remain the **primary focus** during the consultation even if she appears to have limited communication skills. A support worker or family member may play a supportive role by providing some or all of the information required.

A full **gynaecological history** should be obtained.

A **menstrual chart** (see Appendix 3) recorded over several cycles can provide information on timing and degree of blood flow, pain, mood changes, behavioural changes and/or seizure activity. Such a chart is essential to accurately identify and assess the issues and determine whether the presenting problem does in fact relate to the menstrual cycle (e.g. mood changes, behaviour change, seizure activity).

Relevant aspects of **general medical history** should be gathered in the usual way including systematic questioning about coexistent medical conditions and/or symptoms.

Relevant **social and family history** should also be sought.

Note: *Many women with intellectual disabilities will need the support and assistance of a carer to accurately provide the detailed information required. Carers may be family members, friends, volunteers or paid staff. Carers usually do not have healthcare training and therefore questions should be phrased in plain language, without medical jargon.*

Do a thorough examination

As with all women who have possible menstrual disturbances:

It is important to establish **trust and rapport** prior to a general physical examination to put the woman at ease.

The woman may elect to have a **support person** or carer of her choice with her during the examination.

Ensure that the woman understands what the **examination** involves and that she consents to it. Visual aids such as pictures or models and additional time to understand the information presented may be required.

A **gynaecological examination** should be performed if clinically indicated to exclude organic disease such as fibroids or cervical pathology.

If an **internal examination and/or Pap test** is required, particular care with regard to explanation and consent is essential. The internal examination may have to be postponed to allow for adequate preparation and explanation of the procedure.

Indications for a **Pap test** are the same as for any other woman. A Pap test is indicated if the woman has been sexually active or there is a history of sexual activity (including abuse).*

There may be some occasions when examination and further investigation under sedation or anaesthesia are medically indicated. Appropriate **consent** will be required.

** In the case of sexual abuse, explanation of and consent for the Pap test will require particular sensitivity.*



Order the necessary investigations

Investigation should not replace a thorough history and physical examination.

Organic causes for menstrual disturbances should be considered.

Diagnostic curettage and hysteroscopy are still the 'gold' standards in the diagnosis of menstrual disorders.

Ultrasonography may be useful in the detection of fibroids or endometrial polyps.

Women with menorrhagia may require **management** of anaemia.

Systemic causes of menorrhagia such as bleeding disorders or thyroid dysfunction should be excluded by appropriate investigation.

Consider **pregnancy** when the presentation is that of amenorrhoea, irregular or heavy bleeding.

Note: Consider the likelihood of sexual abuse in women with limited communication and/or reduced capacity to give consent who present with sexually transmitted infections or pregnancy.



Assessment of Menstrual Disorders

It is important to be clear about the precise issues needing to be addressed with the woman concerned and/or her carers when issues of menstruation are raised. For example:

- Is there actually a **menstrual disorder**? If so what is it?
- Is further **education** or information about menstruation, sexual development, behaviour or health required?
- Is **contraceptive** information, education or advice and/or contraception required?
- Is there concern about or risk of **sexual abuse**, unwanted pregnancy or exploitation?
- Is there a request and/or need for menstrual **suppression**? Why is this in the woman's best interests?

Disorders Associated with the Menstrual Cycle

It is important to recognise, and where necessary 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 important in recording information objectively and therefore improving diagnostic accuracy.

Disorders of the menstrual cycle may include:

- **Menorrhagia**: Menstruation may be heavy, or may be assumed to be so because of difficulties managing menstrual hygiene. There may be a discrepancy between the perceptions of the woman and her carers in what constitutes a normal period. It is important to establish whether the woman is actually menstruating heavily before taking any action.

- **Dysmenorrhoea:** Attention should be paid to establishing the severity and timing of pain to ensure its relationship to the cycle and that interventions are appropriately targeted. Charting of cycle and pain is usually required.
- **Polymenorrhoea:** It is important to have accurate information about the woman's cycle, including timing and blood loss.
- **Premenstrual Syndrome:** Diagnosis must be based on adequate and accurate evidence. Symptoms are more difficult to assess if the woman has communication difficulties. Again, charting possible symptoms against menstrual cycle helps clarify the relationship of symptoms with the hormonal cycle.
- **Catamenial Epilepsy:** A clear temporal link between menstruation and exacerbation of a seizure disorder must be obtained to make this diagnosis. Once again, charting of seizures in relation to menstrual cycle is essential.

Note: Presentations of suspected menstrual disorders may in fact be *normal menstruation* which has been misunderstood, misreported or inadequately managed. Asking the woman and/or carers to *chart symptoms* over several cycles is helpful in clarifying presenting issues.



Management of Menstrual Disorders

The starting point for all management decisions is:

“How would I treat this woman if she did not have a disability?”

The second guiding principle of medical management for women with intellectual disabilities is that:

The most appropriate intervention is the one that is the least restrictive option that is in the woman’s best interests and meets her individual needs.

Medical Management

- As with women without disabilities, anti-prostaglandin nonsteroidal anti-inflammatory drugs are of value for menorrhagia and dysmenorrhoea.
- Complementary and natural therapies, including Vitamin B6 or evening primrose oil, may be helpful for some women with PMS. While it may be worthwhile women with disabilities trying these preparations, careful consideration needs to be given to the financial cost of treatment and the potential benefit - and how the benefit or otherwise will be determined and monitored.

Note: *Many women will need the support and assistance of carers to monitor the effects of interventions, and report adverse effects. Women and carers need specific information about effects of treatments - both beneficial and adverse - and regular review is required to monitor response to treatment and ensure adverse effects are detected.*



Hormonal Interventions

The **oral contraceptive pill** (OCP) can be used to regulate menstrual flow, reduce menstrual blood loss and relieve dysmenorrhoea.

Many women with intellectual disabilities can reliably take the OCP when given clear specific information. Women may benefit from assistance in devising strategies to help them remember to take their pill on time, such as linking it with their normal morning or evening routine. Other women may require more direct support. Women living in group homes (shared supported accommodation) will usually have their medication pre-packed by the pharmacy and administered by the support staff working in the house.

Low dose monophasic pills are usually the first line option.

A trial of at least three months is usually required to experience the full potential benefit.

If menorrhagia continues, a higher dose pill or a pill with a different progesterone can be trialled.

Reducing the frequency of withdrawal bleeds may be appropriate for some women.

Menstrual suppression with medroxyprogesterone acetate (**Depo-Provera**) or etonogestrel (**Implanon**) are appropriate for some women.

Hormonally impregnated **IUDs** provide long-term management of menorrhagia in selected women.

Specific treatments are indicated for particular medical conditions, such as Danocrine (Danazol) for pain associated with **endometriosis**.



Surgical Management

Surgery is **invasive** and **irreversible** and should only be considered if there are clear indications and less restrictive options have failed.

Surgical options include:

- **Myomectomy:** May be indicated for large solitary fibroids.
- **Endometrial Ablation:** Involves the ablation of the endometrium by diathermy or laser.

Endometrial ablation:

- 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.
- **Hysterectomy:** Involves the removal of the uterus, often the fallopian tubes and sometimes the ovaries.

Hysterectomy:

- Is a major surgical procedure with the inherent risks associated with both the procedure and the anaesthetic.
- Results in permanent amenorrhoea and irreversible infertility.
- May be indicated in older women with menorrhagia and uterine abnormalities e.g. fibroids.
- May have long-term implications for ovarian function, due to compromised blood supply through the broad ligament.

Legal Issues in Surgical Management

Endometrial ablation and hysterectomy cause permanent infertility and are considered **special medical procedures** (as are termination of pregnancy and donation of nonregenerative tissue) 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 previously been appointed), an application **MUST** be made to the Victorian Civil and Administrative Tribunal (VCAT) for consent to perform a special medical procedure. (Appendix 1)

If a woman 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 a criminal offence (assault and battery) and result in disciplinary action by the Courts and/or Medical Registration Board.

Note: See page 15 for further information on legal issues.



Menstrual Suppression

Menstrual suppression is the temporary or permanent cessation of menstruation by the use of pharmacologically active substances or surgical intervention.

There will be some circumstances when the suppression of menstruation is considered to be in the **woman's best interest**.

Menstrual suppression should only be considered if adequate trials of **less restrictive options** have failed.

Consent for interventions to cause **temporary** menstrual suppression can be given by the woman concerned if she has legal capacity or by the 'person responsible' as defined in the Guardianship and Administration Act 1986.

Note: *Consent for procedures leading to **permanent** menstrual suppression, and therefore infertility, MUST ALWAYS be obtained from the Victorian Civil and Administrative Tribunal (for women 18 years or older who are not able to give consent themselves) or from the Family Court (for girls under 18 years). (See Appendix 1).*

Menstrual suppression may be indicated for:

- Gynaecological conditions (e.g. menorrhagia, endometriosis or severe pre-menstrual syndrome) where less restrictive measures have failed
- Serious medical conditions associated with the menstrual cycle (e.g. catamenial epilepsy, severe PMS).
- Situations where a woman has legal capacity to choose this intervention, and provides informed consent to suppress her menstruation.

Types of Menstrual Suppression

Temporary Menstrual Suppression

Menstrual suppression should only be administered after a thorough assessment of the woman's health.

Pharmacological medications in common use include the combined **oral contraceptives** used continuously, norethisterone or depot injection of medroxyprogesterone acetate.

Implanon is a **rod implanted** under the skin of the arm that supplies **slow release** of etonogestrel, a progestagen. It is effective for up to 3 years before replacement is required. Implanon may not suppress periods completely and may cause and prolonged or frequent bleeding. Insertion is regarded as **a medical procedure** and consent of the '**person responsible**' is required if the woman herself is not able to give informed consent.

Mirena is an **intrauterine contraceptive device** which provides slow release of levonorgestonel, a progestagen, for up to 5 years. The insertion of an IUD is considered **a medical procedure** and requires consent by the '**person responsible**' if the woman is not able to provide informed consent. This device may not suppress periods completely and can cause abdominal pain. It is not usually considered suitable for women who have never been pregnant.

Note: Some breakthrough bleeding may occur with any of the above methods of menstrual suppression.

Permanent Surgical Menstrual Suppression

Surgical interventions which permanently suppress menstruation include **endometrial ablation** (which may or may not lead to amenorrhoea and infertility) and **hysterectomy**.

Note: Surgical interventions that do not affect ovarian function 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**, and therefore consent must be obtained from the Victorian Civil and Administrative Tribunal (VCAT), (see Appendix 1), (or the Family Court if the woman concerned 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 woman's best interests.

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 is made.

Hysterectomy

May be indicated for surgical or medical reasons but is **NOT** appropriate simply to manage menstruation (or sexual vulnerability).

Is a **special medical procedure**, and therefore consent considerations are similar to endometrial ablation. (See Appendix 1).

Menstrual suppression is *not* appropriate for:

- **The spreading of blood and other bodily fluids, distress at bleeding, incontinence, hygiene problems or infection control, e.g. Hepatitis B or orogenital contamination.** These require behavioural interventions and infection control procedures and cannot by themselves justify hormonal or surgical intervention.
- **Fear of sexual assault and/or an unwanted pregnancy or concerns regarding sexual vulnerability.** These concerns demand education of the woman herself in protective behaviours, and an appropriate degree of supervision within her environment to ensure her safety. They should never be considered to be indicators for menstrual suppression

Note: Menstrual suppression should never be considered for the sole purpose of the convenience of staff or other carers.

Menstrual Suppression to Change Behaviour

Menstrual suppression may be considered in some situations where identified menstrual or pre-menstrual conditions cause a woman to injure herself or others. The temporal relationship between the menstrual cycle and these behaviours must be clearly demonstrated (through recording on a menstrual chart). In these situations, the principle of management is to create a stable hormonal environment and therefore reduce the behaviours related to hormonal fluctuations.

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.
- If other less restrictive options have been ineffective or are inappropriate in the circumstances.



Legal Issues

Capacity and Consent

It is the doctor's responsibility to determine if the woman has the capacity to consent to investigations and interventions required. If there is any doubt about the woman's capacity to consent or about guardianship then advice should be sought from the Office of the Public Advocate (www.publicadvocate.gov.au).

Many women with intellectual disabilities will be able to give their own **consent** to some medical interventions.

Some women will be able to consent to simple, less complex procedures and interventions but not those with more complex implications.

When a woman is **not able to give informed consent** in relation to decisions concerning management of menstruation, valid consent must be sought from the '**person responsible**' or **VCAT** (see Appendix 1). Wherever possible the woman herself should still be involved in discussion and decision making, even if consent from another party is legally required.

The 'person responsible' (as defined by Victorian Guardianship and Administration Act 1986) is usually the closest family member. **Consent may not be given by a paid carer.** For more information: www.publicadvocate.gov.au

A medical guardian may be appointed through application to the Guardianship List of Victorian Civil and Administrative Tribunal (VCAT) (see Appendix 1). For more information: www.vcat.gov.au

Note: See page 10 for more information on legal issues.

Further Reading

- Grover, S. Menstrual and contraceptive management in women with an intellectual disability MJA Feb 2002 176 3:108-110.

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.

www.publicadvocate.vic.gov.au

- Management Guidelines: Developmental Disability. Melbourne: Therapeutic Guidelines Limited, Version 2, 2005 (also on eTg) Chapters on Management of an Adolescent with an Intellectual Disability, Sexuality, Women's Health and Legal Issues.

www.tg.org.au



Learning and Teaching Resources for Women and Carers

Resources helpful in assisting women with an intellectual disability to understand menstruation and how to manage their menstrual flow.

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**
A Resource Guide about Managing Menstruation for Women with Intellectual Disability, Disability SA, Government of South Australia, Department for Families and Communities, January 2008.
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

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
www.bladderbowel.gov.au/ncms/projects/information/directory.htm
- Continence Aids Assistance Scheme (CAAS)
www.bladderbowel.gov.au/furtherinfo/professional/profcaas.htm
- Continence Foundation of Australia
www.continence.org.au
- Independent Living Centres
www.ilcaustralia.org



Appendix 1 - Applications to VCAT

When a person does not have the legal capacity to provide informed consent, application may be made to the Guardianship List of the Victorian Civil and Administrative Tribunal (VCAT). Consent for special medical procedure and/or appointment of a medical guardian also requires application to VCAT.

Wherever possible, discuss the issue with the client, family members and significant others to determine who is the most appropriate person to make the application.

The GP or any other persons with concern about consent, can make the application to the Guardianship List or 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. The completed application form must be sent to the Guardianship List, VCAT. Queries related to applications can be discussed with the duty worker of the VCAT Guardianship List on ph: (03) 9628 9700

www.vcat.vic.gov.au/vcatguardianshiplist.htm



Appendix 2 - Resource Agencies

Centre for Developmental Disability Health Victoria (CDDH)

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 through a range of interrelated educational, research and advocacy initiatives aimed at enhancing the capacity of generic health services.

The Centre's website contains information, services, fact sheets and resources for health professionals.

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
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.

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:

- an advice service;
- advocacy, guardianship and investigative services, particularly in cases of abuse or exploitation of people with disability;
- 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 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.

www.dhs.vic.gov.au/disability/about_the_division/office_of_the_senior_practitioner

Disability Services Commissioner

The Commissioner has been appointed 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





Notes

