



Disability SA

Managing Menstrual Care



A Resource Guide about Managing Menstruation for Women
with Intellectual Disability

This brochure is the result of a collaborative effort between Disability SA and the Occupational Therapy Department of the University of South Australia and was developed in response to an identified need amongst Disability SA families and health professionals.



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Introduction

The onset of menstruation is a key transitional period for any young girl, and parents/carers of girls with intellectual disability approaching puberty often have similar questions. Some common themes are:

- ▶ I'm unsure of what information is available
- ▶ I haven't been able to find much information
- ▶ Where do I go for help?
- ▶ How will she cope?
- ▶ How will we cope?

Similarly, health professionals and support staff often ask, 'What do I need to know to best support families with a girl reaching puberty?'

Although much information exists on this topic, locating that information can often be troublesome. This document aims to support Disability SA workers and parents/carers of young women with intellectual disability through this transition to adulthood by reviewing available resources and supports.

The document lists the most commonly used and recommended resources on menstrual care for young girls with intellectual disability.

We hope you find this resource useful.

For further information, please contact Disability SA on 1300 786 117 or email disabilityinfo@dfc.sa.gov.au.

Department for Families & Communities Library and Information Service: Disability Collection

Disability SA is part of the Department for Families and Communities (DFC).

The DFC Library and Information Service: Disability Collection contains resources available to clients of Disability SA, parents/carers and the general public. The resources range from books, journals and kits to videos, DVDs and CD-ROMs on a range of intellectual and physical disabilities.

The library is open 9am to 5pm weekdays and staff are on hand to assist you. A free internet service is also available.

Requests for information can be made via phone, fax, email and in person.

If you are unable to come in to the library, materials will be delivered to you by mail, email or by courier to the nearest Disability SA regional office.

Disability SA has an information sheet about the DFC Library and Information Service: Disability Collection—ask for a copy at your local Disability SA office or call 8266 8657 for a copy to be posted.



Department for Families & Communities
Library and Information Service:
Disability Collection

Strathmont Centre,
696–710 Grand Junction Road, Oakden 5086

Tel: 8266 8556

Email: disability.library@dfc.sa.gov.au

www.dfc.sa.gov.au/library

Resources for Families

The following resources can be found at the library and are available for loan to any member of the public.

Sexuality in people with an Intellectual Disability, by L Fegan, A Rauch, W McCarthy, Maclennan & Petty, Aus 1993

Chapter 7 of this text focuses on menstruation and provides information useful for parents/carers wanting to prepare their daughter for her first period. It provides steps for changing pads and appropriate education methods to be used for young girls with intellectual disability.

Janet's Got Her Period: Planning for self-care in menstruation for girls and young women with special learning needs.

Victorian Health Promotion Foundation. Social Biology Resources Centre, Victoria

This is a resource pack for young women and their parents and carers which includes:

- ▶ a 17 minute video demonstrating menstrual self-care
- ▶ an illustrated story book for young women
- ▶ a resource book for parents/carers.

Kylie's private world (DVD). This animated DVD is useful for parents/carers to watch with young girls with intellectual disability. The DVD discusses puberty, menstruation and personal hygiene as well as aspects of relationships, love and sexual interactions. There is an emphasis on safety and cleanliness.

Menstrual Preparation and Management Kit for Women who Have High Support Needs, by J Griffin, G Carlson, M Taylor, J Wilson, developed by Menstrual Management Research Team, University of Queensland in conjunction with the Department of Family Services and Aboriginal and Islander Affairs.

This kit is designed to provide education and lifestyle approaches to menstrual management for women who have high support needs. The kit may be used by families, teaching staff, health care workers and practitioners.

Special Girls' Business, 2005 by F Angelo, H Pritchard and R Stewart

This book has been written for girls with special needs, including: intellectual disability, physical disability, communication disorders and autism. It clearly and methodically takes a girl and her parent/carer through the process of managing periods with the use of colourful characterised diagrams.

Taking care of myself: a healthy hygiene, puberty and personal curriculum for young people with autism,

by M Wrobel, Future Horizons, 2003

The book uses a combination of social stories and activities to reduce the fear and confusion surrounding issues of health, hygiene, puberty (including menstruation) and safety in children with autism from five and up. It is also suitable for use with children with special needs.

Girl's Talk, compiled by L Macmillan, Developmental Services Team, SISS and J Wilmott and J Eckert, IDSC Western Suburbs, September 2000

This information kit was compiled at the request of a parent support group wanting information on how to approach the subject of menstruation with their daughters.

The kit contains two visual stories that explain what menstruation is and the sequences of changing a pad. It uses simple, direct language and the accompanying pictures make it easy for a young woman with intellectual disability to follow without having to read the words.

The kit includes commonly asked questions by parents/carers surrounding menstruation and gives possible strategies for how to

approach these. Myths associated with menstruation are described and the real facts supplied. There is list of suggested further reading for parents/carers.

Period—all about menstruation for boys and girls,
by J Gardner-Loulan, B Lopez, M Quackensbush, M Gribble,
Penguin Books, 1987

This book explains some of the changes that girls go through and discusses body parts, menstruation, pads, tampons, mood changes and common questions.

While this resources is not specific to intellectual disability, it includes pictures and may be helpful a helpful tool for parent/carers learning about menstruation.

Resources for Health Professionals and Educators

Becoming a Woman, by E Cooper. Pavilion Publishing

This is a teaching pack on menstruation for people with learning disabilities. The pack includes guidelines for six teaching sessions, including activities and worksheets that can be photocopied and distributed

The pack is suitable for nurses, health care workers, teachers, social workers, key workers and day care workers.

Centre for Intellectual Disability Health

The Centre for Intellectual Disability Health (CIDH) is a health service of Disability SA, part of the Department for Families and Communities.

General Practitioners at CIDH are well equipped to deal with queries and concerns regarding menstruation, including medication and possible contraceptive options.

You must be registered with Disability SA to access these services. Once registered, you can ring the CIDH clinic to make an appointment.

Disability SA has an information sheet about the Centre for Intellectual Disability Health—ask for a copy at your local Disability SA office or call 8266 8657 for a copy to be posted.



Centre for Intellectual Disability Health (CIDH)
Level 2, Education Building,
Smart Road, Modbury Hospital
Tel: 8397 8100

SHine SA

SHine SA (previously Family Planning South Australia) is the lead sexual health agency in South Australia. It provides individuals and communities with services and information to improve their sexual health so they can enjoy their relationships with safety, pleasure and respect. SHine SA offers specialised services including clinics, one-to-one education and counselling. SHine SA also has a range of resources and information sheets on sexual health.

SHine SA Website

The SHine SA website is well structured and contains a wealth of up-to-date information presented in an easy-to-read format.

For information specific to menstruation, contraception and puberty, enter the term 'menstruation' in the search box on the SHine SA website.

A list of available services for people with a disability can also be found on the SHine SA website, under 'Disability Work'.



Further resources can be accessed from the SHine SA library at :

64c Woodville Road, Woodville 5011

Tel: 8300 5312 (Library)

For further assistance contact one of the SHine SA teams:

Tel: 8300 5300 (Woodville)

Tel: 8252 7955 (Davoren Park)

Tel: 8325 8164 (Woodcroft)

Email: info@shinesa.org.au.

Website: www.shinesa.org.au

SHine SA Resources for Families

Sexuality in people with an Intellectual Disability, by L Fegan, A Rauch, W McCarthy, Maclennan & Petty, Aus 1993

Chapter 7 of this text focuses on menstruation and provides information useful for parents/carers wanting to prepare their daughter for her first period. It provides steps for changing pads and appropriate education methods to be used for young girls with intellectual disability.

Augmentative and Alternative Communication Package on Menstruation, produced by Wesley Mission

Provides picture cards that are useful for educating girls with intellectual disability about menstruation and also provides script cards for the person providing the education.

Demonstration dolls are available from SHine SA to demonstrate and practice pad changing and identifying body parts.

Magnell Kit: colourful magnetic cut-outs of the human body are used on a whiteboard to educate young girls on the process of menstruation. Particularly useful for visual learners. Information represented includes reproduction, menstruation, conception and contraception.

Kylie's private world (DVD). This animated DVD is useful for parents/carers to watch with young girls with intellectual disability. The DVD discusses puberty, menstruation and personal hygiene as well as aspects of relationships, love and sexual interactions. There is an emphasis on safety and cleanliness.

Personal Development Kit, Johnson and Johnson

This kit contains personal development books for boys and girls, sample tampons and pads, laminated cards about puberty and growth, skin and health care plus a video: 'A Period In Time'.

SHine SA Resources for Health Professionals

DASH (Disability and Sexual Health) is a six-day, nationally accredited course for workers who provide services to people with a disability. Students who successfully complete the optional assessment tasks will also achieve two competency standards in sexual health from the Certificate IV in Community Services.

For further details and dates, contact the Course Administrator or Disability Worker Education Coordinator

Telephone: 8300 5300 or email:

SHineSACourses@health.sa.gov.au

Special Education Resource Unit

Special Education Resource Unit (SERU) provides education tools and specialised services to support children and students with disabilities and learning difficulties.

SERU is a South Australian Department of Education and Children's Services (DECS) support centre.

DECS workers, health professionals, officers from agencies such as Autism SA and parents/carers who support children or students with disabilities or learning difficulty are eligible to access these resources.

How shall I tell my daughter? Johnson and Johnson

This 18-page booklet provides parents/carers and teachers with basic information about menstruation including physiological and psychological changes.

A question/answer format is used with scripted responses that the parent/carer or teacher can use in part or in full.

Additional information is also provided about different types of sanitary products and how to use them.

Taking care of myself: a healthy hygiene, puberty and personal curriculum for young people with autism,

by M Wrobel, Future Horizons, 2003

The book uses a combination of social stories and activities to reduce the fear and confusion surrounding issues of health, hygiene, puberty (including menstruation) and safety in children with autism from five and up. It is also suitable for use with children with intellectual disability/developmental delay.



Special Education Resource Unit

72a Marlborough Street

Henley Beach

Contact: 8235 2871

<http://web.seru.sa.edu.au>

Minda Incorporated Outreach Services

Minda's Outreach Service provides assistance to families who have a child with intellectual disability living at home. Minda workers, in conjunction with families, can develop personalised programs for the family, including education and skills development. Minda can also provide resources to be used by the family at home, such as interactive CDs.

One such CD is **Puberty Plus**, an interactive resource on the human body and health, reproduction, relationships and puberty. The CD is presented from a teenager's point of view and the user may explore particular topics in detail as they choose.



Minda Incorporated Outreach Services

1228 South Road, Clovelly Park 5042

Tel: 8179 5222

<http://www.mindainc.com.au>

Useful Websites

Centre for Developmental Disability Health, Victoria

<http://www.cddh.monash.org>

Centre for Developmental Disability Health Victoria in conjunction with Monash University and the University of Melbourne have conducted extensive research on the topic of menstruation in girls with intellectual disability. They have produced the following resources:

- ▶ ‘Options for Menstrual Management—resources and information for staff and carers of women with an Intellectual Disability.’
- ▶ ‘Menstrual Management and women with an Intellectual Disability—a guide for GPs’.

Down’s Syndrome Scotland

<http://www.dsscotland.org.uk>

Down’s Syndrome Scotland offers support and resources to families, siblings, teachers and health care workers of people with Down’s syndrome. They have publications available through the ‘Publications’ link on their home page.

The following resources are also available through Down’s Syndrome Scotland:

Let’s talk about periods—a booklet about growing up for girls who have Down’s Syndrome

This booklet offers information on menstruation, the reproductive system, behavioural changes and hygiene in an easy-to-read format. The pictures and straightforward language make this booklet a useful teaching tool for parents/carers and their daughters.

Let's talk about puberty—a booklet about growing up for young people who have a learning disability

This booklet is also suitable for young people with intellectual disability. Although it is not exclusively aimed at girls, it does deal with the issue of menstruation and body changes, and the wearing of pads and tampons. This booklet also explores body image, relationships and hygiene.



You can find more information online about disability, supports and services at the Disability SA “Disability Info” homepage.

www.disability.sa.gov.au

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This booklet is also available online at:
www.disability.sa.gov.au

