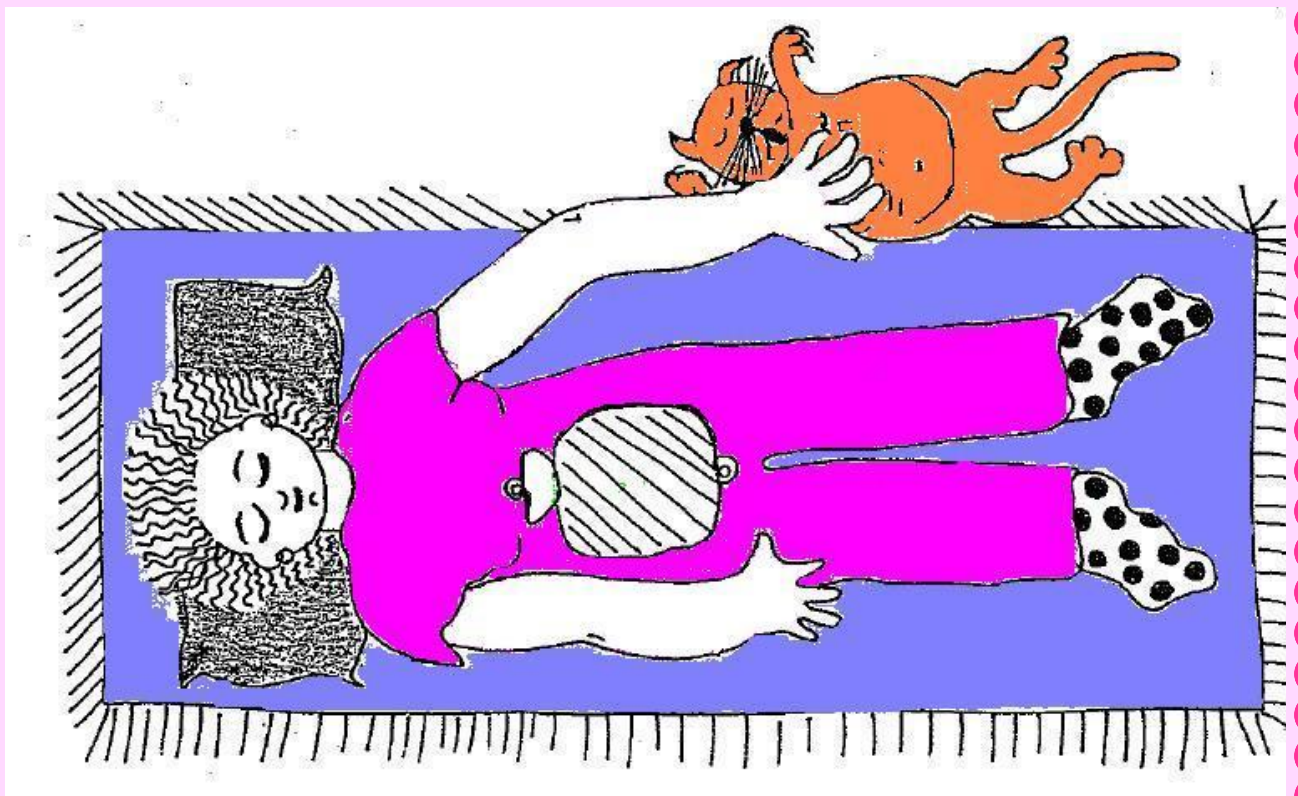


Managing Menstruation



This Australian resource was developed in 1994 by a joint project between the Department of Social Work and Social Policy at the University of Queensland and the Division of Intellectual Disability Services in the Queensland Department of Family Services and Aboriginal and Islander Affairs, with original funding from RADGAC of the Commonwealth Department of Health, Housing and Community Services, and from Sancella Pty Ltd and Libra Products.

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Introduction

A survey in and around Brisbane, of Mothers and people who provide personal assistance to young women with intellectual disability and high support needs, indicated that many of these people wanted more access to information about menstrual management and related issues for these young women.

This booklet is intended for use by people providing personal assistance to young women with intellectual disability and high support needs. This may include family members, school staff, residential staff and friends.

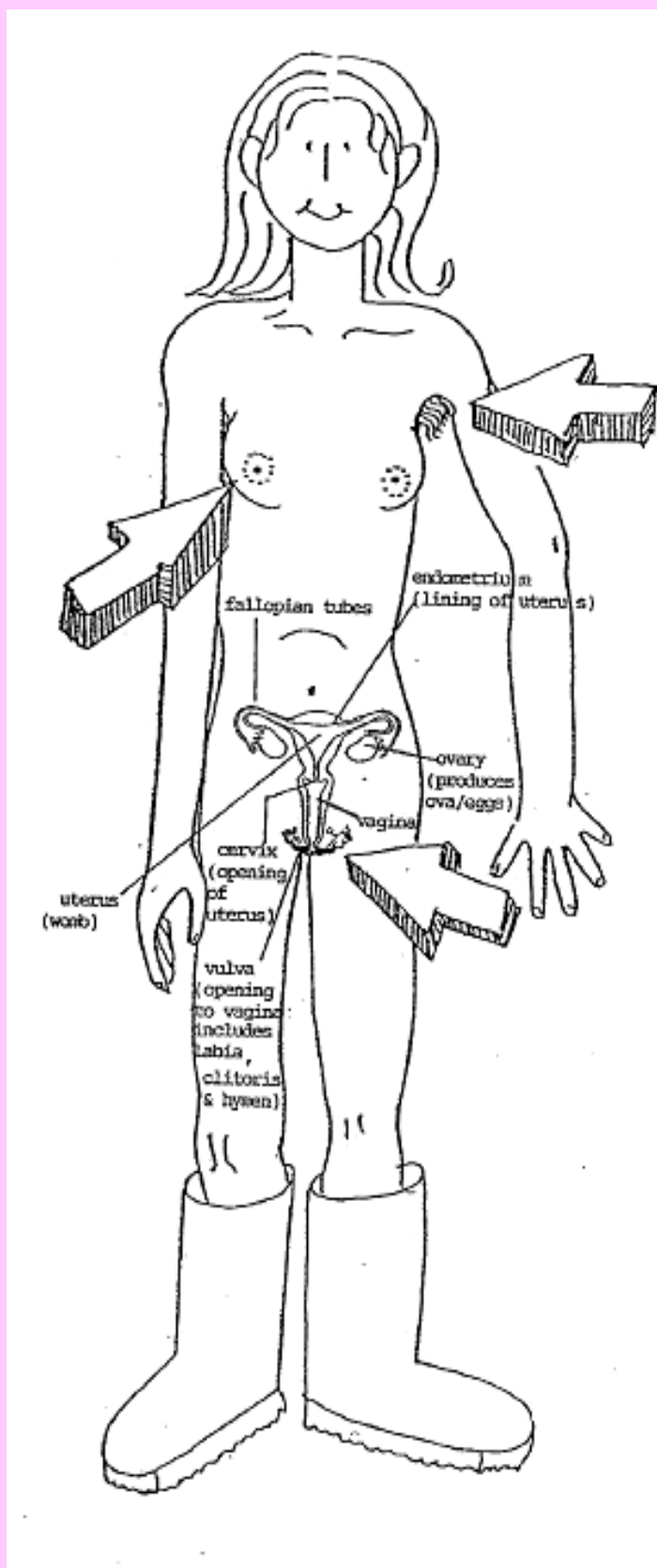
People with intellectual disability and high support needs vary in their abilities. Some are unable to use their hands, are unable to walk or have difficulties communicating verbally. Others are able to carry out most daily living tasks and can communicate a wide range of messages, but still need ongoing support and supervision.

It is recognised that the situation for each young woman and her family is different. While the primary focus of the booklet is on the needs of younger women, the information may also be of assistance for older women with high support needs. It is not claimed that this discussion of menstruation management approaches is comprehensive.

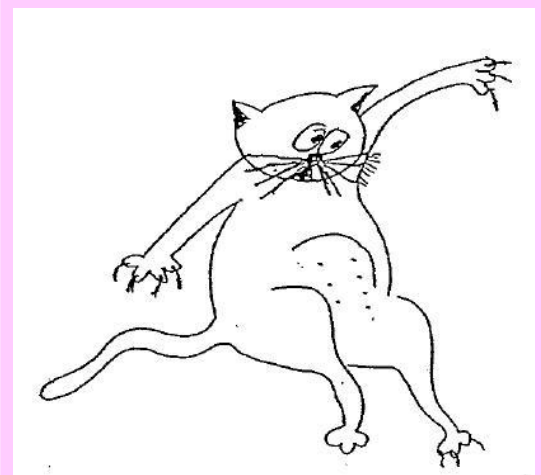
This book focuses on menstrual management using pads rather than tampons. Tampons are rarely used by women with intellectual disability and high support needs. Very few of these women are able to insert tampons independently. When insertion by others is considered, difficulties arise such as the physically personal nature of tampon insertion, and the difficulty in monitoring possible discomfort caused by the tampon. In addition, when a number of people are involved in assisting the young woman, ensuring that tampon removal always occurs may be a difficulty. However a mother and daughter may feel comfortable about the use of tampons for limited times, such as when the young woman is swimming.

This booklet will be included in a kit which contains additional items such as learning guide, individualised menstrual management planner, charting materials and workshop materials. This kit was produced by the Menstrual Management Team, Department of Social Work and Social Policy, University of Queensland.

Menstruation



Menstruation, or having a monthly period, is a normal and natural function of most women's bodies. Menstruation often commences between the ages of 12 and 13, although it can commence at any time between 9 and 17 years of age. Physical changes and the rate of development vary. Signs that menstruation is about to occur may include breast development, appearance of pubic and underarm hair, light white discharge from the vagina, and rounding of the hips.

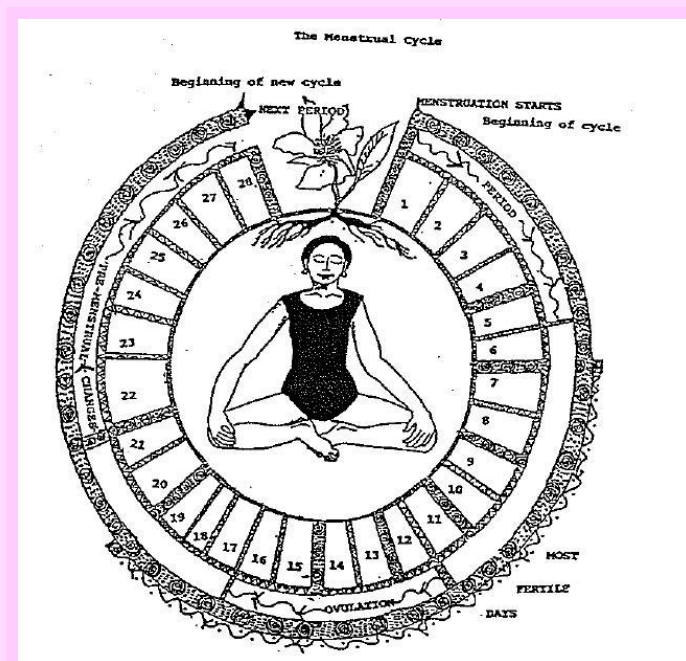


The amount of menstrual fluid which passes from the uterus (womb) is approximately 5 to 6 tablespoons (110 mls or $\frac{1}{2}$ cup), during each period. Only 30-50% of the fluid is blood. Menstrual fluid also contains vaginal secretions, mucus from the cervix and particles from the endometrium as well as blood, which can sometimes be clotted. (See diagram for body part names) Recent research indicates that menstruation may have a further function of decreasing risk of pelvic infections.

Menstruation (continued)

Most of the fluid is lost during the first and second day. Perceptions of menstrual flow vary, because all women have different experience and ideas. What is a heavy period to one woman can seem normal for another woman.

A period generally lasts between 4 and 5 days, but could range between 2 and 8 days. The time from the beginning of one period to that of the next is approximately 28 days (see diagram below). This may vary considerably, and still be normal. Women who are used to periods while on “the Pill”, or using tampons, may regard a normal period without “the Pill” or tampons, as “heavy”.



During the young woman’s first two years of menstruation, the periods may be erratic. There may be no pattern to their appearance and their length. This is normal. It takes time for the body to settle into a menstrual cycle. It may be helpful to chart the young woman’s cycle. A chart may prove useful in the management of menstruation, by showing cyclical changes. For instance, a record could be made of the menstrual flow, or signs of an approaching period such as swollen abdomen, or changes in mood. **See the section about Menstrual Charting in this booklet.**

There is a phenomenon, called “synchrony”, which has a long, cross-cultural recorded history. Synchrony occurs when women who share living or working space experience their menstrual cycles at the same time; that is, they begin their periods on the same day in each cycle. Mothers and daughters living in the same house may experience synchrony. A recent study indicates that premenstrual changes are not experienced in the same ways by women in the same family.

Mothers and others who assist the young woman may need to remember to take care, or seek care for themselves in relation to their own menstrual cycles.

Fertility

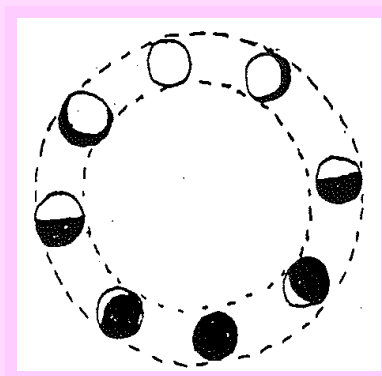
Most women possess the potential for having children. This capacity to bear children is called fertility. Menstruation is a sign of fertility. First menstruation (or menarche), is a definite sign that a young woman's body is changing, and developing into that of an adult. In some cultures this is a time for celebration and rejoicing. Fertility can be a source of concern for some families and staff members. They may be worried about the risk of pregnancy through a young woman's sexual activity. These concerns may be partly alleviated by assisting the young woman to learn affectionate behaviour which is appropriate to her age.

Another concern is that sexual abuse of a young woman may occur. Research suggests that an abuser is most likely to be a man who is known to the young woman: either a family member or a staff member. Much less commonly, a male who has an intellectual disability is involved. Young women with intellectual disability and high support needs are more likely to be "chaperoned" or supervised, but less likely to be able to communicate their specific concerns. Abuse may be prevented by assisting the young woman to learn the basic ideas of Protective Behaviours. **(see Reading list)**

If a young woman does not menstruate due to medical intervention, it does not mean that the likelihood of sexual abuse will lessen. In fact it could be that the abuser knows he is free to continue his abuse, because the young woman will not become pregnant. There may be concern about a young woman becoming pregnant and either bearing a child or undergoing a pregnancy termination. There is very little information available about the experiences of women with intellectual disability during termination, pregnancy or childbirth.

There may be concern about young women with intellectual disability being parents. There appears to be very few recorded situations where women with intellectual disability and high support needs, have become parents.

For some considerations for Planning and Fertility, See Guidelines



Sexual Feelings

A young woman who begins to menstruate may experience normal sexual desires and feelings. How these desires and feelings are expressed varies with each woman. It is very individual. For some young women with intellectual disability, masturbation may be a way of expressing sexual feelings. Masturbation is a natural and healthy way of expressing sexuality. Masturbation means exciting one's own genitals, which may or may not lead to orgasm.

Masturbation by young women with intellectual disability and high support needs, may provide them with an outlet for tension, boredom or curiosity. Some people would say that women with high support needs have the right to masturbate if done in an appropriately private manner. Ongoing masturbation may be an indication that a young woman is not actively involved in something that interests her. Avenues of activity which could capture her interest could possibly be explored. A list of activities and projects which she enjoys could be kept for reference by people assisting her.



Problems arise when masturbation occurs in public or becomes distressing, or causes problems with the spread of bodily products, such as menstrual fluid. Such problems may significantly affect other areas of their daily lives. In the past, people assisting a woman with high support needs, may have been solely concerned with trying to stop the young woman masturbating, regardless of the reasons behind the masturbation. It is now more likely that families and staff members may explore reasons for her masturbation, and examine strategies for more appropriate masturbation. There are various approaches for a young woman to learn that masturbation in public is not acceptable, such as the use of rewards on initial short excursions, or advice that it is a private activity, best done in her bedroom. Practical **short-term** steps such as firm fitting clothing or clothing which reduces access to the genital area (bicycle pants, pedal pushers and overalls) may reduce the opportunity to masturbate in public.

For more ideas about persistent masturbation, please see Part V of the learning guide in the Menstrual Preparation and Management Kit.

Masturbation is often a taboo subject, one not easily discussed. Where appropriate, seek professional advice. **Please refer to Readings and Resources in this booklet for more ideas.**

Cultural Influences and Personal Feelings

In some cultures menstruation is regarded positively and in others negatively. For example, in the Hindu culture a young woman's first menstruation is celebrated with new clothes, ceremonial baths and feasting. In "western" societies menstruation is often regarded negatively and there is a strong social pressure to avoid any visual evidence of menstruation. Many people are not comfortable about discussing menstruation. Research has indicated that men are more likely than women to think that menstruation is distressing and interrupts daily activities (Brooks-Gunn and Ruble, 1986).

A woman's personal feelings about menstruation can be influenced by both cultural attitudes and personal experiences. Women's experiences of menstruation vary a great deal. Patterns of flow vary between women. What seems normal flow for one woman can be seen as heavy for another. Some women experience physical and mood changes around the time of menstruation. These can vary from cycle to cycle. Some women experience positive changes around the time of the menstruation, such as increased energy, creativity and ability to relax (Logue and Moos, 1988).

Young women without disability who have not received preparation for their menstruation have been found to experience menstrual difficulties more frequently and more severely than young women who have received preparation. This may also be relevant for young women with intellectual disability.

Responses of family members, staff members, and friends towards menstruation can influence the reactions of a young woman who has a disability (Gray, 1991; Hasleton, 1989). People assisting a young woman with menstrual management may be uncertain about how to explain menstruation to her and how to teach pad changing. Menstruation can be a reminder that the young woman may not experience adulthood in the way women without a disability might. The young woman may have grown and become heavier, which can add to difficulties for people assisting with bathing, toileting and changing menstrual pads. It is important to encourage people providing personal assistance to have a positive and supportive outlook towards menstruation (Gray and Jilich, 1990). Consistency of approach between personal assistants and across environment is also a priority.



Menstrual Management: Practicalities

These notes are a summary of ideas from Mothers and others who provide personal assistance to women with intellectual disability, as well as from the available literature. An individual plan would need to take the special needs, abilities and circumstances of each young woman into consideration. For young women who are very dependent for self care, reassurance and acceptance of menstruation may be the main aim, rather than teaching of skills.

Establishing Aims and Goals

Long term menstrual management aims and goals may include some of the following components.

For the young woman:

- ✧ To accept her menstruation (that is, to experience menstruation without anxiety or distress).
- ✧ To be as physically comfortable as possible during periods, while those assisting manage pad changing, bathing and washing tasks for her.
- ✧ To behave in a generally acceptable way during her menstruation (e.g. to leave her pads in place).
- ✧ To participate in some, or all, menstrual management tasks.
- ✧ To know by a set routine when pads need changing.

For people assisting the young woman:

- ✧ To feel comfortable about assisting the young woman to manage her period.
- ✧ To be familiar with approaches for managing discomfort arising before or during periods.
- ✧ To be aware of menstrual management plans and established menstrual care routines.
- ✧ To integrate menstrual management into other aspects of life education, for example, self-care, human relations, education and health maintenance.
- ✧ To ensure consistency of approach in menstrual management for women, both between their assistance and across environments.

For Planning Aims and Goals, see Guidelines.

Preparation

Ideas which may be useful for preparing a young woman who has an intellectual disability and high support needs for her periods.

Unlike their grandmothers today, almost all young women are informed and prepared for periods and their management, so that they are not frightened by the appearance of the first menstrual flow. If possible, preparation for menstrual flow should be an ongoing process which begins early in life, so that menstruation is regarded as a normal part of life. Since menarche (first menstruation) begins at different ages for each individual, specific preparation should probably begin when young women are as young as nine years of age. (This is two years before the early end of the usual menarche age range.) Some conditions and syndromes associated with intellectual disability can be linked with early menarche. This could be checked with a medical practitioner. People providing personal assistance to young women have tried some of the following approaches and found them useful (As the ideas relate to menstrual pads some of these ideas won't apply to young women who regularly use incontinence products).

Even if you are not sure that the young woman will understand, it is important to give her basic explanations and reassurance about periods prior to menarche, for example:

"Most girls menstruate."

"You will bleed for a few days."

"To menstruate means blood comes from inside your body and flows out through an opening between your legs."

"Sometimes you can feel the blood coming out."

"Sometimes your tummy (or breasts) might feel a little sore."

"This opening is called a vagina."

"Sometimes you might feel a little cranky."

"When you menstruate, you will need to use a pad."

"Sometimes you might feel really great."

"You leave the pad in your pants."

"The blood is not dirty- it is clean."

"A pad stops the blood from getting onto your clothes."

"Women change their pads in a private place."

"It is good to menstruate. It means you have a healthy body."

"Menstruation is a private thing- it's best to talk about your pads with someone you know very well." (Provide examples such as mother, teacher, and regular house staff.)

"One day you will menstruate, you will get your periods."

"You always change your pad in a private place, like the bathroom or toilet, with the door closed."

"You will have a period every month."

See the "Most Women Menstruate" Communication Cards on this website.

Some of these messages are adapted from the “Janet’s Got Her Period”. (see Resources)

- ✘ When speaking about menstruation, the tone of voice, as well as the words used, will be very influential: if the person speaking is not comfortable, then the young woman is likely to sense this and react accordingly.
- ✘ Television and magazine advertisements may help to illustrate some of this information.
- ✘ It may be helpful to use “anatomically correct” dolls when providing explanations for some young women.
- ✘ Personalised books can be another useful approach; for those who may respond, photographs and/or familiar communication symbols could be used to assist with learning.

Other relevant preparation approaches, especially in the years leading up to menstruation are:

- ✘ Not reinforcing negative reactions to the sight of blood; modelling of calm responses to menstruation by care providers.
- ✘ Encouraging appropriately modest behaviour while bathing, dressing and toileting.
- ✘ Encouraging affection behaviour which is appropriate to her age.
- ✘ Encouraging interactions with the young woman that recognise her approaching adolescence and maturity.
- ✘ Encouraging appropriate (that is, in private) masturbation behaviour if this is occurring.
- ✘ Ensuring consistency of approach in menstrual management for the woman both between people who assist her and across environment.

“Practice Periods” give young women opportunities to become familiar with routines and some sensations related to periods, for example:

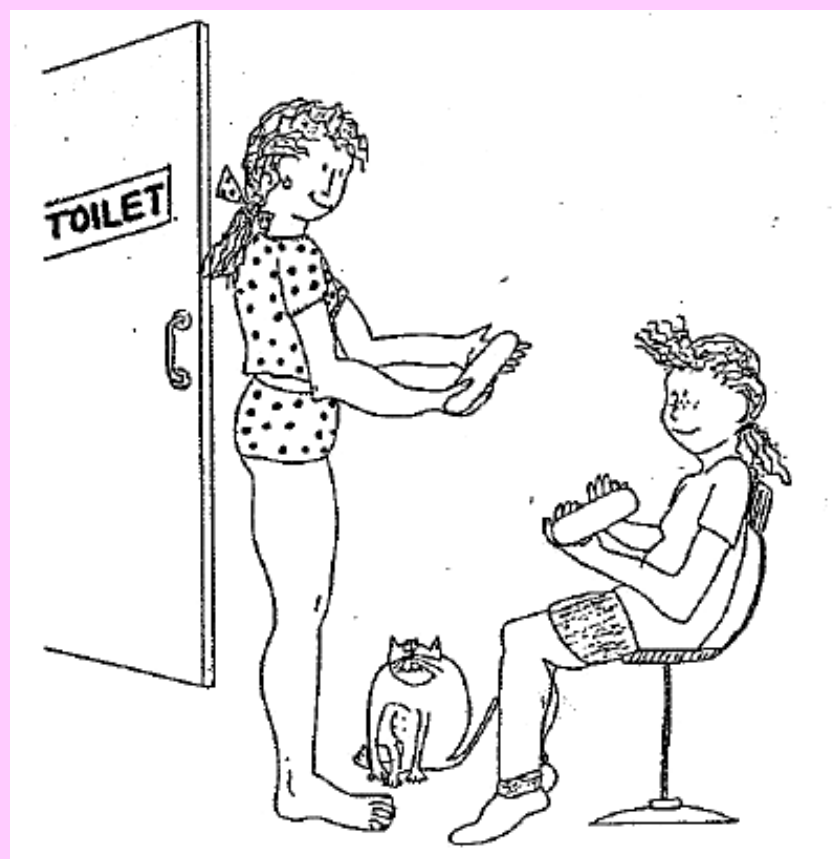
- ✘ Getting used to the feel of pads.
- ✘ Feeling O.K. about menstrual flow- that is part of being a woman.
- ✘ If considered useful, red food colouring can illustrate what menstrual flow looks like on a pad. Different amounts can be used to help the young woman to learn when pads need changing.
- ✘ If appropriate some teaching of pad changing skills could occur at this time.
- ✘ This time could also be spent trying out pads of different sizes and shapes to find out which are most comfortable for her.

Modelling by Mother and sister of what happens during periods, for example, wearing, changing and disposal of pads. The video, “Janet’s Got Her Period”, shows a Mother and sister of a young woman who has an intellectual disability discussing and demonstrating menstrual care. (**see Resources**)

Women’s days/sessions when pads are worn during pleasant, “feminine” experiences like manicures, dressing up, hairstyling and massage; the young woman could be involved in shopping for her own pads to help her to understand that menstruation is a natural part of her life.

Young women who do not appear to have the ability to learn to manage any part of their menstruation still need preparation. Using some of the above ideas may assist them to avoid feeling surprise when menstruation begins.

For Planning Menstruation Preparation, See Guidelines



Communication

Communication skills among women with high support needs can vary a great deal, both between individuals, and different times for the same woman. People assisting these women need to be aware of a range of methods of communicating, to increase the woman's ability to understand messages. Differing approaches may also be needed to help the woman express themselves. Possibilities other than speech may include use of signing, a range of symbols, objects or object symbols, augmentative language by those assisting them (see **Communication**). Communication technology may also assist some women (see **Communication**). Details of possible approaches may be obtained from a Speech Language Pathologist/Therapist.

Two concerns about communication are frequently reported by people providing personal assistance to women with high support needs. The first is how to tell these women about menstruation. The second is about awareness and management of cyclic changes. For example, a woman may experience discomfort or pain before or during menstruation: those assisting her may feel that her limited communication skills may prevent her from communicating this discomfort. They may also be unsure about whether approaches used are reducing the discomfort experienced.



Telling Her about Menstruation and Teaching Menstrual Skills

Every woman needs to be told about menstruation. It is recommended that young women with high support needs are prepared for their first menstruation (menarche) well before it is likely to happen. Providing information is an important part of effective preparation for menstruation.

Some young women who do not speak may be able to understand and use objects, signs and symbols as part of their menstrual preparation and menstrual management. Some examples of how symbols may be used are shown on the following page. These messages and symbols may also be used by older women needing explanations and prompts for menstrual management. For some women it may be necessary to reduce complexity, by using less symbols per message. Other women may be able to understand messages and express their needs and preferences with a greater variety of symbols than those given here.

Text may be made more “user-friendly” by placing each message on a separate card/page OR using different colour paper for each message.

Keep instructions easily accessible for the woman i.e. on the toilet door, hanging beside the toilet roll, etc. **(see Planning Guidelines)**

For more ideas about teaching menstrual skills to women with high support needs, read Teaching Strategies in this booklet.

Some More Communication Ideas

- It is very important for women with high support needs to anticipate daily events. They are then more able to learn more about themselves and their world. Consistency of approach will also enable these women to learn new skills more easily. Think about trying some of the following ideas:-
- Keep a menstrual chart **(see Menstrual Charting)**. Having a particular symbol to mark when the woman’s next period is due. Involve her in her charting, so that both she and people who assist her are aware of when her period is due.
- Calendar Boxes or Anticipation Shelves are ideas which may assist people with high support needs to be more aware of the passage of time, and regular routines. Shelves or storage systems represent the days of the week. Objects, object symbols/tangible objects or symbols **(see Communication)** can be used to represent activities in each person’s daily routine. These ideas may assist some woman to anticipate events such as menstruation. See the diagram below for example.



- Keep a list of activities or objects which each woman enjoys. Some of these can be planned for when the woman has her period. This may help her to associate periods with pleasant experiences. Enjoyable activities may also direct attention away from discomfort, or inappropriate menstrual behaviours.
- It may be appropriate to assist the woman to start using pads a few days before her period is due. This may help to communicate to some women the menstruation will soon begin.
- Changes to the environment can signal to a woman that her period is due. Playing distinctive soothing music, burning a relaxing essential oil, giving her a daily massage in the days before and during a woman's period, may communicate to her in a pleasant way that her period is due.
- Before assisting a woman to change her pad, tell her what you are going to do and give her the object or tangible symbol that has been chosen to symbolise "change of pad" for her. Then proceed with pad-changing, trying always to do so in a similar private place. (**see Planning Guidelines**)
- Show a woman a full packet of pads at the start of her period. Each time that her pad is changed, show her how the packet is becoming less full. On the last day of her period, show the woman the almost-empty packet. When the packet is empty, she may be able to help dispose of it in the bin.

Communication and Management of Physical Changes and/or Discomfort

The possibility that a woman who has high support needs may experience pain or discomfort and be unable to communicate this, can cause serious concern to those assisting her. Even for those women least able to communicate intentionally, it may be possible to evaluate their comfort, as well as the effectiveness of strategies for easing discomfort (**see Tables one and two**).

In Table one, some ways of reducing discomfort such as use of a hot water bottle, massage, taking a bath and resting, are listed. Three or four different ways of telling a woman what is planned are given. In Table Two, the woman's responses can be summarised and recorded. By using a structure approach to communication, people assisting this woman can develop an awareness of messages she sends, and gauge the effectiveness of different management approaches for her. Such recording may also promote consistency of approach between personal assistance and across environments.

Table 1

Some Options for Easing Discomfort	Real Objects	Tangible Symbols	Rebus/Sign	Word
Hot water bottle	Actual hot water bottle			Hot water bottle
Bath		Piece of towel & jar of bath salts		bath
Massage	Massage oil or cream in bottle	Empty oil/cream container		massage
Relaxing music	The cassette	An empty cassette case		music
Lie down		Piece of fabric from quilt		Lie down

Table 2

RECORD SHEET						
REMEDIES	RESPONSES	Smiled	↑ in loud vocalisation	↑ in loud vocalisation		
Massage				✓		
Hot water bottle			✓			
Bath		✓	✓			
Music				✓		

How to record

List each remedy that you attempt in the left hand column. Record the woman's response/s by marking the appropriate response column. Tell the woman how you are interpreting their response. For example, "You have stopped crying since you sat in the bath. I think that means you are more comfortable."



It is good to menstruate.



You have a period every month.



You will see blood on your undies for a few days.



You might feel cranky.



You might feel really great!

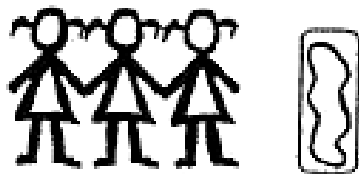
Menstruating is a private thing.



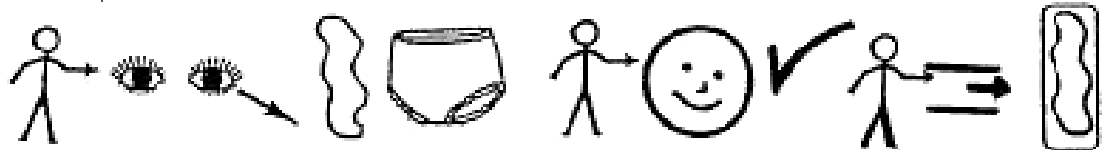
- You don't talk about it to lots of other people.



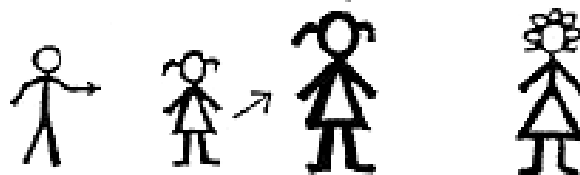
- Your Mum or a very good friend can know.



Most girls menstruate.



When you see blood on your undies you know you have started menstruating.



To menstruate means you are growing up and becoming a woman.



When you menstruate you will need to use a pad.



A pad goes in your undies.



A pad stops the blood from getting onto your clothes.

Teaching Strategies

Useful ideas to assist with acceptance of menstruation and learning of menstrual skills by young women with high support needs:



- ✧ **Consultation:** Ideally all people who regularly provide personal assistance to a young woman need to be involved in both planning and carrying out teaching of menstrual skills. This applies to all the young woman's regular environments. Good liaison is also needed as time goes by, so that different management styles are communicated, and changes monitored.
- ✧ **Consistency:** To maximise a young woman's chances to learn, all people who assist her need to have similar expectations, and to respond to her in a predictable way. As far as practicable, it is suggested that routines of pad changing disposal, methods of communication and personal hygiene be as uniform as possible across relevant environment (**see Communication**).
- ✧ **Gathering information:** Gathering of "baselines" and menstrual charting can be important. Most menstrual management teaching approaches identify relevant behaviour and abilities of young women before teaching begins. If appropriate behaviours are occurring, an understanding of just how often, and in what circumstances the behaviour occur, can be developed through observation and recording. (**see Charting**)

Menstrual Management: Practicalities continued

▣ **Gradual introduction:**

- If pads are to be used, perhaps start with mini pads/ panty liners. After they are accepted, try regular pads, then the larger overnight pads.
- When aiming towards tolerance for pad wearing, set very short wearing times to begin with, then extend the time by only a few minutes, with an eventual aim of up to 4 hours' wear, or overnight.
- Commence practice in one setting only (whenever the young woman seems to have the best chance of success). When she is achieving in that setting, extend opportunities for practice to other places, other times, for example, when out in public.
- When teaching pad manipulation, begin with removing pad from pants, or pad disposal, as these are the least difficult steps to master. (This must always occur in a private place, with suitable disposal facilities).
- Begin at times you judge the young woman will be most likely to succeed. Later, include the more difficult times of day/night.

▣ **Repetition:** Learning sometimes depends on repeating opportunities to practice: some young women with high support needs may need a lot of repetition in order to learn new skills. As menstruation only occurs every few weeks, regular practice opportunities very probably won't occur often enough for effective learning to occur- hence the idea of "practice periods".

▣ **Modelling:** It's very likely that seeing someone being calm and "matter-of-fact" about period management would be reassuring for any young woman. Modelling is suggested by some parents and service providers as a very useful technique. A great deal of learning can happen as a person watches others in their daily routines. The difference with menstruation is that women don't generally discuss the topic, and often avoid revealing when they are having their periods. Some women may not feel comfortable with the idea of talking about periods, or allowing their daughters to observe their menstrual self-care. However, if an appropriate person who feels comfortable is able to model menstrual care, this may prove very helpful.

▣ **Reinforcement:** With the teaching of menstrual care skills, as with teaching in any other area, encouragement of appropriate behaviour, and ignoring/discouragement of inappropriate behaviour, is suggested.

- ✧ **Making it Personal:** A private supply of pads/panty-liners for each young woman may be desirable. A personal toiletries bag or shoulder bag for carrying pads to the toilet may help the young woman to carry out menstrual task in a discrete manner. **(see Communication and Charting)**
- ✧ **Choice of Helpers:** It's probably best that those working directly with teaching of menstrual skills feel positive and comfortable about this. Some young women may be able to indicate whom they prefer to help them with menstrual tasks.
- ✧ **Choice of Place:** As outlined before, teaching and practice needs to occur in a private place. Pads, spare underpants, paper bags, and the disposal unit/bin should be kept in an accessible, predictable spot (so the young woman gets to know where they are). It is preferable that lengthy discussion is not carried out in the toilet cubicle, but that discussion occurs before/after using the toilet. Consistency in the way pads are disposed of in different environments is recommended where possible.
- ✧ **Language:** Choose straight forwards words with which all involved are familiar and at ease.

For Planning of Teaching Strategies, see Guidelines.

Behaviour

Ideas which may be useful for assisting a young woman with high support needs to learn appropriate menstrual behaviours.

Some of these young women may develop inappropriate behaviours which affect management of menstruation. Examples might include removal of pads in public, or a tendency to handle the contents of their pads. Ideas which some people have used in these situations include:

Basic explanation of what is appropriate and why this is so. **(see Communication)**

Firm discouragement of behaviour which is seen as inappropriate, coupled with diversions: for example, activities the young woman is interested in, or enjoys.

- ✧ **Effective encouragement** of appropriate behaviour, for example:
 - ✧ Social rewards, like praise, positive comments, plus a hug, or a smile.
 - ✧ Other rewards, based on individual preferences, such as favourite activities or special treats.
 - ✧ **Consistency of Approach** across environments is important. Consultation among those providing each woman with assistance is necessary. All people assisting a woman need to have similar expectations concerning her behaviour. It is important that they respond to her behaviour in an effective and predictable way.
 - ✧ **For spreading menstrual flow, “logical consequences”** can be effective – have a washer ready. If spreading occurs, calmly but firmly state that there is a mess, and that the young woman may help to clean up (even if a great deal of assistance is required).
- ✧ Another idea, to help avoid the occurrence of spreading, is to try dressing the young woman in clothes which limit her access to her underwear, but which are still comfortable, for example:
 - ✧ Pants instead of dresses
 - ✧ Overalls
 - ✧ Cycling pants/ pedal pushers



Problems arise when masturbation occurs in public, or causes hygiene problems with odour or spreading. Some of the above approaches may be helpful. If difficulties persist, professional advice should be sought.

- ✧ **Disrobing.** Some young women may remove their clothes (and menstrual pads) at times and places which are no appropriate.
- ✧ There has been very little research about disrobing by women with high support needs. Among reported studies, approaches include:
 - ✧ Trying to reduce disrobing by engaging the woman in unwelcome activities;
 - ✧ Encouraging other, appropriate behaviours;
 - ✧ Introducing related routines such as assisting other residents with their personal appearance if disrobing occurred; and
 - ✧ Allowing preferred activities such as daily walks, when clothes were kept on.
- ✧ One study describes how a 12-year-old girl was ignored when she took her clothes off in public, but given positive feedback after each five-minute interval that she remain dressed. This intervention was successful.
- ✧ A number of specific behavioural strategies may help a young woman to keep wearing her clothes and menstrual pads. Popovich (1981) describes a range of reinforcement procedures and gives examples of how to use them.
- ✧ **Comfort** is important to all of us. Check for causes of irritation as a young woman may be uncomfortable. Try to find pads and clothing which she feels comfortable wearing (this may needs some trialling). If the young woman is wearing menstrual pads, could they be thinner, or contoured? Might the edges be “scratchy”?
 - ✧ In later days of each period, panty liners may be enough. Would she prefer modified pants-either commercially made or improvised? **(see Menstrual Pads and Incontinence Products)**
 - ✧ Some variation of products used may also increase comfort levels for young women who use incontinence products. See Tables for information about both disposable and reusable incontinence products.
- ✧ **Personal Hygiene:** Bathing/showering routines may need to be altered or more frequent during periods, as both comfort and odour can be difficulties for young women (or those who spend time with them).

Some ideas to consider:

- The young woman may appreciate a shower or bath more than once per day in hot weather.
- Some people recommend a long bath.
- A long shower hose may allow a quick rinse between the legs. Another alternative may be a bidet.
- For bathing on days of “heavy” flow, one idea is to use a long shower hose, and leave the plug out.
- Ensure pads are changed regularly, and worn for no longer than 4 hours before changing.
- As odour usually results from air mixing with menstrual blood, pads need to be kept “body close”/ Pants should fit snugly (for example, firm fit, especially at waistband and legs).

For Planning Approaches for Behaviour which may arise, see Guidelines.



Charting

These suggestions are based on the experience of a number of women with high support needs, and people who assist them.

- ✧ **Choose the charting approach best suited to the needs of each woman.** For example, for a woman who currently assists at meal times, or while using the toilet, try rubber or self-inking stamp and a large calendar; for a woman with very poor vision, a method which relies more on touch and less on visual information may be more helpful (eg. A wall chart with Velcro-attached objects or shapes); for the most dependent women, for whom charting will be done by others, the whole-year chart at the back of this booklet may be most suitable. The woman should still be present during charting and receive basic explanations of the process. **(see Resources)**
- ✧ **Chart every day.** Regular charting will assist people to be aware of both physical and psychological changes which accompany menstrual cycles. Patterns will probably emerge. The women and those assisting them will become more “in-touch” which cyclical changes, and more able to predict and respond appropriately.
- ✧ **Establish a charting routine.** Choose a time of day which seems suitable. Some people like to chart towards the end of the day or just before bedtime. Others have found it useful to chart twice-daily: this applies particularly to settings where women are assisted by different people at different times of the day, such as in residential services.
- ✧ **Record relevant information.** Each woman experiences different physical and emotional changes during her menstrual cycle. Some, like sore breasts, abdominal swelling, irritability, and fatigue, may seem negative; some women may experience positive changes such as increased energy and enthusiasm. It is likely that for each woman there will only be 3-4 types of information recorded. For some women, it will be important to record changes in mood and behaviour: the personal meaning of “happy” and “sad” stamps for each woman can be noted- either on her calendar or, if appropriate, in her chart. Heaviness of flow may be an issue for some women. If unsure, it is suggested that people assisting the young woman use the Estimation of Menstrual Flow chart **(at the end of this booklet)** for several months. This will help to clarify the type of flow a woman is experiencing. Women’s involvement in their own pad management can also be charted, to record achievements and progress.
- ✧ **Encourage women to assist with their menstrual charting.** The menstrual cycle of many women with high support needs may already be charted to some extent. Some people may not previously have tried to involve the women in their own charting.

- ✧ Possible advantages of encouraging women to assist with charting include:
 - a) Increase awareness of the women about the natural functioning of their bodies;
 - b) Increase opportunity for them to communicate about their experiences and feeling;
(Read Communication)
 - c) Increase independence and. as a result, a greater sense of competence and autonomy.

Types of Menstrual Charts

The Menstrual Preparation and Management Resource Kit includes several charting options developed for women with intellectual disability and high support needs. These include:

The whole-year chart enables all recorded information to be seen “at-a-glance”. This chart is suggested for use by people assisting the woman. Other menstrual charting systems are recommended for women who will be assisting with their charting.

The twelve-month calendar has a 4cm x 3.5cm recording space for each day. Using this calendar, women with high support needs may be able to assist with recording of information about their cyclic changes and periods. It is suggested that the calendar is used in conjunction with stamps provided in the Kit.

The self-inking stamps were devised to assist with charting. Many women with high support needs are not able to assist with pen and paper style recording. Stamps require less advanced ability to use objects such as pencils or markers. Self-inking stamps may allow women with severe physical disability to assist with their menstrual charting: to operate self-inking stamps, a woman needs only to be able to place her hand or arm on the top of the stamp, and to press down. She can be assisted with this. Other women may be able to use self-inking stamps independently, or to assist with use of rubber stamps plus stamp pad. Stamp designs can be used to record key information.

Suggested stamp designs and colours include:-

	Green- the woman has positive physical, mood or behavioural changes.		Red- the menstrual pad has been changed. <i>This symbol can also be used to record that the woman is menstruating</i>
	Blue- there are negative physical, mood or behavioural changes.		Black- the used pad has been placed in the bin/disposal unit.

Stamps should be personalised for each woman. For example, record elsewhere that kind of behaviour changes, type of flow, or method of disposal, applies to each individual **(For details of stamp suppliers, see Resources)**.

The fabric wall-chart can be displayed on a wall, or folder for privacy or transport between care settings. This chart may be particularly useful for women with severe visual impairment. It is designed to make use of functional vision. It also allows the woman to use her sense of touch to find charting symbols, and to locate where they should go. The sound made by Velcro attachments can be very motivating for some women.

Material other than fabric may be suitable for other women. Possibilities may include washable plastic sheeting, magnetic board and symbols, and felt boards. Choices should be based on the individual needs of each woman, including her preference and learning style. **(For information about supplies of some of these materials, see Resources)**. **A pattern for a fabric wall chart is supplied in the Menstrual Preparation and Management Kit.**

Menstrual Pads and Incontinence Products

For women using incontinence pads:

Factors to consider when choosing products for use during menstruation by women with high support needs and incontinence may include: absorbency needed, the woman's comfort, ease of use, cost per year, sizes available, ease of laundering (for reusable products), and impact on the environment. It is suggested that reusable products be used in association with disposable products e.g. reusables at home, disposables for school and outings.

Consider using higher-absorbency pads than usual, for example, Softeze; Hartmann's Moliform; or Tranquility's High-Capacity Pads.

Another option is a high-absorbency fitted napkin, like Sancell's All-in-One, Tranquility's Slim-Line Diaper, or Hartmann's Molicare Ultra. These products have elasticised legs, and resealable tabs. They may offer more comfort and dryness than other products during menstruation, and be easier to manage than a two-part system.

The use of reusable pads may have a place in menstrual care.

For women not using incontinence pads:

Ensure the young woman has firm-fitting briefs (full briefs are better than bikini styles); close fit will assist her pads to remain in place, and will minimise the occurrence of menstrual odour. Cotton blends may be better in warm weather or if she is prone to vaginal infections/rashes. Try chain stores and department stores.

If may be appropriate to have more than one type of pad available for each woman's use, as flow varies from day to day.

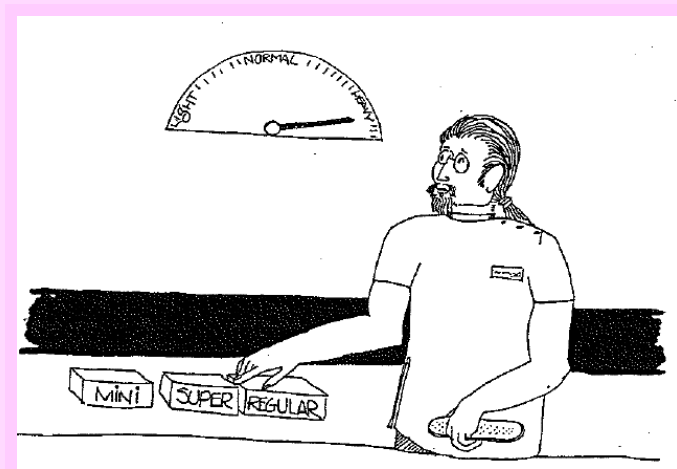
Note: Product details change frequently. Check product packaging for features.

During practice sessions or light flow days: Try panty liners, such as Libra, Carefree Pantyshield, Kotex, or Stayfree Minipads or:

- Stayfree Regular
- Stayfree Prima Light
- Libra Bodyform Light
- Whisper Slim Regular.

For moderate flow days:

- Libra Regular
- Libra Bodyform Regular
- Stayfree Regular Adhesive
- Kotex Regular
- Whisper Ultra Thin



For heavy flow days, or overnight:

- Kotex Overnight
- Whisper Regular Maxi
- Stayfree Overnight adhesive
- Libra Bodyform Super
- Stayfree Prima Long
- Tranquility Hi-capacity Pads
- Softeze Regular, or Super Shields.

If wearing pads is a problem: (see Table III) Try special underpants, either:

- ✧ With built-in pad, for example, “Kylie” pants, “Carefor”.
- ✧ With elastic loops to hold pad – “Modess Feminine Panty”, or pouch to slip pad into, e.g. “Tranquility”, or “Kanga”.
- ✧ By stitching or pinning pads into firm-fitting briefs.
- ✧ People assisting these women may wish to improvise their own versions of modified underpants. To achieve consistency, it is recommended that each woman uses the same menstrual product(s), once the decision is made about which pad(s) are most suitable for her. This may need to be reviewed from time to time.

For Planning of Clothing and Pad/Products, see relevant sections of Guidelines.

Further information concerning incontinence products is available from Independent Living Centres Australia <http://www.ilcaustralia.org/home/default.asp>

Please see Introduction for an explanation of why tampons are not discussed in this section.



Management of Menstrual Difficulties

There is no evidence to indicate that the incidence of menstrual difficulties or discomfort for girls and women with intellectual disability is any higher than that experienced by the general population of women.

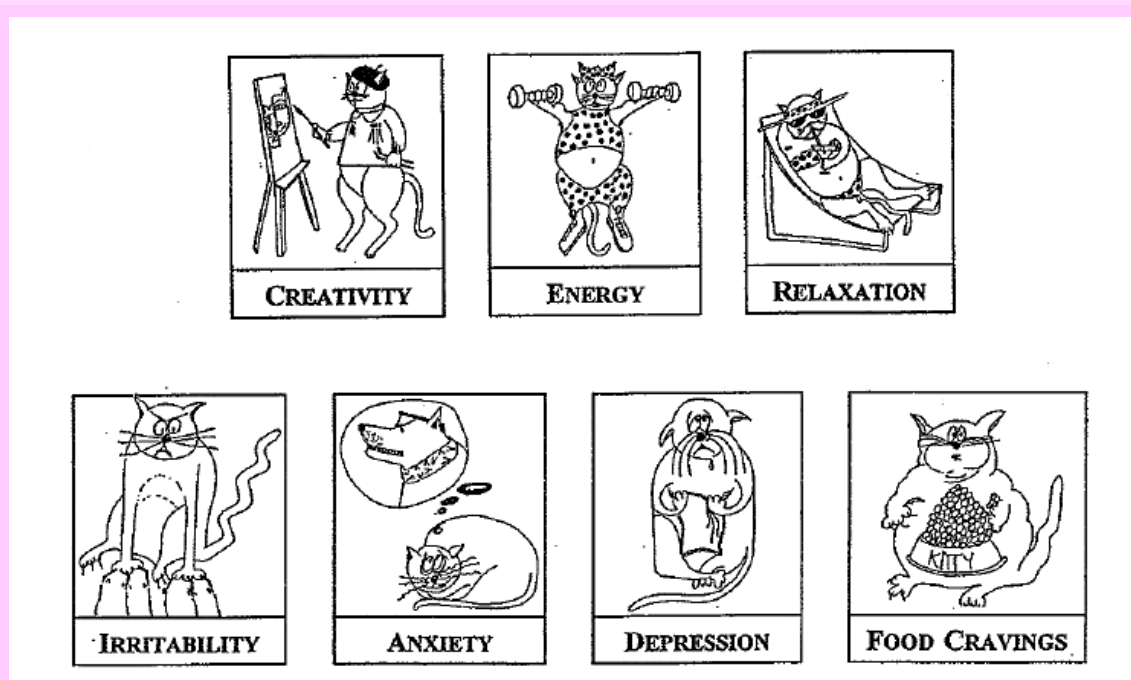
Pre-menstrual changes

In general, research indicates that pre-menstrual changes are not commonly experienced by young women. Pre-menstrual stress (PMS or PMT) relates to one or more physical and emotional signs which occur up to 14 days before a period and disappear by the time a period starts. In a recent survey of young Australian women, it was found that 20% experienced irritability related to their menstrual cycle¹. Physical changes may include fluid retention, breast tenderness, headaches, acne, and general aches and pains. Other signs may include tension, anxiety, irritability, depression, anger, food cravings, increased appetite, and clumsiness.

Some women may also experience a twinge or cramps in the lower back or abdomen, or spotting, when ovulation occurs. This is called Mittelschmerz, or “middle pain”.

Positive pre-menstrual and menstrual changes have been reported by some women. These have included increased creativity, energy, and ability to relax.

It is probable that many women do not notice pre-menstrual changes during every cycle. It has been found that physical discomfort and negative mood changes are often more noticeable during times of life stress or personal disruption.



¹ Adams et al 1988

Management of Premenstrual Changes

- ✧ **Keep a menstrual chart.** By charting cycles, it becomes easier to see patterns, and to become aware of possible changes, both physical and psychological. A pattern may emerge across several cycles if PMS is being experienced. (see some examples of charts at the back of this booklet) **(see also Communication and Charting)**
- ✧ **TLC** (“tender-love-care”) goes a long way. Try to ensure that the woman has opportunities to express her feelings, and to receive comfort and sympathy. People assisting these young women should try to ensure that they too receive support, if they feel it is needed.
- ✧ **Pay attention to diet.** Suggestions include eating of smaller meals rather than three big meals per day; eating plenty of fruit, vegetables, whole grains and cereals, and drinking lots of water. Reducing intake of salt, sugar and meat, or using substitutes may be of value. If possible avoid caffeine, chocolate, and fatty foods.
- ✧ **Try to ensure the young woman has adequate and regular sleep.**
- ✧ **Encourage some enjoyable, regular exercise.** Swimming, walking and assisted floor exercises may help. **(see Exercises)**
- ✧ **Make time for relaxation.** Choose whatever suits best - deep-breathing, sitting under a tree, watching television, or listening to favourite music.
- ✧ **Ensure the young woman is wearing appropriate clothing.** If breast are tender, wear a well-fitting, comfortable bra or vest. Try chain stores for underwear sets.
- ✧ **It is fine to let off steam.** The young woman may need the opportunity to cry, laugh or scream; this may help her to avoid taking out frustrations on others.
- ✧ **A variety of preparations** which may assist PMS are available from chemists, health food stores, supermarkets, and medical and alternative health practitioners; for example, Vitamins B6 and C, iron, “PMT eze”, “Evening Primrose Oil”, and “Formula 3”. Responses to preparations may vary according to the individual. Their precise effects and usefulness do not appear to have been comprehensively documented.
- ✧ **Ensure consistency of approach** once the decision about most suitable strategies for management of pre-menstrual changes is made.

Epilepsy and Cyclical changes

Some women with epilepsy, experience changes in epileptic seizures related to their menstrual cycle. These changes are not always severe. The exact cause of these cyclical changes does not appear to have been identified. These changes have been variously linked to alterations in hormone levels, fluid levels changes, and cramping. If these epileptic changes are affecting the woman's lifestyle, a review of medication could be initiated. Charting of seizures and menstrual cycles would be a first step in this review. **(For other references to epilepsy see also Hormones and drug interactions)**

For Planning the Management of Pre-menstrual Changes, see Guidelines.

Discomfort during Menstruation

Sometimes, periods can involve discomfort or be painful. Most women say that despite premenstrual or menstrual discomfort, they are able to continue with daily activities. In a recent survey of young Australian women, it was found that 23% reported discomfort during periods. Discomfort may include cramps, nausea, diarrhoea and headaches.

Cramping or pain across the lower abdomen or back, can occur two to twelve hours before menstrual flow, and sometimes continues over the next 24 hours. It can be accompanied by nausea and vomiting, diarrhoea, headache and occasional shakiness. For a young woman with high support needs, expressions of discomfort may range from "not being herself" to what may be seen as misbehaviour. **(see Communication and Charting)**

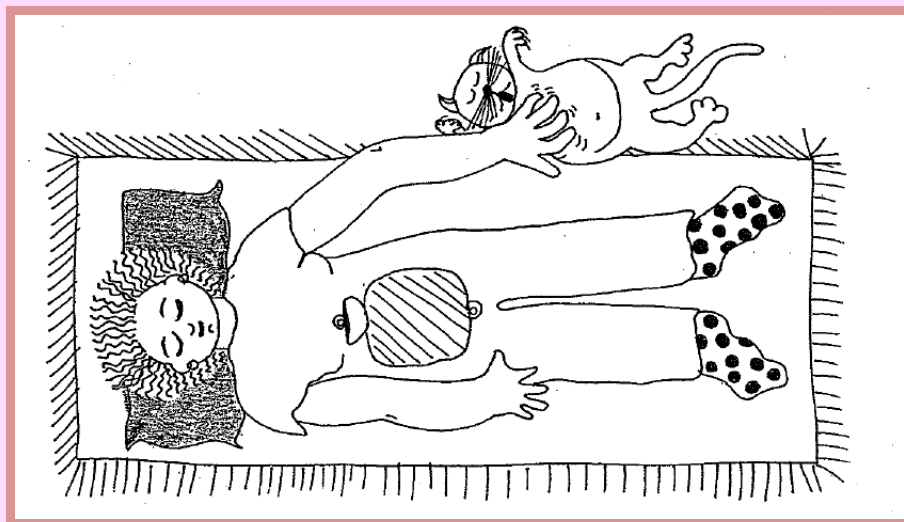
Please Note: Ongoing period pain can sometimes be caused by physical conditions such as fibroids, endometriosis or infection. This pain can also occur at other times in the cycle. Such pain is more commonly diagnosed in women over the age of 25, (Fraser, I. 1988. *Prostaglandins, Prostaglandin Inhibitors and Menstrual Disorders: Dysmenorrhea*. Healthright, 7,4: 34-37) and should be investigated. Diagnostic procedures are available to assist in identifying whether a specific condition or disease is present. If considered necessary for a woman with high support needs, it is suggested that a basic explanation of demonstration of the chosen procedure be given, in order to prepare her for the experience.

Management of Period Pain

- ❖ **By charting periods**, it may be possible to be aware of when pain is likely to occur, and to organise routines around it. During a period, some of the signs of menstrual discomfort may include cramps, heavy flow and loss of energy.
- ❖ **TLC (“tender loving care”)** goes a long way. Try reducing activity expectations; or a little extra pampering, like a bubble bath, a massage, or a facial.
- ❖ **Positioning:** If lying, try a pillow under her knees. When lying on her side, her knees may be brought up to her chest. She may elevate her feet by lying on the floor and putting her feet on some pillows. There are also gentle forms of exercise available. **(see Exercise)**
- ❖ **Place on her abdomen or lower back one of the following:** a hot water bottle; a “Wheat Pillow” (heated in microwave); a “Cold Comfort Pack” (heated in boiling water).
- ❖ **Some women have found acupuncture has relieved discomfort.**
- ❖ **If the young woman can lie on her back**, you may assist to rock her pelvis gently from one side to the other.
- ❖ **Massage** her lower back and buttocks with firm pressure over the lower spine. Also massage around the abdomen and other tension areas such as neck and shoulders.
- ❖ **Take a leisurely walk together.**
- ❖ **Assist the young woman with relaxation techniques.** This may include resting with her feet up, deep breathing exercise, or listening to relaxing music. Assisting her to have a warm bath or shower, or drinking something warm, (maybe some camomile tea – it is a relaxant) may also help her to feel better.
- ❖ **Encourage the young woman to eat lightly and regularly.** Eating causes the intestines to fill and take up more room. By eating lightly, there will be more room for the uterus.
- ❖ **Avoid constipation:** This can usually be achieved by eating more fibre, and drinking more water.
- ❖ **Ensure the young woman has regular sleep**, or greater opportunity for sleep.

- ❖ **Try to ensure that the young woman has opportunity to express her feelings,** and to receive comfort and support during these times.
- ❖ **There are various preparations** available from chemists, health food stores, and supermarkets for menstrual discomfort. In addition, cider vinegar, Irish ginger and diet celery (for fluid retention), has been found by some women to relieve their discomfort.
- ❖ **Pain relief medications** - Panadol (Paracetamol), Ponstan (Mefenami Acid), Naprogesic (Naproxen) or the “Contraceptive Pill”, may alleviate period pain. *Choice Magazine* is a good source of information about over the counter medications. <http://www.choice.com.au/>
- ❖ **Ensure consistency of approach** during days when women seem to be experiencing discomfort. Also try to have similar activity expectations across environments on these days.

For Planning Approaches to Management of Discomfort during Menstruation, see Guidelines.



“Heavy”/ Lengthy/ Irregular Periods

The amount of menstrual loss during each period can vary from cycle to cycle. The average amount of menstrual loss is approximately 5 to 6 tablespoons (110 mls or ½ cup), and can contain “clots”. Some women lose much more than one cup (250mls) of fluid and it may include large “clots” which may indicate heavy loss. Approximately half of the fluid loss during any period is not blood. It is a collection of fluids and materials from the uterine wall, cervix and vagina. The length of the period also varies for each woman, being from 2 to 7 days in duration. Most periods are at their “heaviest” in the first two days.

Management of “Heavy”, Lengthy or Irregular Periods

- ❖ **Menstrual Cycle Chart**- What is normal flow for one woman, may be different for another. so, it can be helpful if a menstrual cycle chart is kept. By charting the menstrual cycles, a pattern may become clearer. **See Charting.**
- ❖ **Menstrual Flow Chart** – Because the first two years of a young woman’s menstruation can be quite erratic, it can be difficult to establish what “normal” loss is. **Please see Menstrual Flow Chart.**
- ❖ **Stress** can affect menstrual flow. Using relaxation techniques can assist in reducing stress. These can include walking, deep breathing, enjoying personal interests or sitting with feet up.
- ❖ **Diet** change can also alter stress, especially by avoidance of fatty foods or caffeine.
- ❖ **Anaemia** – One concern with ongoing heavy menstrual loss is anaemia (low blood iron levels). This can be alleviated by taking iron tablets, or adding sources of iron to the diet. Natural sources of iron include animal tissues (red meat, fish, liver), prunes, beans (soy, kidney), grains, leafy green vegetables, almonds, molasses and dried fruits. Citrus fruits and Vitamin C promote the absorption of iron in the body.
- ❖ **Alternative Health Ideas** – Various preparations available from alternative health practitioners which may reduce heavy menstrual loss include aromatherapy, Beth root, aconitum, ginger, diet celery, vinegar and periwinkle. Use of preparations should be advised by a practitioner. Chinese medicine and acupuncture may alleviate persistently irregular or heavy menstrual loss.

- ❖ **Medical Ideas** – Various preparations are available from medical practitioners and include contraceptive “Pill”. Dilatation and curettage (D&C) may alleviate persistently irregular or heavy menstrual loss. These approaches should be advised by a medical practitioner.
- ❖ **Consistency of approach** to difficulties with “heavy, lengthy or irregular periods” is important: effective charting of flow requires co-operation between all people assisting the woman concerned; forward planning by those assisting will ensure she has adequate supplies of pads and clothes for most situations.

For Planning Approaches to Heavy, Lengthy or Irregular Periods, see Guidelines.



Older Women

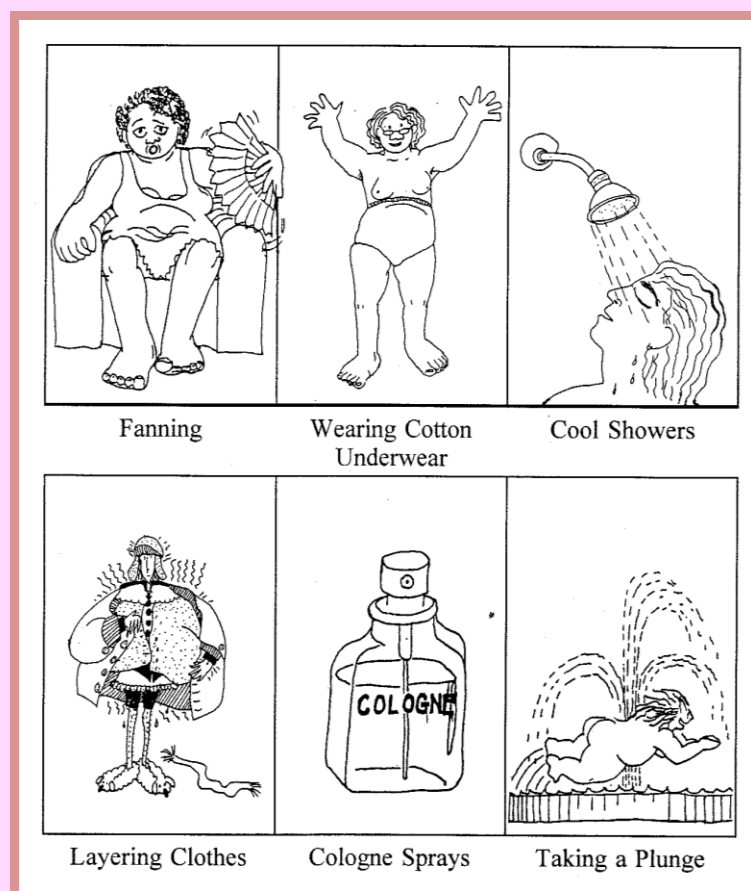
Among the changes that older women experience are changes in menstruation. Menopause is the time in a woman's life when her ovaries reduce production of the hormone oestrogen, and menstruation ceases. This is a normal change in body function and may occur over months or years.

Menopause generally occurs between the ages of 45-55 years. One in 5 women will experience virtually no difficulties. For approximately 3 out of every 5 women, changes experienced during menopause will be mild, while 1 in every 5 women, changes may cause significant concern. The menopausal experiences of women with intellectual disability do not appear to have been documented.

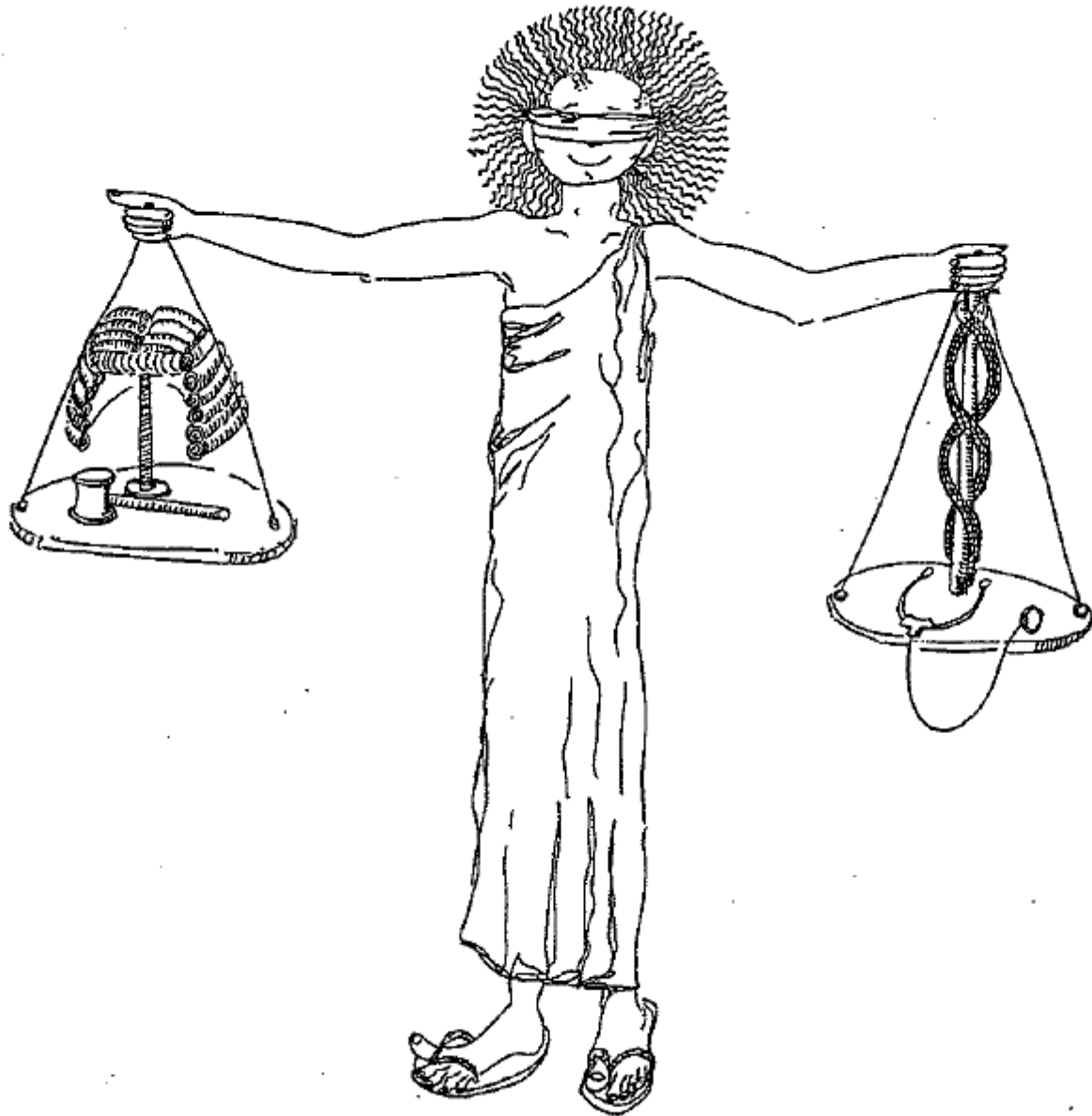
Suggestions for ways to assist older women with high support needs:

- ✧ **For changes in menstrual flow/regularity** – always have a supply of pads, suitable for both light and heavy flow, available in a toiletries bag or hand bag. Some spare, firm-fitting underwear, a washer or refresher towel and plastic bags to carry them in, would be advisable. **Please see previous pages for more ideas about these changes.** Charting of menstruation may help to identify if a woman is experiencing menopause. **(see Charting)**
- ✧ **For hot flushes (of face, neck or upper body)** – wearing of loose shirts and jackets, and cotton underwear may reduce discomfort. Have a spare set of clothes ready in case a change is needed for comfort. Some cologne or water and a paper towel may be used for a quick, easy refresher. If wearing makeup, keep it to a minimum. A rest or nap during the day may help to avoid fatigue, especially if sleep patterns are changing at night. Sensible diet, and the use of relaxation techniques, herbal preparations, and vitamin E, may also be of assistance.
- ✧ **For vaginal changes such as dryness or itchiness**- be alert to signs of discomfort. Itchiness can be relieved by applying bancha tea or Vitamin E oil to the pubic and vaginal area. Scratching should be avoided. Drinking plenty of fluids, and increasing the moisture content of the air at home, may help to reduce discomfort associated with vaginal dryness. Avoid the use of vaginal douches and sprays, and coloured or perfumed powders or soaps. Masturbation helps to maintain vaginal muscle tone.
- ✧ **To reduce the likelihood of osteoporosis** (loss of calcium from the bones), all women need to be provided with a diet including adequate calcium. More mature women will benefit from regular, moderate, weight-bearing exercise, such as walking. Smoking (or passive smoking), and excess caffeine, should be avoided. Long term use of some medications may affect bone density.

- ❏ **To reduce the likelihood of circulatory or heart disease**, all women need regular exercise and a diet low in animal fat is recommended.
- ❏ **Hormone replacement therapy or “HRT”** is usually a combination of female hormones. It is sometimes recommended for older women. The long term effects of HRT remain unclear. HRT can result in the recommencement of menstrual flow. It has been noted that oestrogen occurs in other body tissues, as well as being produced by the ovaries, so that ovarian function does not result in a total lack of oestrogen for post-menopausal women. This is an extensive topic. If you require more information, **see Readings**.
- ❏ **Regular breast checks and “Pap” smears** are particularly important in later life. Careful preparation for these may be needed especially for women with intellectual disability. It may be reassuring for these women to observe a breast check or pap smear either in “real life” or on video. **(see Resources)**
- ❏ **Some extra attention to self image, emotional needs, and mutual support** may also need to occur in older women. **(see Communication)**



Legalities



On 6th of May 1992, as a result of a number of varying legal judgments around Australia, the High court of Australia resolved that consent for the sterilisation (including hysterectomy) of a child (under 18 years of age) with intellectual disability must be obtained from a court, and that consent cannot legally be given by parents. The High Court of Australia recommended that the Family Court of Australia is appropriate for such applications. This ruling is applicable throughout Australia.

Children

Some of the issues raised by the High Court of Australia [The 1992 case is known as *Re Marion*] are outlined below:

- ✧ **Who should decide?** - The High Court concluded that “Court authorisation is required because of the significant risk of making the wrong decision ... and secondly, because the consequences of a wrong decision are particularly grave.”
- ✧ **Therapeutic or Non-Therapeutic?** - In some of the previous Family Court of Australia cases, there was debate about whether hysterectomy was a therapeutic or non-therapeutic procedure if there is no disease present. In response the High Court stated that “... we are not referring to sterilisation which is a by-product of surgery appropriately carried out to treat some malfunction or disease ... We hesitate to use the expressions ‘therapeutic’ or ‘non-therapeutic’ because of their uncertainty.”
- ✧ **Last Resort** - The High Court decision stated that “... sterilisation is a step of last resort.” In future, this may mean that the Family Court of Australia may require all applicants to the court to show that they have tried all other approaches to menstrual management, before applying for consent to a procedure which results in sterilisation.
- ✧ **Family Perspective** - “There is no doubt that caring for a seriously handicapped child adds significant burden to the ordinarily demanding task of caring for children. Subject to the overriding criterion of the child’s welfare, the interests of the family members, particularly primary caregivers, are relevant to a court’s decision whether to authorise sterilisation. However, court involvement ensures, in the case of conflict, that the child’s interests prevail.”

The Family Court of Australia’s guidelines and protocols for medical procedure on children under 18 years of age in Victoria and Queensland aim to:

- a) *Promote positive outcomes for children.*
- b) *Provide intending applicants and other interested parties with the opportunity to identify and discuss all relevant issues.*
- c) *Assist in identifying, where appropriate, alternative options and strategies.*
- d) *Ensure that a Court hearing is of ‘last resort’ after all other options have been tested or considered and failed to, or been assessed as unable to, produce a satisfactory outcome.*

Nicholson, A. 2004, *No. 9 of 2004 Victorian and Queensland Registries: Medical Procedure Applications*, Family Court of Australia

The Family Court of Australia does not give legal aid but can give general information on services on court and administration procedures. As each state and territory legal framework is different, it is

recommended to contact your local state and territory for legal advice on how to approach the Family Court of Australia, should you require it. Links to access to legal aid services can be found for each state and territory: <http://www.familycourt.gov.au/wps/wcm/connect/FCOA/utilities/services/links/Legal>

Adults

Please check with your state and territory on the age at which a person is considered an adult.

In cases where the adult with intellectual disability or developmental disability has been appointed a legal guardian, such as ‘public advocate’, ‘public guardian’, ‘adult guardian’ or ‘statutory health attorney’ by the guardianship tribunal, the legal guardian will not be able to give consent to medical procedures that involve sterilisation. Sterilisation is considered to be a ‘special medical procedure’ and, as such, requires additional consent from a judicial body.

Please contact your local state and territory adult guardian, guardianship tribunal, public advocate departments, or legal aid office for further information. The Australian Guardianship and Administration Council has links to the relevant guardian websites for each state and territory: <http://www.agac.org.au/index.php/Welcome/Links.html>

For Queensland Adults (over the age of 18 years)

- Queensland Civil and Administrative Tribunal <http://www.qcat.qld.gov.au/>
- Queensland Guardianship <http://www.justice.qld.gov.au/17.htm>
- The Public Trustee of Queensland <http://www.pt.qld.gov.au/services/guardianship.htm>
- Legal Aid Queensland <http://www.legalaid.qld.gov.au/>

Further Reading:

Therapeutic Guidelines Limited 2005, ‘Legal issues-consent and guardianship’ in Therapeutic Guidelines Limited (eds), *Management Guidelines Developmental Disability*, 2nd edn, Therapeutic Guidelines Limited, North Melbourne, VIC, pp. 215-221.

Commentaries on the topic of sterilisation of women with intellectual disability:

Brady S, Briton J & Grover S 2001, *The Sterilisation of Girls and Young Women in Australia: issues and progress*, Australian Human Rights Commission.

http://www.hreoc.gov.au/disability_rights/sterilisation/sterilisation_report.pdf.

Brady, SM, Grover, S 1997 *The sterilisation of girls and young women in Australia - a legal, medical and social context*, Federal Disability Discrimination Commissioner for the Human Rights and Equal Opportunity Commission. <http://www.wwda.org.au/brady.htm>.

Queensland Advocacy Incorporated, *Position statement relating the sterilisation of people with disability*. http://www.gai.org.au/documents/doc_175.pdf

Family Court of Australia 1998 *A Question of Right Treatment - the Family Court & Special medical procedures for children; an introductory guide*", Family Court Australia
http://www.familycourt.gov.au/wps/wcm/resources/file/eba9c049d2a7cc1/Question_of_right_treatment.pdf

Medical Approaches

Introduction

This information about medical approaches to menstrual management for women of all ages with intellectual disability, has been summarised from written information and from talking to a range of parents, other care providers and medical practitioners.

An overall difficulty with these approaches appears to be that most of them are rarely, if ever, used with very young women with the exception of those with intellectual disability. Properly documented long term follow up (20 or 30 years later) concerning the effects of prolonged use of these drugs, or of surgery with very young women, does not appear to have occurred.

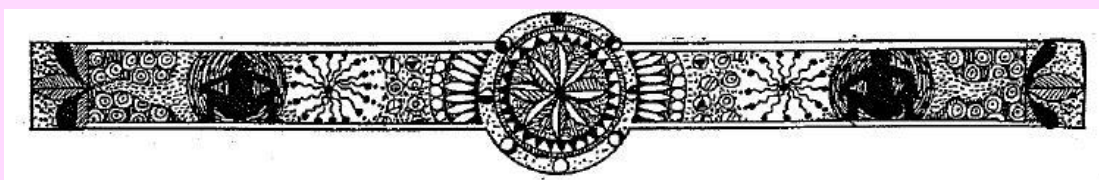
While it cannot be assumed that there will be negative long term effects, it also cannot be assumed that there will not be negative long term effects, from these approaches.

An additional consideration for many young women with intellectual disability, is their difficulty in communicating specific details about their discomfort (e.g. headaches, nausea, depression, anxiety), resulting either from menstruation, or from effects of medical approaches. Long term effects may be particularly difficult to detect by observation alone.

Some people suggest that menstrual regulation or suppression can be used on a short term basis to enable young women to become more emotionally mature, and perhaps to develop more skills. Menstrual regulation on a short term basis is suggested by some people to allow predictability for all concerned.

A number of people working with women with intellectual disability have observed that women in this group do not often have difficulties associated with periods or their management.

Contraception or sterilisation does not eliminate the risk of sexual abuse or sexually transmitted diseases. *The Management Guidelines: Developmental Disability* 2005 suggest, in addition to contraceptive advice, teaching about relationships and protection from sexually transmitted infections (STI), and especially the use of condoms, and education about the right to say 'no' should be in conjunction with contraceptive use. Furthermore, removing the consequence of potential pregnancy may also increase the risk of sexual abuse or STIs.



Key References and Further Readings:

eTG complete 2005, 'Women's health' in Therapeutic Guidelines Limited (eds), *Management Guidelines Developmental Disability*, 2nd edn, internet, Melbourne: Therapeutic Guidelines Limited

<http://etg.tg.com.au.ezproxy.library.uq.edu.au/conc/tgc.htm?id=8f554de80cf707b7bf5b758e83b4dd46>

Sexual Health & Family Planning Australia 2008, *Contraception: an Australian clinical practice handbook*, 2nd edn, Sexual Health and Family Planning Australia, Canberra. This can be purchased online at Family Planning Queensland

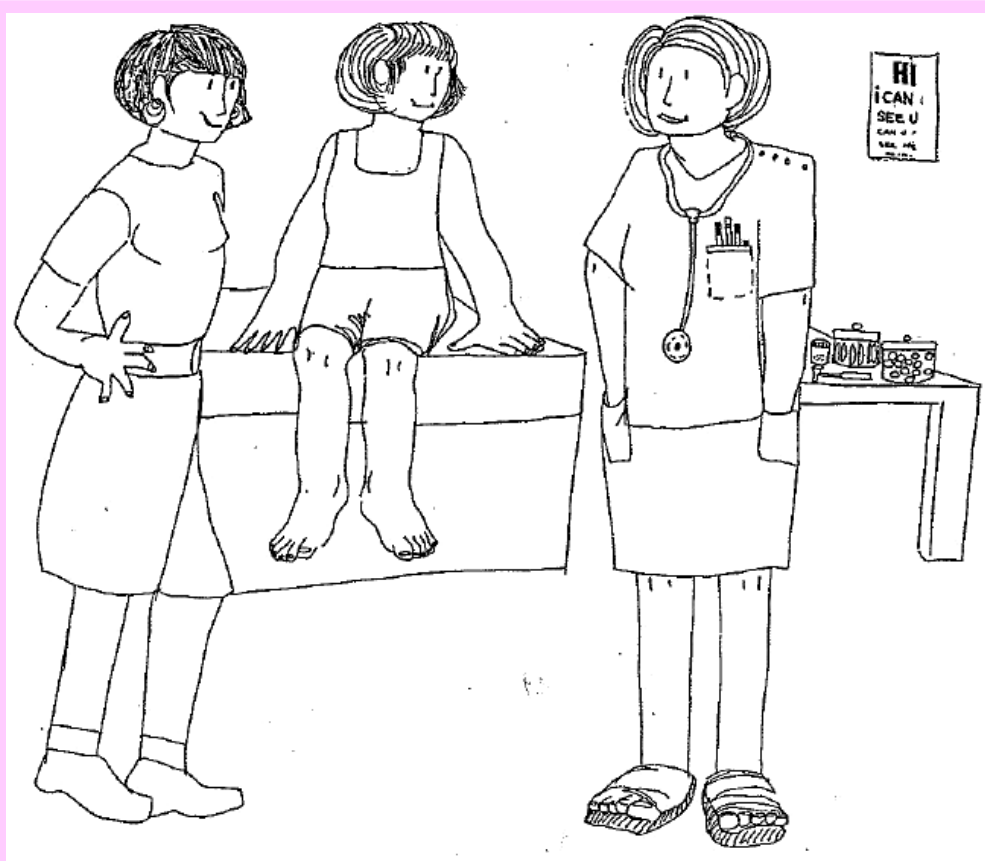
http://www.fpq.com.au/publications/teachingAids/Contraception_handbook.php

MIMS Online database, CMP Medica 2010, <https://www.mimsonline.com.au/Search/Search.aspx>

World Health Organisation 2008, *Medical Eligibility Criteria for Contraceptive Use 2008 Update*, WHO, Geneva, http://apps.who.int/rhl/fertility/contraception/mec_update_2008.pdf

Family Planning Queensland Factsheets

http://www.fpq.com.au/publications/fsBrochures/menu_contraception.php



Hormones

The following female hormonal preparations are used by some women who do not have disability to manage their menstruation and/or fertility. It is not common among the general population for a very young woman to use female hormones for an indefinite time.

“The Pill”

“The Pill” is a widely used contraceptive, particularly in Australia.

The “Contraceptive Pill” is usually a combination of substances similar to the two female hormones, oestrogen and progesterone. While taking “the Pill” there is only a very small chance of a pregnancy occurring, and periods are usually lighter and more regular, that is, they start at a predictable time.

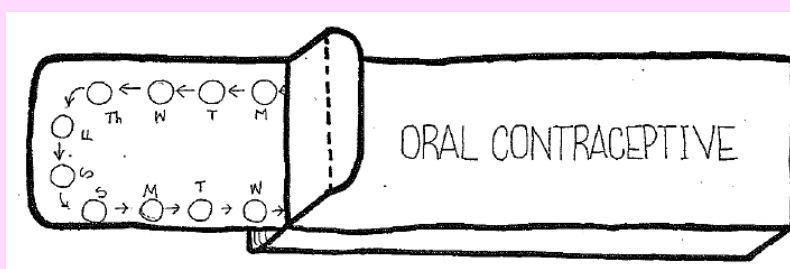
According to the MIMS drug manual, possible short term physical effects of the “the Pill” include sore breast, abdominal cramps and swelling, headaches, nausea, weight changes, increased vaginal infections, tiredness and depression. It is not stated how common these effects are, but they are certainly not experienced by all women. Usage of the “the Pill” can stop at any time, especially if side effects are occurring.

Common problems associated with combined oral contraceptive pills, are: nausea, breast tenderness, bloating and fluid retention, dysmenorrhoea, menstrual migraine, decreased libido and breakthrough bleedings. All these common problems can be managed by altering the concentrations of hormone substance in “the pill”.

eTG complete 2009, ‘Hormone Contraception for Women: Combined Oral Contraception’ (eds),
Therapeutic Guidelines: Endocrinology, 4th edition
<http://etg.tg.com.au.ezproxy.library.uq.edu.au/conc/tgc.htm?id=8f554de80cf707b7bf5b758e83b4dd46>

“Breakthrough bleeding” or spotting between periods may occur while taking “the Pill” especially if one is taken late or missed. Possible long term risk factors include blood clotting and health and liver problems. There is strong evidence to suggest that the risk associated with oral contraceptive use is *venous thromboembolism* and this increases with age. (‘Combined Oral Contraception’ in Therapeutic Guidelines Limited (ed), 2009)

More importantly, coincident disability therefore may be a contraindication to the use of the “the Pill”, such as immobility, past cardiovascular accidents and deep vein thrombosis (‘Women’s health’ in Therapeutic Guidelines Limited (ed), 2005).



In addition, the World Health Organisation (WHO) medical eligibility criteria update in 2008, states that the contraindications for women are:

1. a previous history of venous thrombo-embolism
2. coronary artery disease
3. cerebro-vascular disease
4. uncontrolled hypertension
5. severely impaired liver function
6. malignancy of breast or genital tract
7. some types of migraines

The MIMS online database, 2010 with particular reference to young women/adolescents and combined oral contraception produced by Pfizer, stated: "Because oestrogens may hasten epiphyseal closure [that is, the permanent stopping of growth of bones], oral contraceptives should be used judiciously in young patients in whom bone growth is not complete."

Bone density is especially important during adolescents (puberty until to ages of 18-26 years) because it increases the most during this time period. Research into the long term effects of combined oral contraception on bone density in young women/ adolescents is still limited and the relationship remains unclear (Pitts S AB & Emans S J 2008, 'Controversies in contraception', *Current Opinion in Paediatrics*, vol.20, pp.383-389)

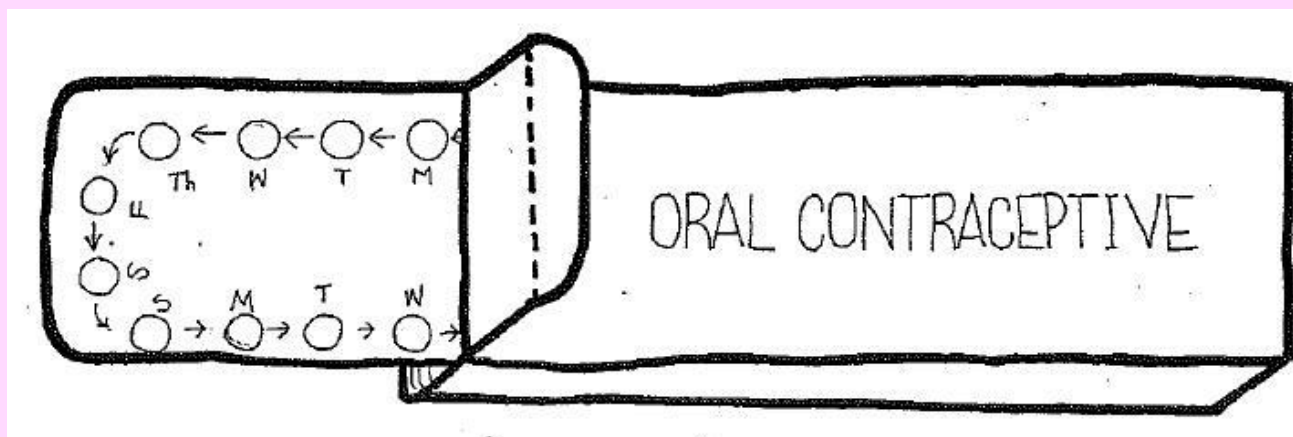
<http://journals.lww.com/co-pediatrics/pages/articleviewer.aspx?year=2008&issue=08000&article=00004&type=abstract>

However, a longitudinal comparison of bone mineral density (BMD) in 370 young women (12-18) showed that low dosage estrogen causes significant reduction of bone density in young women compared with those not on Oral Contraception. (Cromer BA et al 2004, 'Depot Medroxyprogesterone Acetate, Oral Contraceptive and Bone Mineral Density in a Cohort of Adolescent Girls', *Journal of Adolescent Health*, vol. 35, pp.434-441)

[http://jahonline.org/article/S1054-139X\(04\)00190-9/abstract](http://jahonline.org/article/S1054-139X(04)00190-9/abstract)

"The Pill" can affect or be affected by other drugs such as epilepsy medications (anti-convulsants) and antibiotics. Women taking "the Pill" (Pfizer) who have "epilepsy, migraine or asthma, cardiac or renal dysfunction may be influenced by oral contraceptive therapy."... Therefore women with these conditions should be using the pill with caution. (MIMS Drug Manual, Online version, 2010)

As some young women may be reluctant to swallow tablets, prescription of the "the Pill" may not be practical.



The “Continuous Pill” is a term sometimes used to describe the use of the “Contraceptive Pill” continuously without a monthly break, that is, without the use of “sugar pills”. Some women use this occasionally to avoid the occurrence of menstruation during special occasions and sporting events. Effects experienced in addition to those of the “the Pill” include the suppression of periods, although “breakthrough bleeding” (breakthrough menstrual flow) may occur. The “Continuous Pill” appears to be used by very few women on a long term basis.

John Guillebaud (1989, pp. 78-79) raises the following concerns:

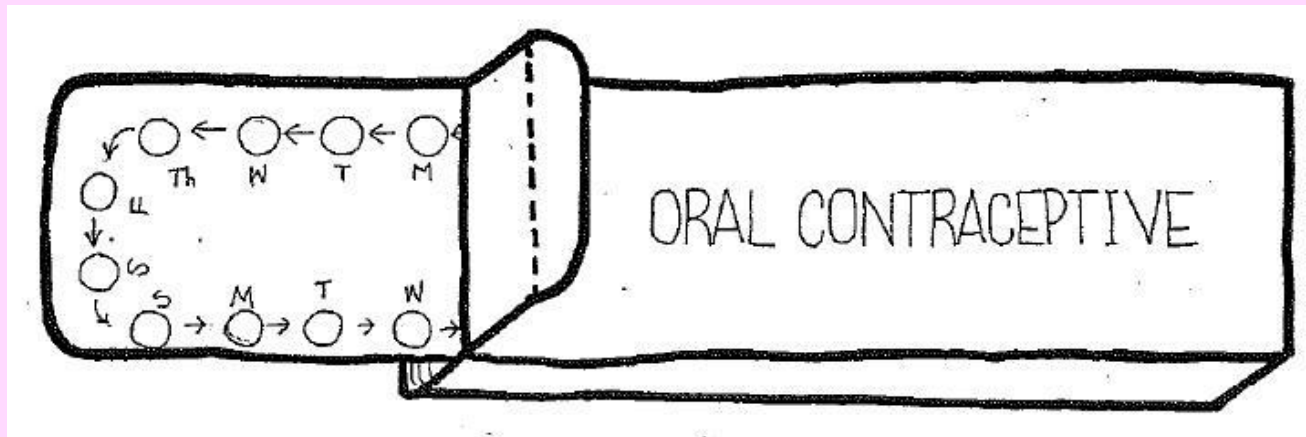
“It is clear that having regular pill free intervals ... is of greater importance than is implied by the simple imitation of the normal menstrual cycle and the regular reassurance of withdrawal bleeds. It leads to a smaller total quantity of artificial steroids being ingested per year than if no break were taken. But possibly more significant, more metabolic variables (such as cholesterol concentrations) altered by the combined oral contraceptive pill, show a tendency to return to normal by the end of the pill free week... it implies a possible important benefit to reversibility, as a consequence of the monthly “rest” from systemic actions of the method.”

Tri-cycling packets of oral contraception are available in Australia, which runs 4 cycles of active hormonal pills (consecutive 21-day packs) followed by 1 placebo pill for 7 days. This form of prescription OC is used to minimise the number of periods per year. Menses can be reduced to 3 or 4 times a year. There is concern about the long term effects of extended cycle compared to the traditional cycle, however long term research into this area has not yet been undertaken.

Contraception: an Australian Clinical Practice Handbook, 2nd edn, 2008, pp.79 states:

“[There is] a theoretical concern of more serious side effects [of tri-cycling packets of OC] because the woman is taking 25% more hormones than required for contraception. An associated increase in serious side effects, while not expected, cannot be excluded.”

Furthermore, the *Management Guidelines: Developmental Disability*, 2005, pp. 200, recommends that the pill should not be taken continuously for more than 12 weeks due to the benefits of the pill-free interval (7 days of placebo) to return lipid and coagulation values to back to normal.



The “Mini-Pill” contains progesterone-like substance only. Some of the “Mini-Pills” have been associated with the effects mentioned above in the “Combined Pill”, others have not. Interactions with some epileptic drugs can occur with the “Mini-Pill”.

- ✧ The “Mini-Pill” needs to be taken very close to the same time every day.
- ✧ One of the adverse effects of the “Mini-Pill” is the effect it has on the menstrual cycle. Bleeding irregularities include amount, duration, cycle length of the menstrual flow. As with the combined oral contraceptive pill, breakthrough bleeding and spotting can occur. Amenorrhoea [periods stopping] could also occur. These adverse effects are variable. (Adapted by the MIMS online, 2010 & Family Planning Queensland factsheets)
- ✧ There is a slightly higher chance of pregnancy occurring with the “Mini-Pill” than with the “Combined Pill”. It appears that this “chance” refers to women who are sexually active.
- ✧ If a woman ceases to use the contraceptive pill it may take up to two years for her menstrual cycle to stabilise.

Drug Interactions with “the Pill”

Drugs which may increase oral “Contraceptive Pill” concentration	Ascorbic Acid (Vitamin C)
A number of medications have been known to decrease the effectiveness of contraception Pills. These include liver enzyme inducing antiepileptic drugs.	Phenytoin, Carbamazepine, Oxcarbazepine, Barbiturates (Phenobarbital/Phenobarbitone), primidone, topiramate, and some anti-retrovirals. (eTG complete 2007, ‘Neurology drugs that reduce the efficacy of oral contraceptives (Table 7.17)’ in Therapeutic Guidelines Limited (eds), <i>Therapeutic Guidelines: Neurology</i>, 3th edn, [internet], Melbourne: Therapeutic Guidelines Limited http://etg.tg.com.au.ezproxy.library.uq.edu.au/conc/tgc.htm?id=8f554de80cf707b7bf5b758e83b4dd46)
Some antibiotics /antifungal can reduce the effectiveness of the oral contraceptive pill. Special concern for liver enzyme-inducing medication.	Rifampin (for tuberculosis) and Griseofulvin (anti-fungal). Contraception: an Australian clinical practice handbook, 2nd edn, 2008, pp. 74
Herbal remedy	St John’s Wort [Popular use in treating mild-moderate depression] has been shown to increase the metabolism of oral contraception and may reduce the efficiency of the oral contraception pill. Contraception: an Australian clinical practice handbook, 2nd edn, 2008, pp. 74
Drugs for pain, cholesterol, anxiety and depression may have their concentrations effected by the oral contraceptive pill.	Clofibrate, Lorazepam, Oxazepam, Salicylates, Temazepam (decrease effectiveness of drug) Benzodiazepine, Beta blockers, caffeine, corticosteroids, Theophylline, Tricyclic antidepressants. (oral contraceptive potential effect of drugs). Cerel-Suhl S, Yeager BF 1999, Update on Oral Contraceptive Pills, <i>American Family Physician</i>, vol. 60, issue 7 http://www.aafp.org/afp/991101ap/2073.html

Drug interactions with the menstrual cycle

Menstrual irregularities may occur due to certain antipsychotic medications.

Women taking *sodium valproate* may be linked to disorders of menstrual disturbances and polycystic ovary syndrome (PCOS) and major tranquillisers (eg *phenothiazine* and *butyrophenones*) can produce hyperprolactinaemia and secondary amenorrhoea (*Management Guidelines: Developmental Disability, 2nd edn, 2005*, pp. 198).

Additional Contraceptive Options:

There are a number of other contraceptives for women being developed, which may become available over the next decade. These include hormonal progesterone based “implants” which can provide contraception for up to 5 years, and a contraceptive which influences the immune system rather than the hormonal system. There has been some controversy about these approaches.

Depo-Provera or Depo-Ralovera

Depo-Provera is a drug that was originally developed to treat problems with the uterus such as endometriosis. It is a progesterone-like drug (active hormone: *Depot medroxyprogesterone acetate* (DMPA)) which is administered by intramuscular injection once every 12 weeks. *Once the injection is inserted the treatment cannot be reversed or withdrawn, until the duration of the contraception.* (*Contraception: an Australian clinical practice handbook, 2008, pp. 96*) Depo-Provera is available for use as a contraceptive in many countries and the World Health Organisation supports its use for contraception.

Depo-Provera has been used to treat problems associated with menstruation in women with intellectual disability (Grover 2002), these include menorrhagia [heavy periods], irregular menses, dysmenorrhoea [painful periods] and contraception.

In the UK, McCarthy (2009) confirmed that the current use of Depo-Provera among women with intellectual disability represents a high proportion of users of Depo-Provera when compared to

general population of women. Her study showed the extent of women with intellectual disability to make 'good' choices about their own reproductive health was limited. Women with intellectual disability currently on Depo-Provera did not understand how the contraception worked or the hazards (adverse effects) of their contraception. In addition, McCarthy (2009) highlights the lack of choice women with intellectual disability are given to the use of Depo-Provera.

Depo-Provera does have a number of important common adverse effects:

- ☼ irregular bleeding
- ☼ weight gain- women who completed four years of DMPA therapy gained an average of 6.3 kg (MIMS online database, 2010)
- ☼ delay in return to fertility
- ☼ headaches
- ☼ breast tenderness
- ☼ acne
- ☼ loss of bone density. (**see information Bone density and Depo-Provera**)

(Adapted by Contraception: an Australian clinical practice handbook, 2008, pp. 95-96)

Other effects can include depression, nervousness, and feeling "unwell". If the person experiences immediate side-effects, it takes several months for the drug to disappear from the body. These changes can be difficult to monitor, especially for a young woman who has difficulty communicating effectively.

Some young women may also experience distress if given injections. If a woman ceases to use Depo-Provera it may take up to two years for her menstrual cycle to stabilise.

While using Depo-Provera there are often no periods, although some people experience "breakthrough bleeding"/menstrual flow. There is very little chance of a pregnancy occurring while using it. No reference to Depo-Provera interactions with epilepsy drugs has been found.

WHO categories on the contraindications to use of DMPA (Depo-Provera):

- ❖ Strong contraindication to use with women with cardiovascular disease, cerebro-vascular accident, current deep vein thrombosis/ pulmonary embolism, migraine with aura, type 2 diabetes with vascular complications and liver disease.
- ❖ not be used with women diagnosed with breast cancer within the last 5 years.

(Adapted by Contraception: an Australian Clinical Practice Handbook, 2nd edn, 2008, pp. 97).

References in this section:

Grover SR 2002, 'Menstrual and contraceptive management in women with an intellectual disability', *Medical Journal of Australia*, vol. 176, pp. 108-110

http://www.mja.com.au/public/issues/176_03_040202/gro10568_fm.html

McCarthy M 2009, 'No Choice? Are women on Depo-Provera being given all the facts?', *Learning Disability Today*, December 2009, pp. 14-16. Available online through subscription

<http://www.pavpub.com/pavpub/magazines/ldt/index.asp>



Adolescents - Bone Density and Depo Provera

In November 2004, the US Food and Drug Administration issued a black box warning about Depo-Provera which stated that:

"[women using Depo-Provera], lose significant bone mineral density. Bone density is greater with increasing duration of use and may not be reversible. It is unknown if use of Depo-Provera Contraceptive Injection during **adolescence or early adulthood**, a critical period of bone accretion, will reduce peak bone mass and increase the risk of osteoporotic fracture in later life. Depo-Provera Contraceptive Injection should be used as a long-term birth control method (e.g. longer than 2 years) only if other birth control methods are inadequate."

U.S. Food and Drug Administration 2004, *Label- Pfizer*, pdf, U.S. Food and Drug Administration

http://www.accessdata.fda.gov/drugsatfda_docs/label/2004/20246s025lbl.pdf

A study by Cromer and team (2004) showed that the bone mineral density in adolescent girls (12-18) using depot medroxyprogesterone (DMPA) was significantly reduced when compared with adolescent girls on oral contraceptive or no hormone treatment, over 12 months (-1.4% compared to 3.8% in non-hormone treatment).

Cromer B, Stager M, Bonny A, Lazebnik R, Rome E, Ziegler J, Debanne S 2004, 'Depot Medroxyprogesterone Acetate, Oral Contraceptives and Bone Mineral Density in Cohort of Adolescent Girls', *Journal of Adolescent Health*, vol. 35, pp. 434-441 [http://jahonline.org/article/S1054-139X\(04\)00190-9/abstract](http://jahonline.org/article/S1054-139X(04)00190-9/abstract)

In addition the Sexual Health and Family Planning Australia recommend that Depo Provera:

“can be used in women **under the age of 18 years** or **over 45 years** but not as first line (that is, where alternative methods have been considered and/or trialled, and are not suitable), a detailed assessment and advice regarding osteoporosis risk factors should be undertaken for new users and every year for continuing users. Note: there is no recommendation to routinely perform bone densitometry during DMPA use.”

(Contraception: an Australian Clinical Practice Handbook, 2 edn, 2008, pp. 99)

A recent cross-section study based on women with intellectual disability, living in nursing homes in Finland showed that women with intellectual disability on progesterone-like contraception had high prevalence of osteoporosis compared to the control group, (57% vs 2%) (Arvio et al 2009).

Arvio M, Kilpinen-Loisa P, Tiitinen A, Huovinen K, Makitie O 2009, ‘Bone mineral density and sex hormone status in intellectually disabled women on progestin-induced amenorrhea’, *Acta Obstetrica et Gynecologica*, vol. 88, no. 4, pp. 428-433 <http://informahealthcare.com/doi/abs/10.1080/00016340902763244>

Another study has shown women with developmental disability using Depo-Provera and/or anti-epileptic drugs had an increase risk of osteoporosis fractures. (Watson & Lentz & Cain 2006).

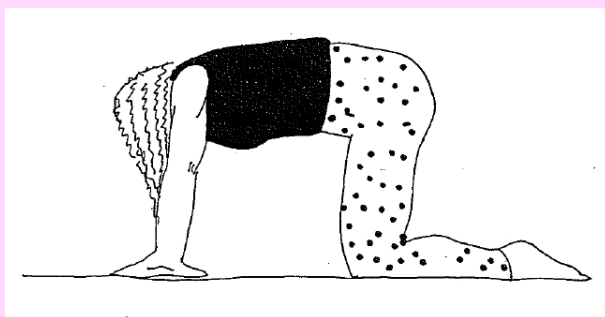
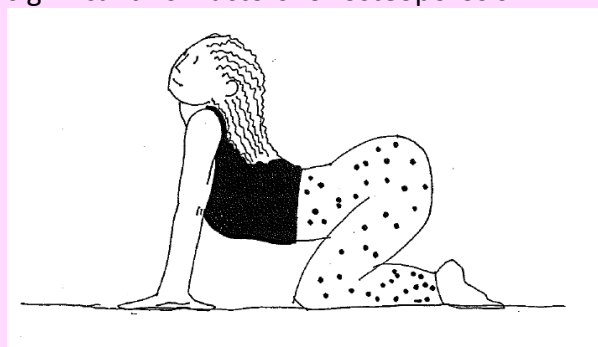
Watson KC, Lentz MJ, Cain KC 2006, ‘Associations between fracture incidence and use of depot-medroxyprogesterone acetate and antiepileptic drugs in women with developmental disability’, *Women’s Health Issue*, vol. 16, pp. 346-352 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1899250/>

There is already an increasing level of osteoporosis in people with intellectual disability. Some of the risk factors associated with osteoporosis in people with intellectual disability are small body weight, impaired mobility, impaired weight bearing, impaired nutritional intake (specifically low levels of dietary intake of calcium) and lack of vitamin D (adapted from Management Guidelines: Developmental Disability, 2005, pp. 73)

The use of Depo-Provera can cause less mobility through increased weight gain, and thus increases the risk of osteoporosis in women who are already immobile. (Albanese & Hopper 2007)

Albanese A, Hopper NW 2007, ‘Suppression of menstruation in adolescents with severe learning disability’, *Arch Dis Child*, vol. 92, pp. 629-632 <http://www.ncbi.nlm.nih.gov/pubmed/17588976>

The Management Guidelines: Developmental Disability, 2005, pp. 200, therefore recommends that if Depo-Provera is not used for longer than 5 years, bone mineral density needs to be monitored, and if bone mineral density (BMD) is low, stop Depo-Provera, particularly if there are other significant risk factors for osteoporosis.



Intrauterine Contraceptive Device

Mirena is a small T-shaped device made of plastic, containing levonorgestrel (a progestogen-like hormone) that is steadily released over time inside the uterus (womb). A trained medical practitioner is required to surgically insert and remove the device in women.

The adverse effect of Mirena as a contraception or menstrual suppression is that **irregular or break through bleeding is common**. Irregular bleeding is reported in the first three to five months of use, but can decrease over the next 6 months. Other studies have shown that in 50% of women, infrequent bleeding occurs by nine months of insertion and 10-15% of women have amenorrhea [stopping of periods]. It is recommended that woman wanting this type of contraception receive careful counselling before the procedure to discuss their ability to tolerate changes in bleeding pattern. This should also be considered in woman with intellectual disability. (**Therapeutic Guidelines: Endocrinology 2009, Chapter: Hormone Contraception for Women: Other hormone contraception devices**)

Pelvic inflammatory disease (PID) risk is higher in users of Mirena and is related to the insertion procedure and background risk of sexually transmitted disease. This exposure can also translate into infertility.

Expulsion or displacement (partially or completely) is the commonest cause of Mirena failure, and occurs more frequently in younger women or women who have never had children. This is because insertion of Mirena through the nulliparous cervix [woman cervix that has never given birth] is difficult. Mirena may not be suitable for these women.

Women with intellectual disability may have communication differences and may not be able to communicate pelvic pain. This may cause delay in detecting symptoms, such as infection after surgery (Albanese & Hopper 2007). Insertion and follow-up checks of correct placement of Mirena may be distressing for women with intellectual disability, because it involves vaginal examinations and procedures. (Management Guidelines: Developmental Disability, 2nd edn, 2005, pp. 196)

References:

Family Planning Queensland 2006, *The progestogen-releasing intrauterine device-Mirena®*, Fact Sheet, Family Planning Queensland funded with assistance by Queensland Health.

http://www.fpq.com.au/publications/fsBrochures/Fs_Mirena.php

eTG complete 2009, 'Hormone Contraception for Women: Other Hormone contraception' in Therapeutic Guidelines Limited (eds), *Therapeutic Guidelines: Endocrinology*, 4th edn, [internet], Melbourne: Therapeutic Guidelines Limited
<http://etg.tg.com.au.ezproxy.library.uq.edu.au/conc/tgc.htm?id=8f554de80cf707b7bf5b758e83b4dd46>

Lethaby A, Augood C, Duckitt K, Farquhar C 2007, *Nonsteroidal anti-inflammatory drugs for heavy menstrual bleeding*, Cochrane Database of Systematic Reviews 2007 <http://www.cochrane.org/reviews/en/ab000400.html>

Marjoribanks J, Lethaby A, Farquhar D 2006, *Surgery versus medical therapy for heavy menstrual bleeding*, Cochrane Database of Systematic Reviews 2006 <http://www.cochrane.org/reviews/en/ab003855.html>

Surgery

The following surgical interventions affect menstruation and/or fertility permanently. For women who do not have a disability, such surgery is not generally considered as a first option in health management.

Hysterectomy

Hysterectomy is removal of the uterus (womb). Sometimes the ovaries are removed as well (overiectomy or oophorectomy). Hysterectomy is a surgical procedure undertaken under a general anaesthetic.

After a hysterectomy there is no chance of pregnancy occurring. No menstrual flow or discomfort directly related to menstrual flow can occur either. Some side effects have been known to occur: immediate effects may include infection or allergic reaction to anaesthetic (not common). Bladder difficulties and damage to the bowel have also been reported.

According the Management Guidelines: Developmental Disability, 2nd edn, 2005, pp. 201:

“The only long-term adverse effect related to hysterectomy with ovarian conservation is a possible lowering of menopausal age by 3 to 4 years. This is possibly due to an alteration in ovarian blood flow. If bilateral salpingo-oophorectomy is performed at the time of hysterectomy, a surgically-induced menopause will occur which is often distressingly symptomatic and in the longer term is associated with the increase risk of coronary artery disease and osteoporosis.”

If ovaries are not removed it is assumed that hormone cycles will continue, therefore the chance of experiencing premenstrual discomfort and cycle-related epilepsy would also continue.

Some research with women who have had hysterectomies in their late 20's or in their 30's has found that for some ovarian function is reduced leading to menopause several years earlier than expected. This may then lead to problems such as “brittle bones” (osteoporosis).

Some research has found that women who have had a hysterectomy, even without the ovaries being removed, have a higher chance of developing heart-related (cardiovascular) disease. The lining of the uterus (the endometrium), excretes substances called prostaglandins. These have been linked by some medical researchers to protection of women from heart related disease. Prostaglandins have also been linked with menstrual “cramps”. The functions of prostaglandins are not yet fully understood.

Research has indicated that women who have a hysterectomy between 39 and 60 years of age are more likely to experience menopausal signs including hot flushes, osteoarthritis, constipation, depression, sexual problems, neurological problems, premature hormone changes, and vaginal dryness. If a woman has a hysterectomy with ovaries removed as well, she experiences instant menopause. Hormone replacement therapy is necessary immediately.

Hormone replacement therapy (HRT) can alleviate menopausal related effects.

Hormone Replacement therapy (HRT)

The long-term use of Hormone Replacement Therapy has been linked to an increase risk of breast cancer, cardiovascular events and stroke.

“Although the benefit of HRT in relieving the symptoms of menopause is well known, the Women's Health Initiative (WHI) study examined the harms and benefits of HRT (oestrogen only or oestrogen plus progestin) in women without menopausal symptoms. The major endpoint of this study was the incidence of disease known, or thought, to be affected by the use of exogenous sex hormones. It should be noted that the results of this study referred to the use of oral oestrogen and progestin of a particular formulation. Neither the benefits nor the harms can be assumed to apply to other preparations or delivery methods.”

eTG complete 2009, 'Long term use of sex hormone replacement therapy' in Therapeutic Guidelines Limited (eds), *Therapeutic Guidelines: Endocrinology*, 4th edn, [internet], Melbourne: Therapeutic Guidelines Limited. <http://etg.tg.com.au.ezproxy.library.uq.edu.au/conc/tgc.htm?id=8f554de80cf707b7bf5b758e83b4dd46>

Information about the effects of HRT on epilepsy and PMS has not been found.

No monitoring of ovarian function after hysterectomy (ovaries not removed) in young women with intellectual disability appears to be occurring.

Emotional or mood responses to a hysterectomy may include depression and changed sexual response. These responses do not appear to have been monitored for women with intellectual disability.

Endometrial Ablation

Endometrial ablation (or resection) is a surgical procedure which involves partial or complete removal of the endometrium (lining of the uterus). The ablation can be limited to an area of the endometrium felt to be related to heavy period flow.

This procedure does not require an abdominal incision, and therefore less post-operative care is required. Heat, lasers, and electrical currents are some of the methods used in the ablation. A general anaesthetic is used.

Since this is a relatively new procedure, long term effects have not been studied. In addition, since one of the functions of the endometrium is to produce prostaglandins, the long-term effects of its removal as in hysterectomy may also apply to endometrial ablation.

Endometrial ablation can result in permanent cessation of periods; however “breakthrough bleeding”/menstrual flow may continue to occur. A second ablation may be necessary in some cases. After endometrial ablation the chances of becoming pregnant are greatly reduced.

Problems which may occur during endometrial ablation include perforation of the uterus and damage to the bowel.

Female sterilisation or Tubal ligation (tying the tubes)

In female sterilisation, the fallopian tubes (between the ovaries and the uterus) are closed off by cutting or clipping. A general anaesthetic is used for this procedure. A very small number of pregnancies have been known to occur afterwards in sexually active women.

Ovulation and menstruation continue to occur. Some women experienced increase menstrual flow afterwards. For some, this increase may occur because they have stopped taking “the Pill”. Some women may require medical intervention. The relationship between tubal ligation and increased menstrual flow afterwards has not been clearly determined.

Some damage to ovarian blood supply, with consequent decrease in ovarian function, has been linked with tubal ligation. However this may relate more to earlier than to current methods of tubal ligation.

Recent research indicates that some adverse side effects may include increased twisting of fallopian tube, endometriosis, and shoulder pain following laparoscopy, menstrual pain, and cervical cancer.

Avoiding Infections

People providing direct assistance to women for menstrual tasks may need to be aware of precautions for avoiding conditions which can be spread through contact with blood. These suggested safe practices enable both the woman and the people assisting them to minimise chances of infection.

Hepatitis B is a virus which is spread via contact with body fluids such as blood, saliva, breast milk, semen and vaginal secretions. Of these, blood poses the greatest risk. Hepatitis B is very contagious. While most people recover from this illness, for some it is very serious, even fatal.

Hepatitis C was discovered in 1988, and is thought to be more common than any of the other Hepatitis viruses. Transmission is not yet fully understood. One way it is known to be spread is by contact with blood. It does not seem to be spread via domestic contact or from mother to baby, in the way Hepatitis B is. The chance of developing chronic infection from Hepatitis C is 20-50%. At present there is no vaccine available.

Human Immunodeficiency Virus (HIV) which usually results in AIDS is a virus discovered in 1981, which affects the body's immune system. As a result, other infections can become serious.

While all people who have the disease are infectious, the HIV virus can be spread by contact with blood, and dies rapidly outside the human body. Infection **cannot** occur via social contact, sharing cutlery, swimming pools or toilets, coughing, spitting, or insect bites.

The risk to health workers of contracting HIV disease is known to be low (less than 0.1% per year of exposure) and has principally been the result of accidental contact with used syringes.

Safe practices to reduce risk of HIV, Hepatitis B or Hepatitis C infection

- **Protective equipment:** When in contact with body fluids such as menstrual flow, or when cleaning areas/items where menstrual flow is present, disposable rubber or vinyl gloves should be worn. Hands should be washed with soap and cold water after removing the gloves. (Hot water coagulates blood and may protect the HIV virus from soap, detergent or bleach).
- **Hand Care:** Always wash hands carefully after assisting with toileting/menstrual care. Use skin cream regularly to avoid drying and cracking of skin. Cover any cuts or abrasions with a water-proof dressing.
- **Laundering:** Wash soiled clothing or linen separately from other laundry. Before washing soiled articles, soak them for 30 minutes in a freshly diluted solution of bleach. Wear gloves to remove solid matter, which should be removed with paper towels; then rinse the

item in cold running water. Rubber household gloves may be washed and re-used, but should be discarded if showing any signs of deterioration.

- **Cleaning of accidental spills:** Wear gloves. Remove as much of the spill as possible with paper towels/tissue. Place these immediately in a plastic bag, tie and discard the bag. Mop hard surfaces with cold water and detergent. Then wipe with freshly-prepared household bleach. For soft surfaces like carpets and rugs, sponge with cold water and soap, rinse, and air to dry. To clean stainless steel, avoid using bleach, as it corrodes. Use 7 parts methylated spirits to 3 parts water. Leave it on the surface for 20 minutes, then wipe off.
- **Disposal of soiled materials:** Place items such as menstrual pads, tampons, dressings, and paper towels into plastic bags, tie, and incinerate. If waste is to be disposed of elsewhere, “double-bag”, tying both plastic bags securely.

Additional approaches to reduce the likelihood of Hepatitis B infection.

- Provision of uncrowded housing.
- Covering of wounds and abrasions.
- Avoidance of sharing of toothbrushes, razors, syringes.
- Protection from insect bites, to reduce possible scratching, which might result in open sores.
- Vaccination (Hepatitis B): this protects about 95% of people vaccinated.

Thinking and deciding about Menstrual Management and Contraception

Any decision made on behalf of another person is difficult. There are no straight forward guidelines. The following suggestions and observations may help people making such decisions.

Think about your own experiences and feelings about menstruation, and about your daughter/student/client:

- Are these affecting the way that you are feeling about her menstruation?

Think about your own ideas about menstruation and your daughter/student/client:

- Are these facts or assumptions?
- How can you check out the facts?

There is a need to weigh up the risks and benefits and to do what is best for your daughter/student/client. However, different people can interpret “risk”, “benefits” and “best” differently.

Is it perhaps important to emphasise the approach that:

- Is most “normal”?
- Is “safest”?
- Is most “comfortable” and “dignified”?
- Affects her body and its processes the least?
- Is “least restrictive”?
- Will be best for her long term “quality of life”?

Once again, all these words can be interpreted differently by different people. For example, does “safety” involve being safe from such things as pregnancy, sexual abuse, immediate side effects, or from long term effects? It is important to think about the following questions:

- What is the problem?
- Who is it a problem for?
- Is it a possible problem, or is it actually happening?
- Might the problem change over time?
- What are all of the possible solution to the problem?
- What are all the effects of the solutions?
- How would I feel if it was me?
- Who will I discuss this with in the family?

- Who will I discuss this with outside the family?
- Would changes to resources or more resources (such as more access to practical support) assist the young woman and/or her family? How could the extra resources be requested and obtained?

Some parents find that the imminent onset of menstruation for their daughter is an emotional time. It can be another reminder of the limitations in lifestyle that their daughter will experience. Sensitivity to these feelings is important.

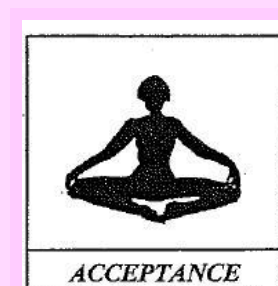


Planning Guidelines for Menstrual Management

This planning guide consist of lists of points which families, school staff, residential staff or others may wish to consider when a young woman is approaching menarche, or encountering difficulties with menstruation. Each set of questions is cross-referenced with relevant information sections of this booklet. It would usually not be necessary to consider all the points for each young woman. Those involved in planning may focus on specific topics relevant to each young woman.

Establishing Aims and Goals

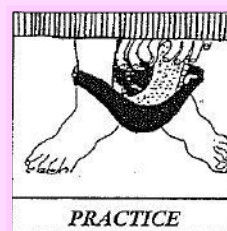
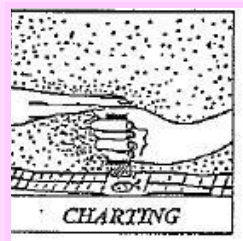
- Is the young woman going to need to use incontinence pads indefinitely, or is using menstrual pads a possibility?
- Might the goal involve assisting the woman to accept her own menstruation and/or to feel comfortable with others assisting her with pad changing?
- Might the goal involve increasing the comfort level of people assisting the woman with pad changing, or changing the pad for her?
- Is long term assistance with pad changing (that is, partial independence), a reasonable goal?
- Is independence in pad changing a reasonable goal?
- How can menstrual management be incorporated into a whole lifestyle approach (e.g. can it link in with daily living tasks, human relationships, and health for each woman)?
- Consistency: do all people assisting this young woman agree about suitable menstrual management goals for her, and strategies for achieving them?



Preparation for Menarche or the very First Menstruation

Can the young woman:

- Be assisted to be aware that other women menstruate (e.g. through videos, observing peers, or observing a family member)?
- Be involved in charting her menstrual cycles (with emphasis on both physical and emotional changes)?
- Experience pad-wearing practice prior to menarche (if not using incontinence pads)?
- Experience pad changing practice prior to menarche (if partial independence or full independence is a goal)?



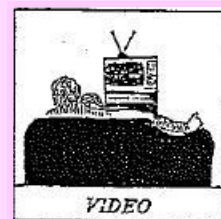
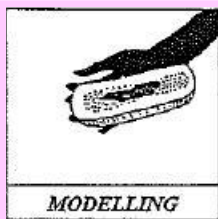
Can menstrual preparation be integrated with positive experiences relating to body/self image and being a young woman (e.g. hair care, hand care etc)?

Can family or staff members be assisted to prepare for menstruation, for example through access to information and opportunity to discuss feelings and issues?

Teaching and General Management Strategies

General

- What prompts will probably be needed initially, and in the long term?
- Could teaching start with part of the process only – e.g. removal and disposal of pads (which may be easier than placing clean pads on underwear) – rather than the entire task?
- Are all people who are involved with the young woman aware of and committed to a consistent management/teaching approach?



Individual Considerations:

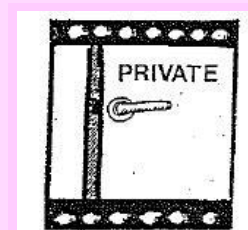
- Would an individualised baseline and task analysis be useful for goal setting and planning? (**see Menstrual Management Planners included in the Menstrual Preparation and Management Kit**)
- How does the woman currently manage her underwear?
- Does she use her hands to grasp and manipulate items in other activities?
- Is she independent in toileting, or toilet-regulated? What kind of assistance does she receive/need?
- How does the woman use a bath or shower? How much assistance does she receive/need?
- How is she involved in hand-washing?
- Can the woman be involved in individualised pad purchasing?



- What kinds of messages does she most readily understand? (e.g. words, objects, signs, symbols) **(see Communication)**

Environmental considerations:

- Where does/will the woman change her pads? Is there variation across regular environments?
- Does she have access to privacy for pad changing?
- Where are the pads stored? Are they easily accessible to the young woman?
- What is the preferred method of pad disposal where the young woman lives/attends school/visit the community? Is there variation across regular environments?
- Are paper bags or newspapers available for wrapping used pads?
- Are disposal bins available inside or very near to the toilet in each of the regular environments?
- Is the opening mechanism of the disposal bin appropriate – would an alternative be more easy-to-use for the young woman?



Choice of clothing:

- Does she have firm-fitting, comfortable underwear?
- Would it be useful to mark underwear to assist with accurate pad placement?
- For some young women, might it be useful to consider some of the underwear developed/home-made for partial incontinence, with built-in pads? **(see Table III)**
- Does outer clothing need to be chosen more carefully during menstruation (e.g long pants or cycling pants rather than dresses)?

Choice of pads:

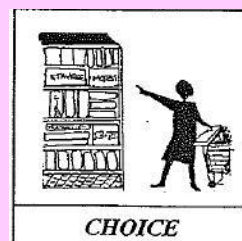
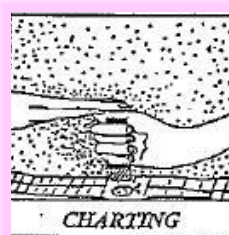
- What size and shape of pad seems to best suit the woman's shape and menstrual flow?
- Might more than one type of pad need to be trialled to find out what is most comfortable or suitable?
- Would pads with different thickness/absorbencies be appropriate for use on different days of periods?
- If the young woman is already using incontinence products, might she need some variation to provide increased absorption during periods/ overnight? (see Table II, III and IV)

For women learning to change pads:

- What sort of packaging are the pads in – easy to open? – individualised?
- How many adhesive strips does the pad have? (Some women may have difficulty using pads with more than one strip.)
- Would it be useful for either the “top” or the “sticky” sides of the pad to be visually identifiable? (Some pads have a coloured marker strip).
- Is the chosen pad tapered? (This may assist or hinder correct pad placement, depending on the young woman's abilities.)
- Is an easily opened toilet bag or shoulder bag needed to carry pads to the toilet?
- Are all people assisting this woman with her pad changing using the same equipment, in the same sequence, and with similar prompting?

Individualising:

- Can individualised charting occur? (Involve the young woman if possible – e.g. with stamps or colour codes. Can charting materials be kept in an accessible but private place?) (see Charting)
- Can the woman indicate her preference for people she wishes to assist her with pad changing?
- Frequency of pad changing may vary from woman to woman and day to day. Is this taken into account?
- Has each woman's preference for type of pad been investigated?



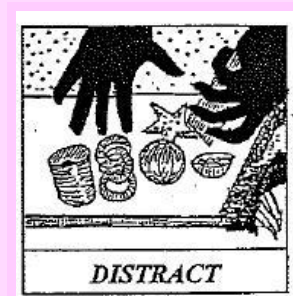
Reviews:

- Are there regular reviews to identify any factors which have changed, and to ensure that the least restrictive approach to menstrual management is occurring?
- Would family or staff members find access to more information about issues and options, helpful?
- Is there a need to clarify what are medical and what are non-medical factors?



Behaviour

- Can frequency, place, antecedent circumstances and current consequences of a behaviour which is causing difficulty be clarified?
- Who is the behaviour actually a problem or an embarrassment for?
- Are the reactions of other people reinforcing a behaviour? (For example, are other people modelling shock/distaste to the sight of blood in general?)
- Are other, enjoyable activities available as an alternative?
- Is pad and clothing comfortable? (Pads can be irritating – some plastic edges are scratchy.)
- Might more frequent bathing or showering help her to feel more comfortable?
- If masturbation is involved – is a private time and place available?
- Is the woman involved in cleaning up (e.g. if she has spread menstrual flow onto objects?)
- Is the woman “picking up negative vibes” from others about menstruation? **(see Cultural Influences and Personal Feelings)**
- Has the woman ever received explanations and skills teaching for menstrual management?
- Would family or staff members be assisted by accessing more information?
- Are all people who assist this woman using a similar approach for behaviour management?



Premenstrual Changes

- Has charting occurred over a number of cycles to clarify indicators, frequency, etc of premenstrual changes?
- In what ways is the woman expressing signs of premenstrual changes?
- If the woman has epilepsy, are cyclical changes in epileptic seizures occurring?
- Could other lifestyle factors be involved? (Lifestyle disruptions – such as loss of a person who is close, change in residence, or significant illness – may result in temporary changes in pre-menstrual stress)
- If cyclical changes are noted, can a range of approaches be identified, including lifestyle approaches, to alleviate the premenstrual discomfort?
- Can daily activities be adjusted to require less involvement of the woman if this appears to be her choice?
- When is it appropriate to seek medical advice, or the advice of an alternative health practitioner? What is expected from this advice?
- Would family or staff members be assisted by accessing more information?
- Are all people who assist this woman using a similar approach for management of premenstrual changes?

Discomfort during Menstruation

- Can care providers think about the reactions of the woman which are felt to indicate discomfort? **(see Communication)**
- How frequent and prolonged does the discomfort appear to be?
- Can the discomfort be identified as pain, or pad related?
- Can a range of approaches be identified, including lifestyle approaches, to alleviate the discomfort? What are the family and staff member's suggestions?

- When is it appropriate to seek medical advice or the advice of an alternative health practitioner? What is expected from this advice?
- Would family or staff members be assisted by accessing more information?
- Are all people who assist this woman using a similar approach for management of her discomfort during menstruation?

Fertility

- Do care providers perceive a need for fertility management?
- Is the woman choosing to be sexually active, or is there concern about sexual abuse?
- Are family or staff members aware of a possible increase in the risk of sexual abuse if fertility management occurs?
- Are family or staff members aware of the identity of possible abusers?
- Is input concerning protective and modesty behaviour, and appropriate behaviour with male acquaintances, needed by the young woman?
- Have risks of sexually transmitted disease been considered?
- What is the “least restrictive alternative” in terms of physiological impact on the woman, if fertility management is decided on?
- Would family or staff members be assisted by accessing more information?

Heavy/ Lengthy / Irregular Periods

- Can perceptions of “heavy flow” by care providers be clarified?
- Do all people assisting her perceive the menstrual flow as heavy?
- Is there a uniform system for observing/recording the amount of flow? (**see “Estimation of Flow” chart at the back of this booklet**)
- Has reliable/accurate charting occurred over a number of cycles?

- Are people aware of the range of flow which is normal, especially for women who are not on “the Pill”? **(see Estimation of Flow Chart)**
- What impact are the heavy periods having on the woman’s health/lifestyle?
- Can practical adjustments be made – e.g. more frequent pad changing, more absorbent pads or incontinence products? **(Table I-IV)**
- How recently was menarche (first menstruation)? Menstruation may be erratic for 2 or more years after menarche.
- Might the woman be approaching menopause? Marked by temporary changes in flow can occur at the time.
- Has the woman been using any form of hormonal medication – menstrual cycles can take some time to “stabilise” during or after the use of these medications?
- Have there been any major lifestyle changes for the woman in recent times? Lifestyle disruptions – such as loss of a person close to the young woman, changes in residence, or significant illness – may result in temporary changes in menstrual cycles.
- If staining is occurring, who is embarrassed – the woman or the care provider?
- Is it possible to anticipate menstruation and provide pads for the day or days before periods are due to start?
- If not possible to anticipate, could it be arranged for pads and a change of clothes to be “on hand”? (Can these preparations be uniform across environments?)
- Can clothing and, if necessary, bedding colour and styles, be adjusted to minimise visibility of stains (e.g. use of dark and/or patterned fabrics)?
- Can daily activities be adjusted to require less involvement of the woman if this appears to be her choice?
- When is it appropriate to seek medical advice or the advice of an alternative health practitioner? What is expected from this advice?
- Would family or staff members be assisted by accessing more information?
- Would “wait and see” be an appropriate approach?

Myths that affect attitudes to Menstrual Management

Myth	Fact
The menstrual flow of women with intellectual disability is “unclean” and different from other bodily function	The menstrual flow of women with intellectual disability is no different from that of other woman. Menstruation is a natural function of women’s lives.
A woman who has an intellectual disability will never understand or learn to manage her own menstruation.	Women with intellectual disability and high support needs, and those who assist them, if given appropriate and realistic education, may be able to accept and manage menstruation.
A woman who has an intellectual disability will have difficulties such as painful or heavy periods, or premenstrual stress.	The occurrence of physiological menstrual difficulties among women with intellectual disability is probably no greater than its occurrence among other women.
A woman who has an intellectual disability and who is fertile is most at risk of pregnancy from sexual abuse by a stranger.	A woman who has an intellectual disability is most at risk of sexual abuse from someone who is known to her. She is at this risk whether or not she is fertile.
Women who need assistance from others to manage their menstruation will find this embarrassing and undignified.	These women may already receive extensive assistance with other self care such as toileting. Any embarrassment may be a reflection of care provider attitudes and feelings.

Developed from the Community Services Victoria’s Menstruation Policy document, 1991.

Readings

General Resources

National Association of People Living with HIV/AIDS <http://napwa.org.au>

Queensland Association for Health Communities <http://www.qahc.org.au> Check your local state or territory government health website for hepatitis program.

Independent Living Centres Australia, <http://www.ilcaustralia.org/> contains information and ways of purchasing assistive technologies to help individuals improve their quality of life.

Disability and Community Care Service supported by the Queensland State Government Department of community, <http://www.disability.qld.gov.au/news-events/>

Avoiding Infections

Australian Federation of AIDS Organisation & National Association of People Living with HIV/AIDS 2007, *Treat yourself right: information for women with HIV and AIDS*, 3edn, resource, Queensland Positive People http://www.qpp.net.au/treat_yourself_right.pdf

A health information resource written for women living with HIV and AIDS
Contains lengthy paragraphs and is more suited for carers to read.

Queensland Health 2008, 'Elements of infection control' in *Infection control guidelines*, health professional resource, CHRISP
http://www.health.qld.gov.au/chrisp/ic_guidelines/sect2_elements.pdf

Suited for carers to read on purpose of infection control, contains relevant sections on avoiding infectious disease. 1. Key principles of infection control. 2. Hand hygiene and 3. Standard precautions.

Queensland Health 2009, *Sexual Health Fact Sheets*, Queensland Health, Queensland
<http://www.health.qld.gov.au/sexhealth/factsheets.asp>. Comprehensive website containing links to factsheets on Hepatitis B, Hepatitis C, HIV/AIDS and other sexually transmitted diseases. It contains animated movies on blood to blood transmission, Hepatitis and the Liver, HIV and the immune system.

Challenging Behaviour

Queensland Centre for Intellectual and Developmental Disability 2006, *Challenging Behaviour Mentoring Programme*, Centre's homepage, University of Queensland
<http://www.som.uq.edu.au/research/qcidd/cbmp.asp>. Local QLD support for carer and people with challenging behaviour. Contact the centre for more information.

Autism Institution 2009, *Autism Institute*, Centre's homepage, University of San Diego,
http://www.sandiego.edu/soles/centers/autism_institute/. A helpful website for carers and families to access information on positive behaviour management, and communication differences with people with autism. Check out the "resource links" page.

Popovich, D 1981, "Chapter 10: Decreasing Inappropriate Behaviour", In Popovich D (eds), *Effective Educational and Behaviour Programming for Severely and Profoundly Handicapped Students: A Manual for Teacher and Aids*, Paul H. Brookes, Baltimore. Check your local state or territory library holdings: <http://trove.nla.gov.au/>, search for "Popovich Dorothy".

McVilly, KR 2002, *Positive behaviour support for people with intellectual disability: evidence-based practice, promoting quality of life*, Australian Society for the Study of Intellectual Disability Inc, Sydney.

Carr, J 2004, *Behaviour Management*, Understanding Intellectual Disability and Health,
<http://www.intellectualdisability.info/mental-health/behaviour-management>.

Presland, JL 1989, *Overcoming difficult behaviour: a guide and sourcebook for helping people with severe mental handicap*, BIMH Publication, England.

Communication

The following references are resource websites, which contain links to resources and information on supporting communication with people with intellectual and developmental disability.

International Society for Augmentative Alternative Communication, <http://www.isaac-online.org/en/about/index.html>.

AGOSCI Inc. an Australian website that represents people with complex communication needs,
<http://www.agosci.org.au/index.htm>.

The following are products and technological tools, which can be helpful for developing communication with people with communication differences.

Computer Pictographs for Communication, 1989, North Balwin, Victoria; Compic Development association.

COMPIC is communication through the use of pictures (pictographs) and each picture represents a concept or word. An Australian developed resource that can be used by teachers, speech pathologies, parents and carers. It is especially designed for people with communication differences. To purchase a COMPIC communication technology resource pack in Australia, please visit Independent Living Center Australia site for more details:

<http://www.ilcaustralia.org/home/search4.asp?state=NSW&page=2&MC=62&MinC=67>.

Picture Communication Symbols, 1992, Fifth Edition. Meyer-Johnston Co. The picture communication symbols (PCS) is an extensive library of graphics to help in communication. For more information on the picture communication symbol resource pack visit: <http://www.mayer-johnson.com/education/symbols/pcs/>.

Walker, M 1985, *Symbols for Makaton*. Blackhill, Ely-Cambridgeshire, U.K. Communication through key words, signs and gestures.

UK website: <http://www.makaton.org/>

Australian website: <http://www.newcastle.edu.au/centre/sed/makaton/whatismakaton.html>

Communication Books

Beukelman, D & Mirenda P 2005, *Augmentative and alternative communication: supporting children and adults with complex communication needs*, 3rd edn, Paul H. Brookes, Baltimore.

Butterfield N, Arthur M, Linfood K, Phillips S 1994, *Creating Communicative Contexts: An Instructional Manual for Teachers of Students with Severe Intellectual Disability*, Department of School Education, NSW.

Butterfield N, Arthur M, Sigafoos J 1995, *Partners in everyday communicative exchanges: a guide to promoting interaction involving people with severe intellectual disability*. MacLeanna & Petty, Sydney.

Sigafoos J, Arthur K, Butterfield N, Foreman P, Green V, O'Reilly M 2006, *Enhancing everyday communication for children with disability*. Paul H. Brookes Pub. Co, Baltimore.

Available from university and educational library services for each state and territory.
(<http://trove.nla.gov.au> search for "Partner in everyday communicative exchanges")

Bloom, Y. (1990). *Object symbols: A Communication Option*. Monograph Series Number One. The Royal New South Wales Institute for Deaf and Blind Children. North Rocks: North Rocks Press.

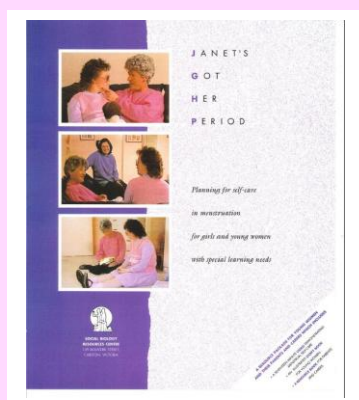
Bloom, Y., Bhargava, D., (2003). *The great ideas manual update: another resource for people with severe communication impairments and intellectual challenges*. Beecroft, N.S.W: Innovative Communication Programming.

Coupe, J. & Goldbart, J. (Eds.) 1987. *Communication before speech*. New York: Croom Helm
Further reading with same author:

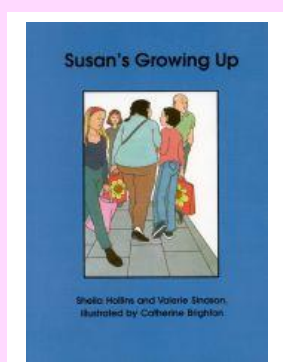
Coupe, J., Goldbart, J. (Eds.) 2nd edition 1998. *Communication before speech: development and assessment*. London: David Fulton.

Van Oosterom, J., Devereaux, K., (1985). *Learning with Rebus Glossary*. Blackhill, Ely-Cambridgeshire, UK.

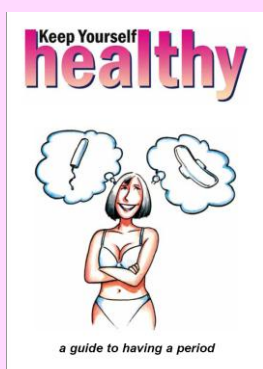
Kits and Manuals



Gray, Judi. & Jilich, Jitka. & Social Biology Resources Centre (Carlton, Vic.) 1990, *Janet's got her period [kit] : a resource package / produced for Social Biology Resources Centre ; project workers Judi Gray & Jitka Jilich* Social Biology Resources Centre, Carlton Vic. The package includes a resource book for parents and care workers; illustrated storybook; pictography for teaching aid. It may be useful for some women, to screen the pad changing sequence in the video. This video was produced for young women with mild to moderate support needs. This video can be used with family or staff members when preparing for a woman's menstruation. Available from Family Planning Australia or check for holdings from National Library of Australia (<http://trove.nla.gov.au/>) search for 'Janet's got her period'



Hollins, S, Sinason, V & Brighton C 2001, *Susan's Growing Up, Shelia Hollins and Valerie Sinason, illustrated by Catherine Brighton*, Gaskell/St George Hospital Medical School, London. This is part of the Books Beyond Words series, developed by the Royal College of Psychiatrists. This is a picture book that can be used with adults or adolescents, with reading difficulties. Available from the Royal College of Psychiatrists, <http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/190124251x.aspx>



Fair/ NHS Health Scotland & Mudie P 2003, *A guide to having a period*

An online brochure developed by the NHS health Scotland. This can be used with women with intellectual disability in explaining menstrual hygiene by using pads or tampons.

<http://www.healthscotland.com/uploads/documents/9744-GuideToHavingAPeriod.pdf>.



Cooke, K 2009, *Kaz Cooke- Books*.

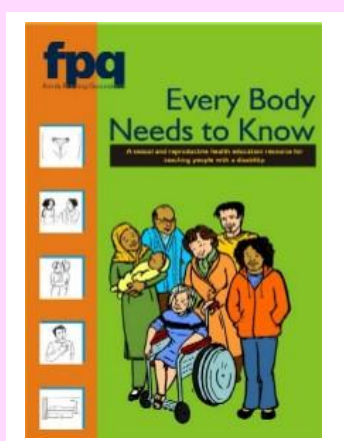
Kaz Cooke writes a variety of books on women's health in a humorous way and also in Australian language. It contains cartoons and pictures. *Girls Stuff* by Kaz Cooke can be a good resource for adolescents with mild intellectual disability, and covers topics on growing up and puberty.

<http://www.kazcooke.com.au/kazcooke/books/>



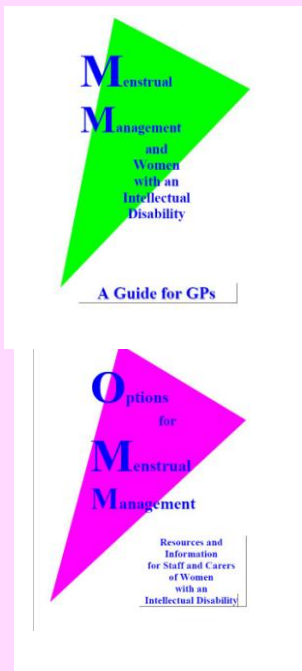
Angelo, Fay. & Pritchard, Heather. & Stewart, Rose. & Davey, Julie. 2005, *Special girl's business / written by Fay Angelo, Heather Pritchard and Rose Stewart ; illustrated by Julie Davey* Secret Girl's Business, North Balwyn, Vic.

An illustrated story book using short sentences to help parents or carers approach menstruation positively with young people with developmental disability. This has been recommended by Family Planning Queensland staff, for teaching women with intellectual disability about menstrual hygiene. The topics covered include changes in a woman's body; periods are private; managing blood flow through the use of pads (step by step instructions); and feelings experienced during menstruation. Check for holdings in your local state or territory library, from the National Library of Australia (<http://trove.nla.gov.au/>) search for 'special girls' business' or purchase directly from Secret Girls' Business (www.secretgb.com).



Family Planning Queensland, revised edition 2007, *Every Body Needs to Know* Family Planning Queensland, Brisbane, QLD. "A sexual and reproductive kit health education resource for teaching people with a disability" Includes sections on periods, managing periods and menopause. Developed to use in practical workshop settings. The kit includes visual aid materials, tips and hints for different disability, workbook questions and exercises. Available to through Family Planning Queensland:

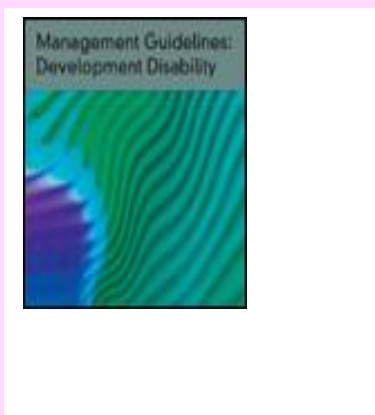
http://www.fpq.com.au/publications/teachingAids/everybody_know.php



Burbidge, Mary. & Butler, Jenny. & Trumble, Stephen. & Centre for Developmental Disability Health Victoria (Monash University), Revised 2003, *Menstrual Management and Women with an Intellectual Disability*, Centre for Developmental Disability Health Victoria (Monash University), VIC.

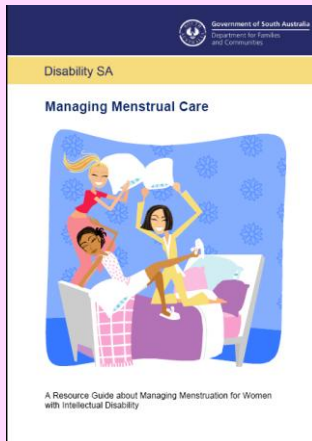
Burbidge, Mary. & Butler, Jenny. & Tracey, Jane. & Centre for Developmental Disability Health Victoria, Revised 2003, *Options for Menstrual Management, Resources and Information for Staff and Carers of Women with an Intellectual disability*. Centre for Developmental Disability Health Victoria, VIC.

These are information resource kits on menstrual management for women with an intellectual disability, composed of two documents available online: <http://www.cddh.monash.org/products-resources.html#menstrual> These are useful guides for the general practitioner (<http://www.cddh.monash.org/assets/menstrual-management-guide-gp.pdf>); staff and carers of women with intellectual disability (<http://www.cddh.monash.org/assets/menstrual-management-guide-staff.pdf>).



Therapeutic Guidelines Limited 2005, 'Women's Health' In *Management Guidelines Developmental Disability*, 2nd edn, Therapeutic Guidelines, North Melbourne VIC

Recently edited book on the management of intellectual and developmental disability written for general practitioners and medical professionals. The chapter on women's health covers onset of puberty, menstrual management, reproduction and contraception, menopause of menstrual suppression. The handbook contains chapters covering challenging behaviour, to developing effective communication within clinical settings and women's health. Available online if you hold a current subscription to eTG complete, <http://www.tg.org.au/index.php?sectionid=93#mozTocId602326>.



Disability SA 2008, *Managing Menstrual Care*, Government of South Australia Department of Families and Communities, online brochure (PDF version).

A reading list developed in collaboration with Disability SA and Occupation Therapy Department of University of South Australia for health professional, carers and families. It contains references to a number of relevant resources and kits that are available to support in managing menstruation with women with developmental disability.

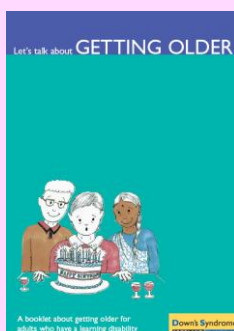
[http://www.sa.gov.au/upload/franchise/Community%20Support/Disability/Information%20sheets%20-%20Disability%20SA/Managing%20menstrual%20care%20\(PDF%20527kb\).pdf](http://www.sa.gov.au/upload/franchise/Community%20Support/Disability/Information%20sheets%20-%20Disability%20SA/Managing%20menstrual%20care%20(PDF%20527kb).pdf).



Smith, L & Perry, G 2005, *A girl's guide to growing up!*, Marsh Film Enterprises, Inc. Kansas City, US.

American produced kit specialized in teaching people with mild to moderate disability about external anatomy; puberty; health and hygiene; safety and privacy. Available to purchase from:
http://www.marshmedia.com/online/product_desc.cfm?ordernum=9242IN&cat=sn

Menopause Kits



Marsden L, Smith G & The Graphics Company n.d. *Let's talk about getting older*, resource, Down Syndrome Scotland.

Available online developed to be used with older women with learning difficulties, to learn about growing older and menopause. It contains illustrated pictures and words.

http://www.bristollearningdifficulties.nhs.uk/synd_conditions/talk-about-getting-older.pdf

Hollins, S, Downer, J & Webb B 2000, *Keeping Healthy 'Down Below'*, Gaskell, London. Is a Books beyond Word series that is developed to be read with women with learning difficulties. This book covers the topic of having a pap smear test.

Available to purchase from <http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242544.aspx>

Resources on Women's health

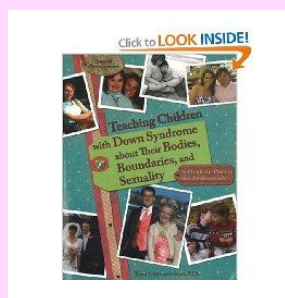
Our bodies, Ourselves 2008, *Our Bodies our selves*, Boston Women's Health Book Collective Inc.

American based women's health resource website that contains useful information on women's health in general. The resource will not be suitable for women with intellectual disability; however will be a helpful resource for carers and parents who wish to learn more about menopause, menstruation and sexual health.

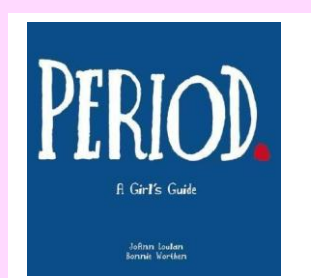
<http://www.ourbodiesourselves.org/>

Women's Health Queensland Wide Inc 2009, *Women's health Queensland Wide Inc- information and education since 1985* <http://www.womhealth.org.au/index.htm>. The Women's Health Information Folder from the Division of Intellectual Disability Services, Queensland Department of Family Services and Aboriginal and Islander Affairs. Contains a range of easily accessible information on women's health based in Queensland and contains a video streaming on a range of women's health issues, http://www.womhealth.org.au/videostreaming/vs_index.htm

Books on Puberty (including menstruation)



Couwenhoven, T 2007, *Teaching children with Down syndrome about their bodies, boundaries, and sexuality: a guide for parents and professionals*, Woodbine House, Maryland, US. This is a resource developed for parents and carers to help them prepare and teach children with developmental disability (specifically Down syndrome but not limited to), about puberty, boundaries and sexuality. Chapter 5: “Teaching your child about physical changes of puberty” contains extensive information on how to teach young women with developmental disability about menstruation and menstrual hygiene. Also includes tips to manage menstrual hygiene problems accounted when learning. It covers step by step instructions to help teach young women about pad changing. Check for holdings at the National Library of Australia (<http://trove.nla.gov.au/>) for your state or territory, or available to purchase through Amazon or Google Books.



Gardner-Loulan, J, Lopez, B, Wold, DC, & Quackenbush, M 2001, *Period: a girl's guide to menstruation with a parent's guide*, Revised and updated, Book Peddlers, Minnetonka, MN, US. This is a mainstream book on periods, which can be read with young women with mild intellectual disability. It might be difficult for young women with intellectual disability to read, as it contains a lot of words. It does have a number of illustrated pictures. Available at good book stores or check your local libraries.

Internet Video Streaming on Menstruation

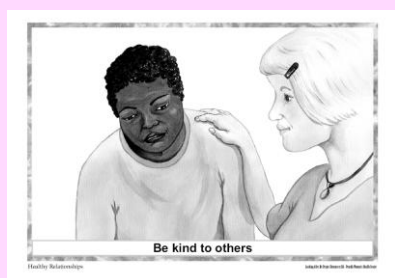
AVERing HIV and AIDS 2009, *Puberty, periods and girls*, Avert.

<http://www.avert.org/aids-hiv-charity-avert.htm>. Information on puberty and menstruation, developed for young women and adolescents. Suitable for young women with mild learning difficulties, which contains a YouTube link to UK Channel 4's program: Embarrassing Bodies on menstruation.

Prevention of Sexual Assault

Protective Behaviour Australia Inc, 2008, <http://www.pbaustralia.com/>. Contact your State and Territory about kits and manuals on preventative protective safety programs.

<http://www.pbaustralia.com/contact.html>



Dunnett, Maeve. & Pitty, Jennifer. & Penrith Women's Health Centre, 2008, *Looking after me resource kit* Penrith Women's Health Centre, Penrith, NSW. Free online access and use:

http://www.whnsw.asn.au/Looking_After_Me/Resource-Looking_After_Me.htm

Resource kit including stories and large visual aids on "issues relating to healthy relationships and domestic violence to women with intellectual disability"

Resources

Anatomically Correct Dolls can be helpful to teach women with intellectual disability about menstrual management. The dolls can come in all shapes and sizes with underwear and clothes included. “Homemade” pads (cut up pads) can be used to illustrate what it means to change a pad. These are available at your local Family Planning Association, <http://www.shfpa.org.au/>. The anatomically correct dolls can also be purchased online at Teach-a-body, <http://www.teach-a-bodies.com/>

Communication:

For further assistance with communication problems it is best to contact a speech pathologist. They have skills and training to help with communication differences.

Speech pathology Australia 2009, *Speech Pathology Australia*, <http://www.speechpathologyaustralia.org.au/>

Disposable incontinence products:

These are readily available in supermarkets and pharmacies. Factors to consider include the capacity of the product, the size offered, its comfort, cost and biodegradability. Re-usable incontinence systems can be used in conjunction with disposable products. “Mix and Match” the products, for example a disposable pad with a shield/waterproofed pants, or reusable pad with a shield/waterproofed pant.

The Continence Foundation of Australia, <http://www.continence.org.au/> is a website designed for promotion, management and advocacy for continence in Australia; it contains helpful information on a range of products available (these include disposable, re-usable and ‘special’ pants for use in incontinence.)

In addition, contact your local Independent Living Centres Australia, <http://www.ilcaustralia.org/>.

Alternative to disposable pads:

There is a range of cloth-made reusable pads. They can come in a range of different colours and styles, and are good for those that have allergies to disposable pads.

When using it with women with intellectual and developmental disability, it is important to teach them when to change the pad as it might be harder to visually see, where to place them (for

laundering) and how to clean the pads properly (if they are to do so). The absorbance may not be suitable for some with a heavier menstrual flow, and the clip on wings may be harder for those with less dexterity.

Australian products:

Rad-pad, <http://www.radpads.com.au/>

We-moon natural menstrual pads, <http://www.wemoon.com.au/>

Moon Pads, <http://www.thenaturalcompany.com.au/>

UK products:

Organic Washable Pads: www.moontimes.co.uk

Disposable Pad Products

Things to consider when looking for the right pad for women with intellectual and developmental disability.

Size and shape of the pad	➤ Is the pad the best suited for the woman's shape and menstrual flow? ➤ Is a tapered pad better for her? ➤ wings or non-wings?
Absorbency	➤ Which pads with different thicknesses/ absorbencies are appropriate for use on different days of the periods?
Comfort	➤ Does she prefer thick or thin pads? Or some pads can be irritating with some plastic edges scratchy.
Allergies to disposable pads	➤ Sometimes the scent or plastic uses can cause an allergic reaction.
Packaging	➤ Is the design of the packaging easy for the woman to remove from the package? ➤ Is it easy to remove the plastic adhesive strip? Less adhesive strips to remove, might make it easier for women with intellectual disability to manage.
Design	➤ Are the 'top' and the 'sticky' sides of the pad visually identifiable?
Cost	➤ Will it be cost effective?

Exercises to Relieve Menstrual Discomfort

Please Note:

BE GENTLE!

DO NOT Force!

Any sign of discomfort, DO NOT proceed!

If in doubt, consult a physiotherapist.

When doing floor exercises, use a soft floor surface.

It is important to explain each exercise to the young woman by using words and other forms of communication appropriate to her.

Some ideas are given in the following exercises.

Exercise One

Lie comfortably on your back with knees raised and feet on the ground.

Relax.

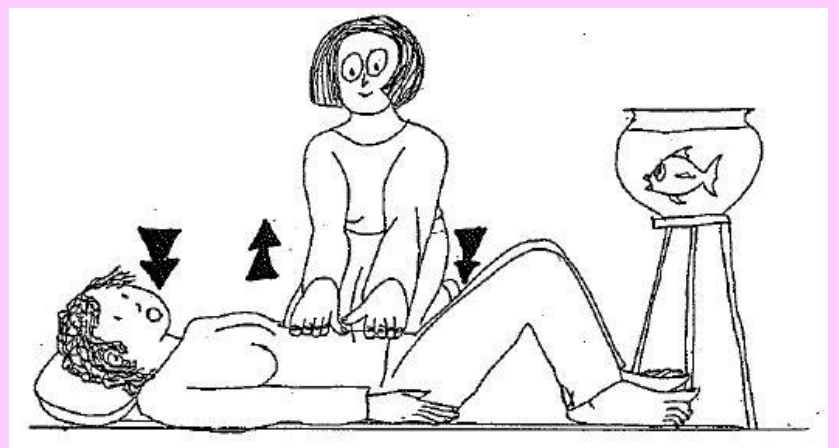
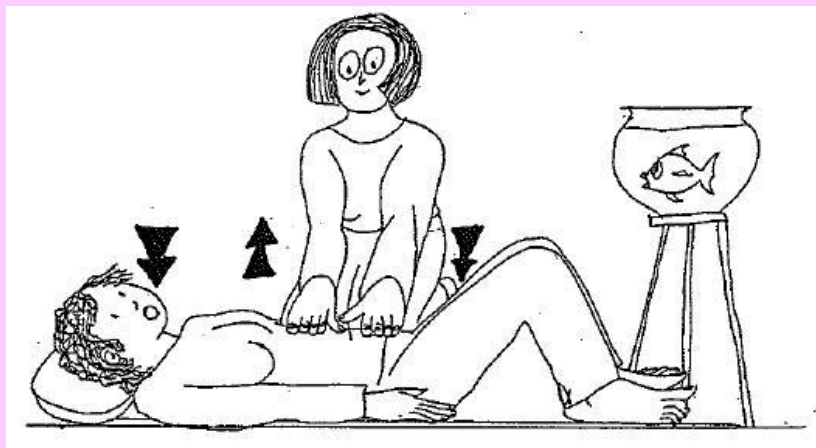
Breathe deeply and slowly.

Put your hands on your stomach.

As you breathe out, your hands will move down.

As you breathe in, your hands will move up.

Repeat this exercise four times.



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

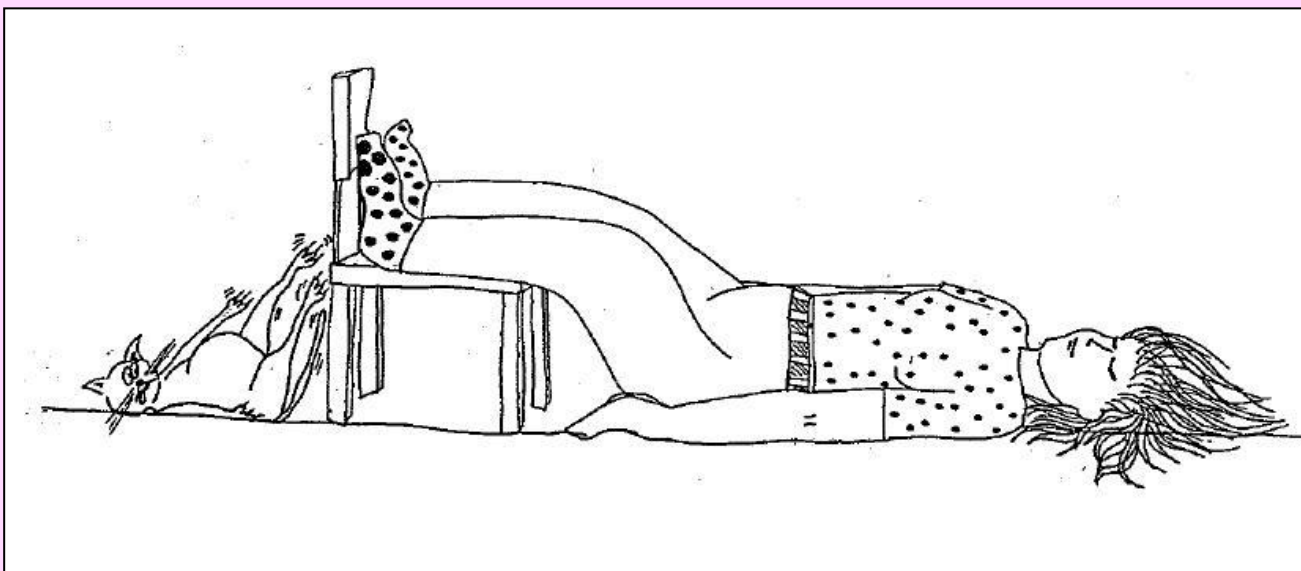
Exercise Two

Lie comfortably on the floor.

Your assistant places your legs on a chair or foam cylinder.

Your legs are supported from knee to heel.

Lie comfortably for about ten minutes.



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Three

Lie comfortably on your back.

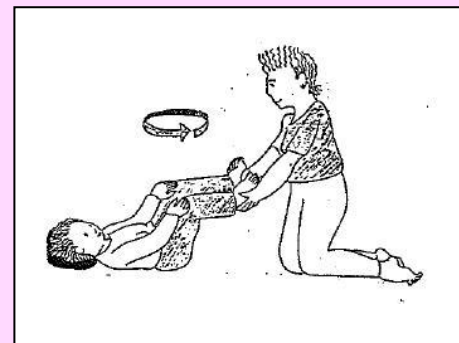
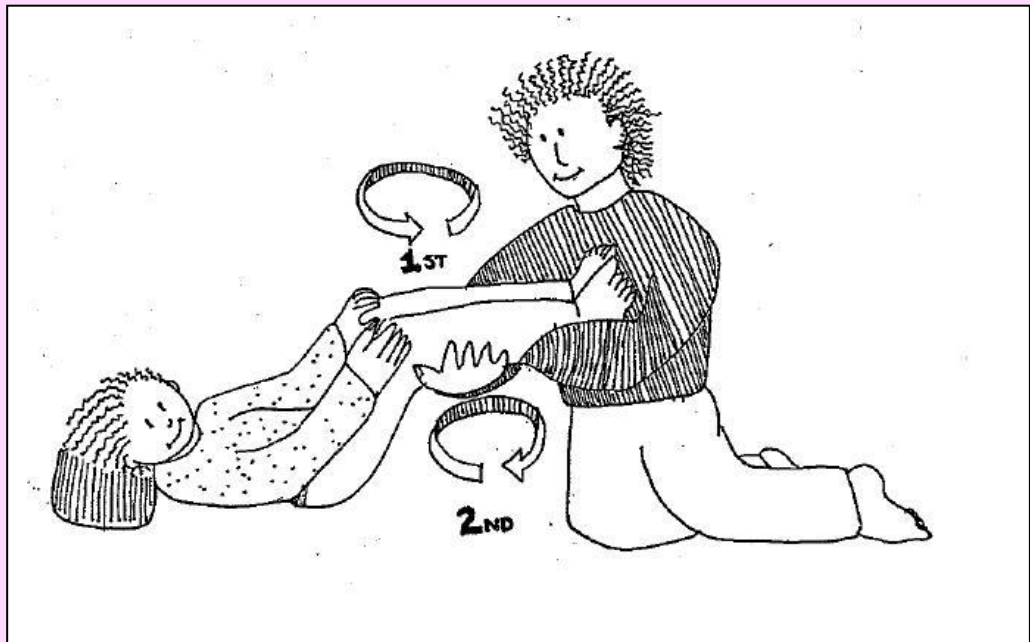
Place a pillow under your head.

Your assistant places one of their arms under your knees and their other one under your ankles.

Your legs are moved in small circles.

First in one direction and then in another.

[For women who are unable to hold their knees together, more than one assistant may be needed]



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Three

Lie comfortably on your back.

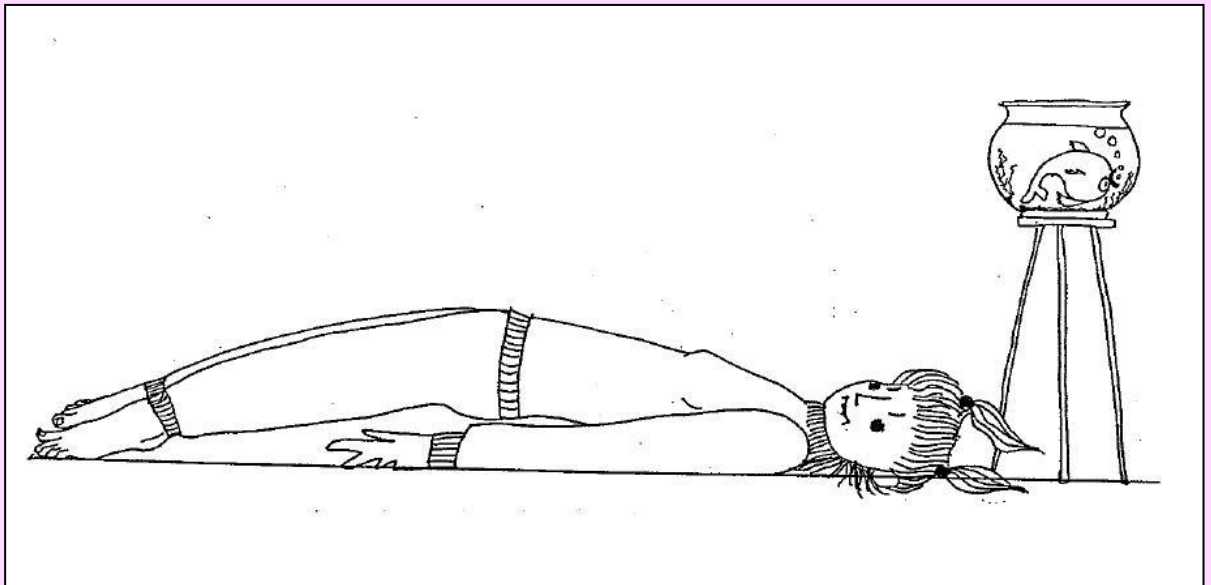
Lift your bottom off the floor.

Slide your hands underneath your bottom.

Or use your hands on the floor to push your bottom off the floor.

Hold for 5-10 seconds only.

Repeat this 5 times.



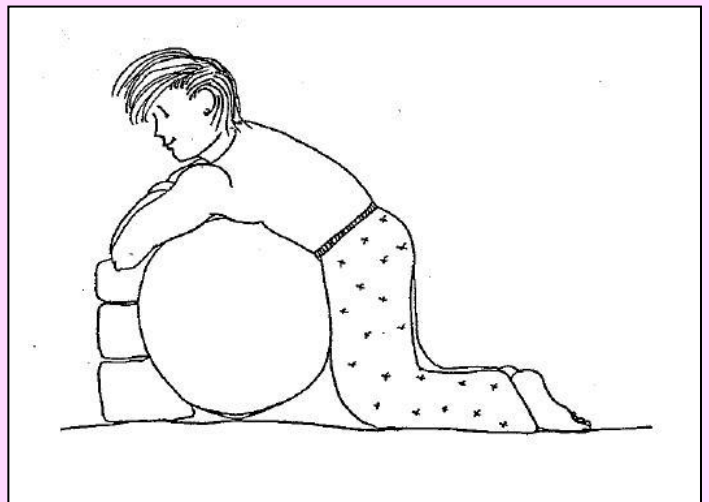
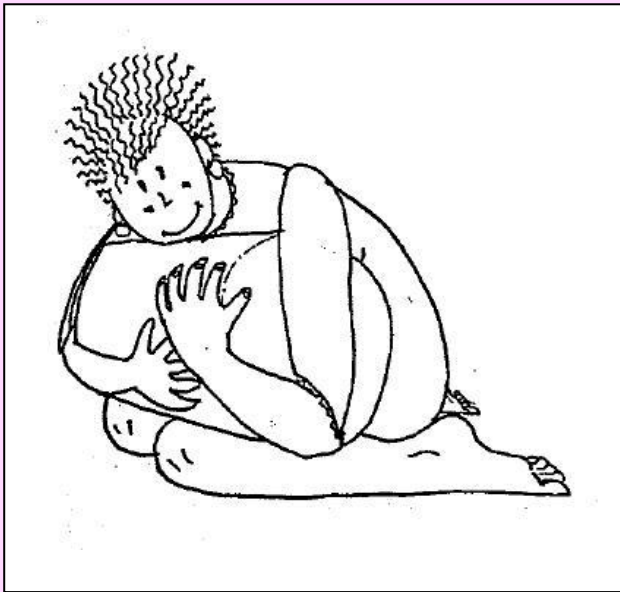
Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Five

Kneel down and hug a pillow, or beanbag or big covered foam cylinder like a Rompa Roll.

Your assistant places a warm pack on your lower back.

You may be able to watch television or listen to some music while doing this.



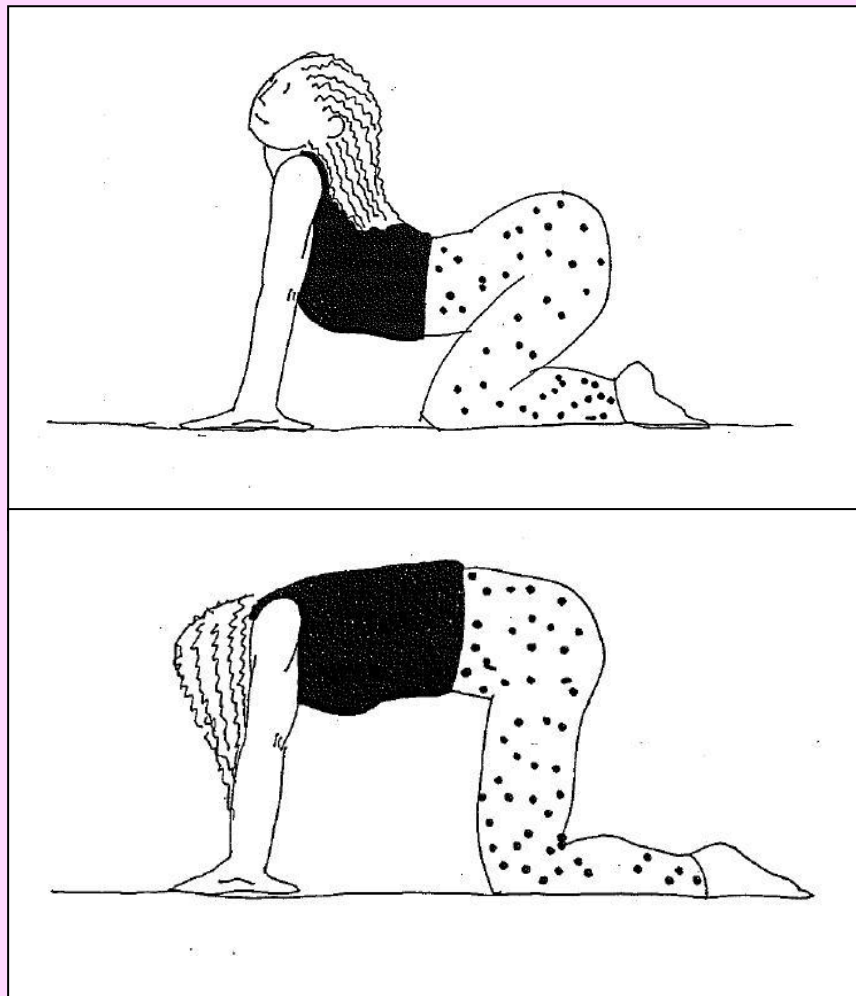
Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Six

Kneel down with hands and knees on the floor.

Your assistance helps you to comfortably arch your back like a cat, first upwards, then downwards.

Repeat this four times each way.



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Seven

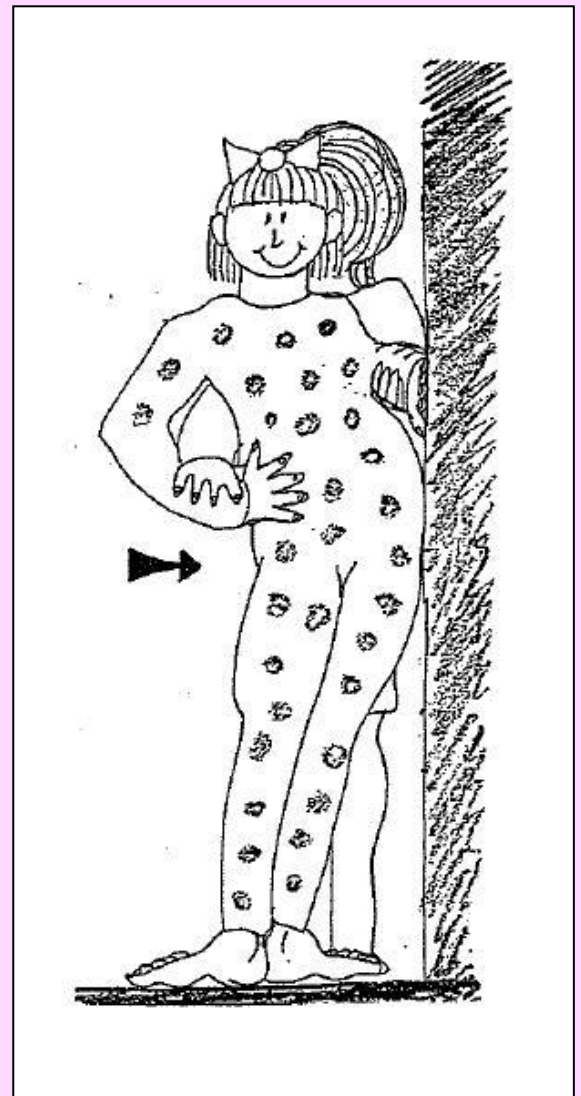
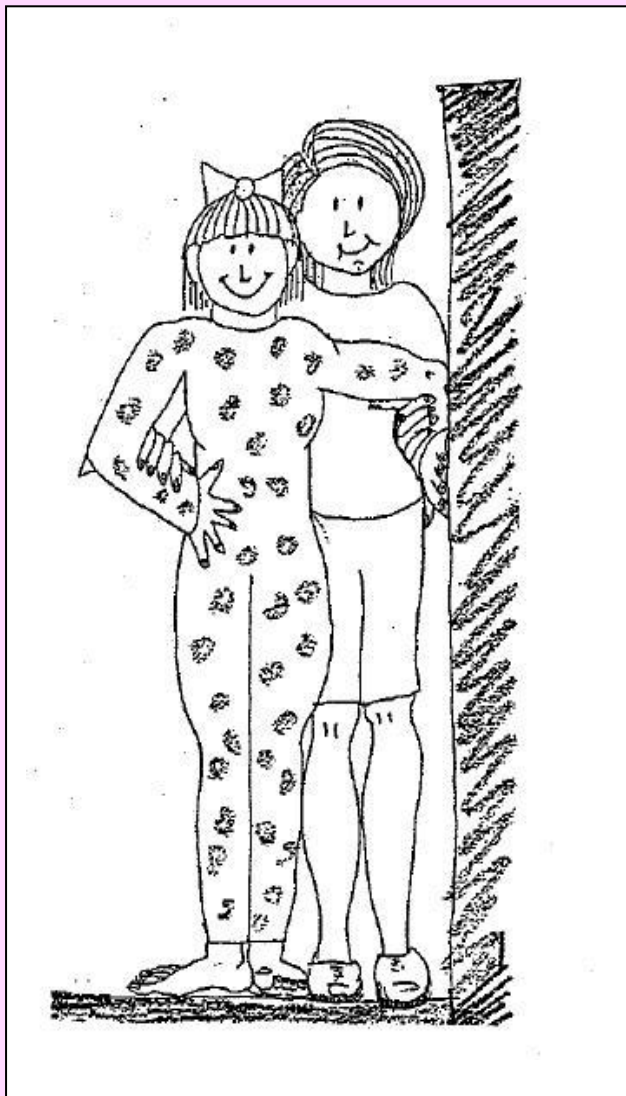
Stand with your arm elbow to palm against the wall, and the other hand on your hip.

With feet flat, try to touch your hip to the wall.

Repeat this four times.

Turn around and use your other hand and hip.

Repeat the exercise on this side four times.



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Eight

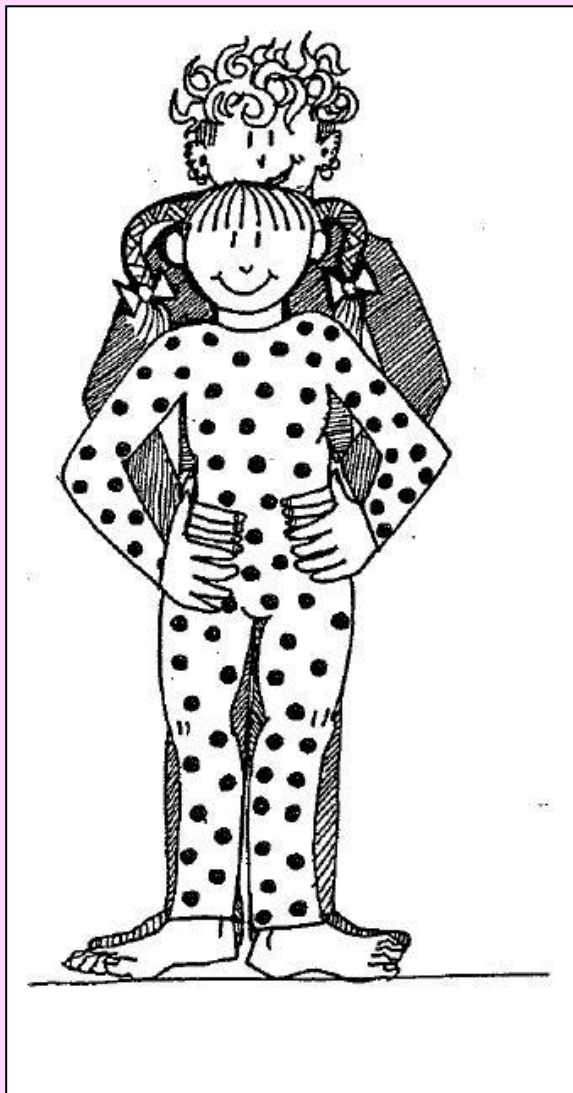
Stand with hands on your hips.

Your assistant helps to rotate your hips in a circle like a belly dancer.

First one way, then another.

Try to keep feet flat on the floor.

Repeat this four times each direction.



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Exercise Nine

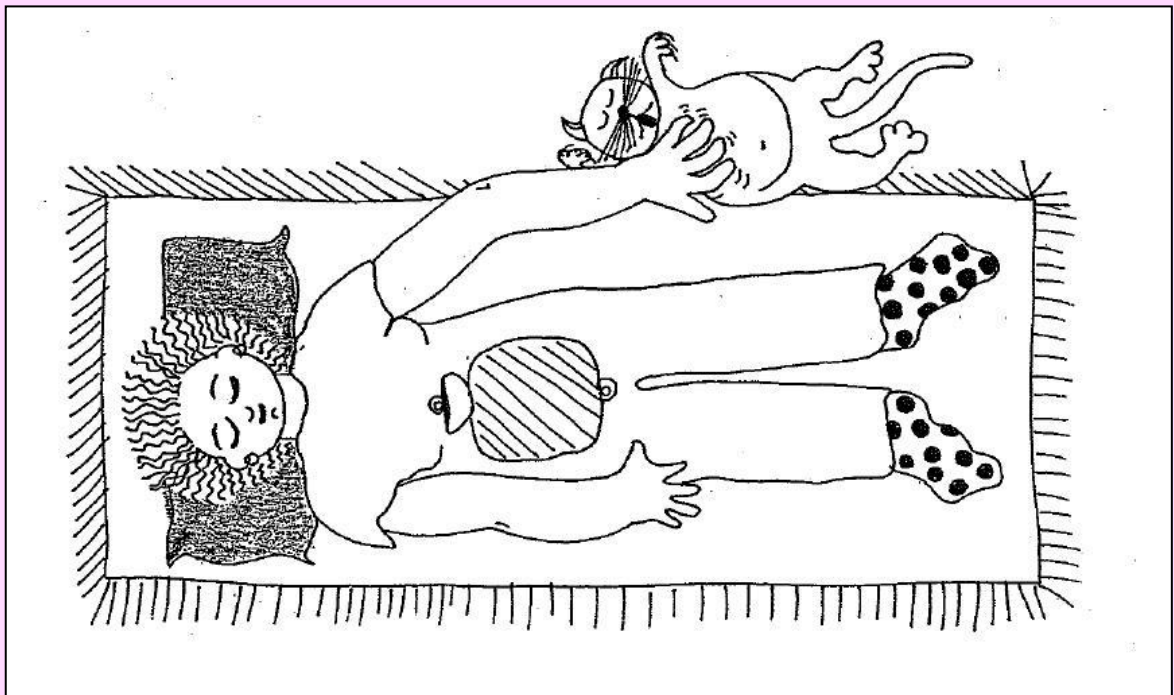
Lie comfortably on your back.

Your assistant places a warm pack on your lower abdomen on top of your clothing.

Your assistant turns on some relaxing music.

Close your eyes and relax.

Your assistant checks the warm pack every few minutes to make sure it is not too hot for you.



Adapted from the Johnson & Johnson 1987 *"Perhaps You've Noticed You're Changing"*.

Menstrual Charting

Menstrual Charting

By charting, it becomes easier to see monthly patterns and changes. This can help to provide solutions and reduce concerns. Other menstrual charting options are available in the Menstrual Management Kit.

SUN	MON	TUE	WED	THU	FRI	SAT
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28

Some Possible Codes

- **Seems Happy** (e.g. creative, relaxed, concentrating, interacting positively)
- **Seems irritable**
- **Energetic**
- **Light flow**
- **Moderate flow**
- **Heavy flow**
- **Seems to have sore breasts**
- **May have cramps?**

Adapted from the chart developed by the Family Planning Association of Queensland

Estimation of Menstrual Flow Chart

Time:				Time			
Date	Light	Medium	Heavy	Date	Light	Medium	Heavy
							
							
							
							
							
							
							

Notes:

- **Recording-** to Record the type of flow, compare diagrams with the flow patterns on the used pad. Tick the diagrams which look the closest.
- **Pads** – ensure that the same brand/absorbency of pad is used consistently by the woman while using this chart and not which type of pad is used.
- **Timing** – pads should be checked at times stated on the chart. Establishment of these times will depend on the woman's individual needs and her daily routines. Length of time pad has been worn should be noted, when recording occurs.

	Jan	Feb	Mar	Apr	May	June
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
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31						

Codes:

H – Positive Mood (Happy)

P – Period +++ Heavy ++ Moderate +Light

S – Premenstrual Stress PMS (mood, headaches)

D- Discomfort (Cramps, pain aches)

	July	Aug	Sept	Oct	Nov	Dec
1						
2						
3						
4						
5						
6						
7						
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31						
Codes: F – Food changes (eating more/craving) T – Tiredness (lack of energy) - Discharge						

Regional Listing Guide for Local Contacts

Check the White and Yellow pages for details relevant to your area.

[illegible]

Drugs	Incontinence Advice
Information of different pharmacological preparation can be requested from medical practitioners, health centres and state health departments. Ask your librarian for MIMS reference.	See your local health department office or home nursing service.

Incontinence & Menstrual Products	Sexual Abuse
Check the contact addresses on these products. Some are available from pharmacies and supermarkets. Check product details in Tables for suppliers.	If sexual abuse is suspected, you are required by law to report it to authorities such as school principals, the police, or state community service offices. There may be various services in this area which can provide counselling for victims of sexual abuse.

Legal Ask you local women’s legal services or government services for people with intellectual disability, for details of issues which might affect you.	Sexuality & Fertility Management Ask your local women’s health centre or family planning association for details.
Menstrual Difficulties Try your local women’s health centre or family planning association for information.	Sexually Transmitted Diseases Try the AIDS council in your state or the family planning association for information.

Notes

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