The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Excellence in Women's Health

Fertility and menstrual management in women with an intellectual disability

This statement has been developed and reviewed by the Women's Health Committee and approved by the RANZCOG Board and Council.

A list of Women's Health Committee Members can be found in Appendix A.

Disclosure statements have been received from all members of this committee.

Disclaimer This information is intended to provide general advice to practitioners. This information should not be relied on as a substitute for proper assessment with respect to the particular circumstances of each case and the needs of any patient. This document reflects emerging clinical and scientific advances as of the date issued and is subject to change. The document has been prepared having regard to general circumstances.

First endorsed by RANZCOG: February 1997
Current: March 2016
Review due: March 2019

Objectives: To provide advice on fertility management to women with intellectual disabilities.

Target audience: Health professionals providing gynaecological care, and patients.

Values: The evidence was reviewed by the Women's Health Committee (RANZCOG), and applied to local factors relating to Australia and New Zealand.

Background: This statement was first developed by Women's Health Committee in February 1997 and reviewed in March 2016.

Funding: The development and review of this statement was funded by RANZCOG.

Recommendation 1	Grade
As in all clinical situations, treatment offered to women with intellectual disabilities must be in accordance with the legal and guardianship provisions of the relevant jurisdiction.	Consensus-based recommendation
Recommendation 2	**Grade**
Consultation with others experienced in the care of young women with disabilities prior to considering irreversible approaches is strongly recommended.	Consensus-based recommendation

All women, including those with a disability, have the right to make their own informed choices about which method of contraception they use. Women with an intellectual disability face the same issues of fertility and menstrual management as other women. The focus of care is the best interest of the woman with regards to her quality of life and her reproductive rights. Women with an intellectual disability should be assessed and offered the least restrictive options and approaches as would be considered for women of the same age but without an intellectual disability. Reversible methods, including long acting reversible contraceptive (LARC) implants (e.g. Implanon or Mirena) should be considered in preference to irreversible surgical options.

Women with an intellectual disability may have difficulty comprehending the nature, extent, consequences, and risks associated with a specific medical treatment. As a result, they may lack the capacity to provide legally valid consent. In routine situations where the woman verbally consents to a minor reversible medical treatment, a practitioner may obtain the written legal consent from the *person responsible*, such as a legally appointed medical agent under an enduring power of attorney, the patient's spouse or domestic partner, primary carer, or nearest adult relative.

However, procedures that are intended or are reasonably likely to render a patient **permanently infertile**, or involve a **termination of pregnancy** are special procedures that mandate an application to an independent statutory body such as a guardianship board or public advocate. Practitioners must be aware of their local regulations regarding the provision of special procedures to women with intellectual disability. Where there is doubt as to the patient's ability to provide informed consent to the special procedure proposed, advice should be sought from a medical professional qualified to make a capacity assessment (for example, a neuropsychologist or psychiatrist). Consultation with others with experience in the care of young women with disabilities prior to considering permanent contraception or termination of pregnancy is strongly recommended.

Other suggested reading

Family Court of Australia: http://www.familycourt.gov.au/

Family Court of New Zealand: http://www.courts.govt.nz/family/

The relevant Guardianship authority in States and Territories in Australia can be located in the Office of the Public Advocate's Interstate Offices and Tribunals.

Wen X. The definition and prevalence of intellectual disability in Australia. Australian Institute of Health and Welfare (AIHW) Catalogue no. DIS 2. Canberra: AIHW. 1997. Accessed 3 April 2007. Available at: http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442455468

Zacharin MR, Savasi I, Grover SR. The Impact of Menstruation in adolescents with disabilities related to cerebral palsy. Arch Dis Child 2010; 95 (7): 526-30.

Savasi I, Spitzer RF, Allen LM, Ornstein MP. Menstrual suppression for adolescents with developmental disabilities. J Pediatr Adolesc Gynecol 2009; 22 (3): 143-9. doi:10.1016/j.jpag.2007.10.008. Available at: http://www.ncbi.nlm.nih.gov/pubmed/19539199?dopt=Citation#

Quint EH, Ann NY. Menstrual issues in adolescents with physical and developmental disabilities. Acad Sci 2008; 1135: 230-6.

Savasi I, Jayasinghe K, Moore P, Jayasinghe Y, Grover S. The use of the levonorgestrel intrauterine system in adolescents. Journal of Paediatric and Adolescent Gynaecology 2012.

Links to other College statements

Consent and provision of information to patients in Australia regarding proposed treatment (C-Gen 02a)

Consent and provision of information to patients in New Zealand regarding proposed treatment (C-Gen 02b)

Emergency Contraception (C-Gyn 11)

Evidence-based Medicine, Obstetrics and Gynaecology (C-Gen 15)

Appendices

Appendix A Women's Health Committee Membership

Name	Position on Committee
Professor Stephen Robson	Chair and Board Member
Dr James Harvey	Deputy Chair and Councillor
Associate Professor Anusch Yazdani	Member and Councillor
Associate Professor Ian Pettigrew	Member and Councillor
Dr Ian Page	Member and Councillor
Professor Yee Leung	Member of EAC Committee
Professor Sue Walker	General Member
Dr Lisa Hui	General Member
Dr Joseph Sgroi	General Member
Dr Marilyn Clarke	General Member
Dr Donald Clark	General Member
Associate Professor Janet Vaughan	General Member
Dr Benjamin Bopp	General Member
Associate Professor Kirsten Black	General Member
Dr Jacqueline Boyle	Chair of the ATSIWHC
Dr Martin Byrne	GPOAC representative
Ms Catherine Whitby	Community representative
Ms Sherryn Elworthy	Midwifery representative
Dr Michelle Proud	Trainee representative

Appendix B Overview of the development and review process for this statement

i. Steps in developing and updating this statement

This statement was originally developed in February 1997 and was most recently reviewed in March 2016. The Women's Health Committee carried out the following steps in reviewing this statement:

- Declarations of interest were sought from all members prior to reviewing this statement.
- Structured clinical questions were developed and agreed upon.
- An updated literature search to answer the clinical questions was undertaken.
- At the March 2016 face-to-face committee meeting, the existing consensus-based recommendations were reviewed and updated (where appropriate) based on the available body of evidence and clinical expertise. Recommendations were graded as set out below in Appendix B part iii)

ii. Declaration of interest process and management

Declaring interests is essential in order to prevent any potential conflict between the private interests of members, and their duties as part of the Women's Health Committee.

A declaration of interest form specific to guidelines and statements was developed by RANZCOG and approved by the RANZCOG Board in September 2012. The Women's Health Committee members

were required to declare their relevant interests in writing on this form prior to participating in the review of this statement.

Members were required to update their information as soon as they become aware of any changes to their interests and there was also a standing agenda item at each meeting where declarations of interest were called for and recorded as part of the meeting minutes.

There were no significant real or perceived conflicts of interest that required management during the process of updating this statement.

iii. Grading of recommendations

Each recommendation in this College statement is given an overall grade as per the table below, based on the National Health and Medical Research Council (NHMRC) Levels of Evidence and Grades of Recommendations for Developers of Guidelines. Where no robust evidence was available but there was sufficient consensus within the Women's Health Committee, consensus-based recommendations were developed or existing ones updated and are identifiable as such. Consensus-based recommendations were agreed to by the entire committee. Good Practice Notes are highlighted throughout and provide practical guidance to facilitate implementation. These were also developed through consensus of the entire committee.

Recommendation category		Description
Evidence-based	A	Body of evidence can be trusted to guide practice
	B	Body of evidence can be trusted to guide practice in most situations
	C	Body of evidence provides some support for recommendation(s) but care should be taken in its application
	D	The body of evidence is weak and the recommendation must be applied with caution
Consensus-based		Recommendation based on clinical opinion and expertise as insufficient evidence available
Good Practice Note		Practical advice and information based on clinical opinion and expertise

Appendix C Full Disclaimer

This information is intended to provide general advice to practitioners, and should not be relied on as a substitute for proper assessment with respect to the particular circumstances of each case and the needs of any patient.

This information has been prepared having regard to general circumstances. It is the responsibility of each practitioner to have regard to the particular circumstances of each case. Clinical management should be responsive to the needs of the individual patient and the particular circumstances of each case.

This information has been prepared having regard to the information available at the time of its preparation, and each practitioner should have regard to relevant information, research or material which may have been published or become available subsequently.

Whilst the College endeavours to ensure that information is accurate and current at the time of preparation, it takes no responsibility for matters arising from changed circumstances or information or material that may have become subsequently available.