

**CONSENSUS STATEMENT: MENSTRUAL AND CONTRACEPTIVE  
MANAGEMENT IN WOMEN WITH AN INTELLECTUAL DISABILITY.**

The Australian Society of Paediatric and Adolescent Gynaecology (TASPAG) Working Party.

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## **CHAIRMAN'S FORWARD**

A National Consensus meeting was held on Sunday 28th of October 2001 to discuss the evidence-based management of menstrual problems in women with intellectual disability. Participants were all active members of The Australian Society of Paediatric and Adolescent Gynaecology. Prior to the meeting, an extensive literature review was undertaken to review best clinical practice. In addition, members consulted with State based Guardianship Boards or Family Courts to obtain information relevant to individual states. The outcomes listed in this document were achieved by complete consensus of participants.

## **CONSENSUS STATEMENT**

- Most girls who have an intellectual disability pass through menarche at the usual time and go on to menstruate with the same regularity as their non-disabled peers.
- Women with intellectual disabilities have the same right to the full range of management options as other women, tailored to their specific needs.
- Treatment options recommended should be the least restrictive and always in the woman's best interest.
- The management of menstrual problems in young girls (minors) rarely requires destructive surgery such as hysterectomy or endometrial ablation.

## **Issues for consideration and assessment in women with Intellectual Disability**

- Level of functioning; dressing, self-care, toileting, communication skills.
- Behavioural issues particularly around the time of menses including catamenial epilepsy, head-butting, smearing of menstrual blood.
- Mobility- wheelchair, dexterity; hand skills for menstrual /tampon change, capacity and practicalities of menstrual care.
- Complicating medical factors; risk for osteoporosis, cardiac problems, anticoagulants, epilepsy / anticonvulsants.
- Careful documentation should be made of the history with information from other doctors, psychologists, etc included.

## **Initial Assessment**

- Cognitive skills.
- Extent of physical disability.
- Care arrangements – who is responsible for blood products.
- Respite care for family relief.
- Consider assistance for care in day facilities and schools – management of blood products by carers should not be different to concerns regarding urinary and faecal toilet management (see menstrual management and contraceptive options below)
- Ask about other factors contributing to osteoporosis – diet (calcium), exercise (weight bearing), oestrogen, Vitamin D / sunlight exposure.

## **Investigations**

- May be influenced by disabilities.
- Principles of investigation are the same as for other women.

- Consider testing Vitamin D levels.

### **Menstrual management and contraceptive options**

- Amenorrhoea can generally be achieved by reversible, less invasive methods than hysterectomy.
- Hysterectomy will not solve perimenstrual behavioural or other cyclic problems.
- Many parents are concerned by sexuality and risk of abuse. Contraception, while preventing unwanted pregnancies, will not address either of these issues.

#### **1. Non pharmaceutical interventions**

- Information, reassure/acknowledge, acceptance, training/education, for the patient and her parents. Consider respite care to give parents a break.

#### **2. Reversible (consent not required from Office of the Public Advocates (OPA) / Guardianship Board)**

- Non-steroidal anti-inflammatory drugs (NSAIDs).
- Tranexamic acid.
- Progestagens- for polymenorrhoea (where contraception not required); in emergency to stop metrostaxis, for lengthy bleeds. Use 21/28day treatment schedule.
- Oral contraceptive pill (OCP)
  - Monophasics generally much better.
  - Can be used continuously.
  - 30mcg ethinyl estradiol will generally give good control and has a cost advantage.
  - 3-month trial minimum before considering other options.
- GnRH analogues (not recommended in the context of menstrual management – in view of their markedly negative impact on bones)
- HRT – continuous, to be considered in young women with hypo-oestrogenic states.

#### **3. Reversible (Consent may be required from OPA/ Guardianship Board – some variation between states, consultation is advisable).**

- Consider these second-line in view of long term issues – breakthrough bleeding, possible risks of osteoporosis, and side effects.
- The new progestagen delivery systems may have long-term advantage, in the reduction of osteoporosis, but limited information on their long-term use in teenagers is currently available. Use of these options for menstrual management is currently not approved by the TGA.
- Implanon may not be appropriate for menstrual management due to the low rate of amenorrhoea, although if marked reduction in menstrual loss is acceptable this may be considered.
- Depo medroxy progesterone acetate
- Levonorgestrel IUS (Mirena) – uterine size needs to be adequate

**4. Irreversible- consent required from Family law court or Tribunal.**

- Endometrial ablation – the use of endometrial destructive procedures is not recommended due to the failure rate/recurrence rate in young women with a normal life expectancy. In a small proportion of women where life expectancy is severely limited and where Mirena is not suitable endometrial ablation may be appropriate. It must be remembered that endometrial ablation is not contraceptive.
- Hysterectomy – this is a last resort – after failure of all other appropriate less invasive modalities.

**FURTHER INFORMATION OR ASSISTANCE**

Information and support in the care of young women with a disability can be sought from the RANZCOG or the authors; information regarding additional services and support can be obtained from the Commonwealth Dept of Health, Community Care; educational resources are available from the Family Planning Association.

Contact information for authors willing to provide advice or assistance on these matters is held at RANZCOG ([ranzcog@ranzcog.edu.au](mailto:ranzcog@ranzcog.edu.au)).

Note: This statement was endorsed by RANZCOG Council, February 2003