

Part One: Introduction

What is the menopause?¹

The menopause is often referred to as the 'change of life' or simply 'the Change'. These terms all refer to the time of life when a woman stops having her periods. This usually happens around the age of 50 years old, but can be earlier or later. The menopause is caused by a decrease in the female hormones, oestrogen and progesterone. The menopause is a natural process and not an illness or disease. But some women experience symptoms which make them feel unwell and for which they may seek medical and other help.

Every woman's experience of the menopause is different. Some experience very little in the way of physical or emotional symptoms and may say that they 'sailed through the Change'. Some women may experience very severe symptoms which cause them pain, discomfort or distress. For some women, the menopause marks a distinct turning point or transition in their lives. For others it will have less significance.

Some common symptoms are listed below, but do remember that the rate and extent of these changes will vary significantly from woman to woman.

Physical effects

- **Changes in the pattern of menstruation**

This is one of the most obvious signs of the menopause, especially for women who have always had regular periods. Women may find that the gaps between their periods get longer or shorter, that there is no regular pattern, that bleeding becomes lighter or heavier. However, less bleeding less often is the commonest pattern.

- **Hot flushes (and night sweats)**

This is one of the most frequently experienced menopausal symptoms. A woman's body temperature rises, she may sweat profusely, her heart will beat faster and she may experience palpitations. The rise in body temperature occurs throughout the whole body, but is usually felt most severely in the face, neck and chest areas.

- **Skin condition**

Because of the fall in oestrogen, and the effects of the ageing process generally, various changes happen to the skin. It may become drier and itchy and it will lose its elasticity. It may bruise more easily and wounds heal more slowly.

¹ The term 'menopause' is used in this pack in the commonly understood sense of the whole process of changes a woman goes through in mid-life. In medical terms this time of change is more correctly referred to as the 'climacteric' and the menopause itself actually means a total cessation of menstruation, usually defined as an absence of periods for one year.

- **Changes to hair condition and growth**

Women often notice that the condition of their hair is poorer than when they were younger. It may become drier, duller and thinner. Some women experience the growth of some facial hair.

- **Vaginal and urinary problems**

Because the skin of the vagina and vulva becomes thinner and lower oestrogen levels mean less natural lubrication on the vaginal tissue, women may become prone to genital itching and vaginal infections. Lack of lubrication means women may also experience pain during sex, especially penetrative sex. The urinary tract in women lies very close to the vagina and its membranes also become thinner. This can lead to discomfort and/or an increased frequency in passing urine.

- **Tiredness**

If a woman is anxious, has her sleep disturbed by night sweats or by the need to go to the toilet in the night, then this is bound to lead to tiredness. There can also be a reduction in the deepest 'dream' stage of sleep, so that sleep is experienced as less refreshing.

- **Aches and pains**

With increasing age and the decrease in oestrogen, women often experience aches in their muscles and joints, leading to discomfort or pain, sometimes with limitations in movement.

- **Headaches**

Headaches can become more frequent during menopause and can happen in reaction to hot flushes. Migraines can be affected (for better or worse) by HRT.

- **Weight gain**

Although weight gain is not inevitable during menopause, most women do find that they gain some weight and that their body shape may change somewhat; before the menopause women tend to carry their body fat on their hips, bottoms and thighs, whereas after the menopause fat is distributed more around the waist and abdomen.

Longer term health problems

- **Heart problems**

Oestrogen has a protective effect on the heart. Therefore, with the decline of oestrogen during menopause, the risk of heart disease in women significantly increases.

- **Osteoporosis**

This refers to the condition of having thinner, weaker bones and is *the* major health hazard for women past the menopause. It is a major cause of fractures and consequent disability. Eating a calcium-rich diet and taking regular exercise can help strengthen bones.

Women who have an early menopause, either naturally or because they have their ovaries removed surgically, are at increased risk of heart disease and osteoporosis. This is because they lose several years of protection from the oestrogen that would have been part of their normal menstrual cycle. Medical advice would normally recommend HRT (see opposite) to these women.

Emotional effects

These can be caused by some of the physical symptoms listed above ie a woman may become worried or unhappy about her bodily changes. However, even in the absence of physical changes, the menopause can have emotional effects. Mood swings, irritability, tearfulness, tension, anxiety and depression can all occur singularly or sometimes together. It is also important to remember that changes in individual women's circumstances (such as divorce or bereavement) may coincide with her menopausal years. Because of social pressures, older women may also perceive themselves as less physically attractive and less valued. This can lead to loss of self-esteem and other negative feelings.

Cognitive effects

Oestrogen levels have an affect on the memory, especially verbal memory and storing and retrieving information. Consequently some women find that their thinking processes are affected by the menopause: forgetfulness and an inability to concentrate are commonly reported.

Psychological effects

Some women find the loss of their fertility difficult to come to terms with. Women who have wanted, but not been able to have children, may find themselves angry and upset at the realisation that this is never going to happen. Other women, who have had children, can still find it hard to accept that a major part of their lives is over. Alternatively, other women may very much welcome the end of their childbearing potential and/or be glad not to have to use contraception anymore.

Psychological stress can, of course, be related to events in women's lives. For many women, the menopausal years may coincide with children leaving home, elderly parents becoming ill, in need of care or dying.

Social effects

In societies where attractiveness and activity is associated with youth, ageing can be a stressful experience in itself, for both women and men. But in societies where women, in particular, are judged by the way they look, growing older can be experienced as especially difficult. Added to this is the social 'silence' surrounding matters relating to menstruation and menopause, which makes it difficult for women to talk about what is happening to their bodies, particularly to men or mixed company, and in social and work situations. The combination of these factors may mean that menopausal women feel that, despite all the changes they may be experiencing, they do not want to draw attention to themselves.

Hormone Replacement Therapy (HRT)

HRT is a substitute for the female hormones, oestrogen and progesterone, which decline during and after the menopause. HRT is only available on prescription and comes in a variety of forms: tablets, patches, gels, creams, pessaries and implants.

Each of these different forms of treatment works in different ways: for example, HRT in vaginal creams or pessaries only works where they are applied ie they are useful for treating vaginal dryness and urinary problems, but do not work on hot flushes or protect against heart disease or osteoporosis. On the other hand, HRT tablets are effective against a variety of physical and emotional symptoms, but may cause side-effects such as breast tenderness and stomach upsets. Because of the diverse range of HRT treatments now available, it is usually possible to find the right kind of treatment for women who wish to take it and for whom there are no contra-indications (see below).

Oestrogen is given in HRT to maintain the health of the whole female body. Progesterone is given because it causes the lining of the uterus to shed, which is believed to reduce the risk of uterine cancer. This means that women will still experience bleeding, either at monthly intervals or longer. However, it is possible to take a form of HRT where there is no withdrawal bleeding. Each woman needs to discuss with her doctor which treatment method would be right for her.

Many women stop taking HRT after a relatively short period (ie a few months) because of side-effects. However, adjusting the dose, the combination of hormones and/or treatment methods usually enables women to continue to take it, if they wish to do so. To gain the protective effects of HRT against long-term health problems, such as osteoporosis and heart disease, it needs to be taken for several years and some doctors would recommend indefinitely.

The decision whether or not to take HRT can only be made by each individual woman, after consultation with her doctor. There is no doubt that it has many benefits, not only in alleviating troublesome menopausal symptoms, but also in offering protection against the long-term problems of heart disease and osteoporosis. However, the benefits have to be weighed against the possible side-effects eg weight gain, breast tenderness, headaches. Many women are also very concerned that HRT is believed to increase the risks of certain types of cancers eg breast and ovarian cancer. Some women instinctively feel that taking medication for a natural process is wrong for them, even in the short term, whilst others are happy to take it on a long-term basis.

Women for whom HRT is not generally considered to be appropriate, include:

- those with a history of breast cancer or uterine cancer
- those with a history of unexplained abnormal vaginal bleeding
- those with acute liver disease
- those with deep vein thrombosis.

Medical opinion changes over time with regards to the advisability of taking HRT. For example, in the past, it was generally not judged to be appropriate for women with a family history of heart attacks to take HRT. Now it would be recommended, as HRT is known to protect against heart disease. However, it cannot be emphasised strongly enough that women should always be expected to discuss their full medical history with their doctor before HRT is prescribed.

For women who cannot, or do not want to, take HRT, there are other approaches which some women prefer to try. Some of the more well-known alternative approaches to managing menopausal symptoms include:

- a healthy balanced diet (including adequate calcium and vitamin D intake) and regular weight-bearing exercise
- avoiding smoking and heavy drinking
- natural remedies or supplements available over the counter in chemists and health-food shops
- homeopathic or herbal remedies available from qualified practitioners
- skin creams and moisturisers for dry skin conditions
- lubricants to be used during sex eg KY Jelly for vaginal dryness
- avoiding the foods and drinks which seem to bring on hot flushes (this will vary from woman to woman, but often includes coffee, tea, alcohol and spicy foods)
- massage, relaxation or yoga for general health and wellbeing.

The menopause and women with learning disabilities

Having a learning disability does not necessarily mean women will have a different menopausal experience from their non-disabled peers. Research on the menopause for women with learning disabilities is relatively limited (but see **Further reading** list on p21 for details). However, it is possible to recognise that there may be some differences for women with learning disabilities.

Physical effects

Evidence suggests that women with learning disabilities generally tend to have a somewhat earlier menopause than most other women, and that women with Down's Syndrome have a significantly earlier menopause (ie average age 46 years compared to 51 in the general population). An earlier menopause in women with Down's Syndrome may be due to the fact that the ageing process generally appears to take place prematurely for people with this condition. Why women with learning disabilities, but without Down's Syndrome, have an earlier menopause is more difficult to determine, but may be due to the fact that women who have never given birth, tend to have a earlier menopause than those who have.

Menstrual changes may be masked by long-term use of the Pill (often into their 40s) for women with learning disabilities (this would be unusual for other women). Women who have had hysterectomies will obviously not have any menstrual changes to observe. If a woman has had her ovaries and womb removed, then she will effectively have gone into the menopause at the time of the operation. However, if only her womb was removed, then she will still experience some menopausal symptoms at the usual time. Many women with learning disabilities who have had a hysterectomy will not know if their ovaries were removed or retained. This information may be possible to obtain from carers or from medical records.

Emotional effects

There is no reason to think that women with learning disabilities would not also experience mood swings, irritability, depression and so on, as other women do. They may feel more anxious than other women due to their likely lack of knowledge and understanding about what is happening to them. They may live in group homes or other settings where they have relatively little privacy, which may be an additional stress. It is important that staff and family carers recognise the menopause as a possible cause of tension and difficulties for middle-aged women and not jump to conclusions about ‘challenging behaviour’.

Cognitive effects

If certain cognitive effects, such as forgetfulness and an inability to concentrate, occur in middle-aged women with learning disabilities, then it is important to recognise that these may be due to the menopause and not necessarily be related to the learning disability itself or to a general decline in intellectual ability. For women with Down’s Syndrome, where the early onset of dementia is considerably more common than it is for the general population, it may initially be difficult to determine what is causing the cognitive changes.

Psychological effects

Psychologically adjusting to the loss of their fertility and status as mothers is likely to be a different process for many women with learning disabilities compared to their non-disabled peers. Certainly the emotional and psychological changes which are frequently raised in relation to other middle-aged women (eg the so-called ‘empty nest’ syndrome, which refers to a loss of function, role, sense of usefulness) are rarely reported either by the women with learning disabilities or those close to them. Few women with learning disabilities get the chance to ‘use’ their fertility in the first place, therefore the loss of it is likely to impact on them differently, and for some, not impact at all. Added to this is the fact that many women with learning disabilities do not understand that the menopause does actually mean the end of a woman’s fertility. However, there may be some women with learning disabilities who have wanted to have children and who may need considerable support in coming to terms with the fact that this will now never happen.

Social effects

During the menopause, most women have to make major adjustments: attractiveness is associated with youth, childbearing years are over and sons and daughters are beginning to lead independent lives. Women with learning disabilities are likely to have had different experiences from other women; many will not have had children, and they may not perceive the menopause as such a watershed in their lives.

Many women with learning disabilities will rely on other people for their information, support and access to healthcare. Their views on menstruation and the menopause are likely to be strongly influenced by those close to them. However, few women with learning disabilities have any opportunities to discuss how they feel about their reproductive health and learn about other women’s experiences. Women’s groups can play an important role in providing those opportunities.

HRT and women with learning disabilities

There is very little research evidence about the use of HRT in women with learning disabilities. The decision whether or not to take HRT is a complex one, involving weighing up the risks and benefits. It may be helpful to encourage women to think in terms of the possible advantages and disadvantages to them. For instance:

Possible advantages

- helps with the major menopausal symptoms eg hot flushes, menstrual problems, vaginal and skin dryness
- helps to protect against heart disease
- helps to protect against osteoporosis

Possible disadvantages

- may contribute to a small increase in certain types of cancer (eg breast cancer or uterine cancer)
- women may still have regular bleeding, although not necessarily every month
- women may experience side-effects, such as breast tenderness, nausea
- women may gain weight

It is unlikely that many women with learning disabilities would be able to weigh up the pros and cons of HRT without support, advice and clear, accessible information. Women should not be denied the benefits of this treatment because they have a learning disability. However, nor should they be exposed to unnecessary risks or be expected to put up with unpleasant side-effects. Whether or not it is in the best interests of any particular woman with learning disabilities to take HRT depends on a number of factors, including the severity of her menopausal symptoms, her ability (or the ability of those around her) to recognise and report adverse side-effects and her medical history.

It should be expected that doctors, practice nurses, learning disability service staff and family carers will have to work in partnership with each other and with women with learning disabilities themselves to provide the best possible treatments to those women who need it. In any event, the importance of regular health checks and monitoring of any treatments given is emphasised.

Summary of findings from the GOLD-funded research project – the experiences of women with learning disabilities as they go through the menopause

The Growing Older with Learning Disabilities (GOLD) programme of research was funded and managed by the Foundation for People with Learning Disabilities and ran from 1999–2002. It funded a total of 13 research projects, which covered a wide variety of age-related concerns for people with learning disabilities, their family carers and service providers. The research project reported here was conducted by Michelle McCarthy and Lorraine Millard and its overall aim was to explore how women with learning disabilities experienced the menopause. Further details of the research project are to be found in the papers listed under the authors' names in the **Further Reading** section (p21).

Rationale for the study

Amongst practitioners and academics, the general consensus is that the menopause as it affects women with learning disabilities is under-researched. All previous research has been from a medical perspective and has been aimed primarily at establishing the timing of the onset of menopause for women with learning disabilities. The overall aim of the research study reported here was to explore the experience of the menopause as far as possible from the perspective of women with learning disabilities themselves. In particular, this study set out to explore the following themes:

- a) what women with learning disabilities *understood* about what happened to their bodies during menopause
- b) what they *experienced* when they went through it
- c) what *support* they wanted, needed and got as they went through this transitional time in their lives.

Research methods

- Semi-structured in-depth interviews with 30 women with learning disabilities, aged (approximately) in their 40s, 50s and 60s
- Postal questionnaires to GPs, staff in learning disability residential and day services and parents of older women with learning disabilities still living at home

Participants with learning disabilities

The experiences of 30 women are reported in this study. Their ages ranged from 43 (a woman with Down's Syndrome) to 65, with an average age of 51. Twenty-five women were white British, five were from minority ethnic backgrounds. All the women had mild or moderate learning disabilities. All used specialist learning disability day, residential or community services. The researchers approached these services and asked to speak to all women who were of the appropriate age and who had sufficient intellectual and communication skills to be able to relate their experiences. There were no other criteria

for participation. Once suitable participants were identified, they were approached by the researchers, who tried to explain the methods and purpose of the study in clear and accessible terms. Women were also given an accessible information sheet about the research project, which explained what they would and would not have to do (eg that they would be asked only to talk about their views and experiences, there were no other procedures) and what their rights were (eg that they could decline to participate or withdraw from the study at any time with no adverse consequences to them). All participants signed a consent form. Ethical approval for the research was given by a university research ethics committee. All participants were paid a small fee in recognition of their contribution.

Brief summary of findings

From the women with learning disabilities

Most of the women with learning disabilities who were not yet menopausal did not know that their periods would eventually cease. However, most of the women who were already menopausal did know that women eventually stopped having periods, but did not know why this happened or what it meant (ie that it signifies the end of a woman's fertility).

None of the women interviewed for this study had had children and the majority did not express strong views about having wanted to or being sad now that they could no longer do this. This is likely to be a reflection of the fact that most of the women used learning disability services and did not lead independent lives. Certainly some of the women with learning disabilities who formed part of an advisory group for the project, and who tended to be more able and independent, did express sadness at this part of their lives having been denied.

The vast majority of the women did not know anything about other women's experiences of the menopause (eg staff or relatives). Most women did not recognise or understand the commonly used terms 'menopause' or 'change of life'. This suggests that most women with learning disabilities do not pick up on informal routes of learning about women's mid-life changes.

Most women did not know about the risks of osteoporosis and the importance of trying to keep their bones strong.

Almost all the women said they wanted other women to give them support through the menopause. This was usually staff in learning disability services, sometimes family members, sometimes doctors. They saw little role for men in giving them advice, emotional or practical support. However, those women who had male partners wanted them to be aware and generally supportive.

We did not find any particular differences in the physical symptoms experienced by women from Black and minority ethnic communities compared to white British women. However, there were more social differences, in that the Black women tended to have more contact with their extended families and get more social support from their communities eg church groups. However, the numbers are too small to make any generalisations from these findings.

Talking to women about the menopause inevitably raised more general issues about ageing and ill-health and many women got upset thinking about the bereavements they had experienced (usually the death of one or both parents).

From the GPs

The majority of GPs had little or no experience of treating women with learning disabilities for menopause-related concerns.

Very few women (except the most able and independent) visited the doctor alone. Usually a relative or carer would accompany the women. Whilst this can have a positive effect (eg acting as advocates for the women, explaining and interpreting symptoms and treatments), it could also have a negative effect (acting as a ‘filter’ or ‘barrier’ to ration women’s access to medical help).

GPs frequently suggested that they would recommend HRT for troublesome menopausal symptoms. Some doctors recognised the problems of obtaining informed consent to this treatment from women with learning disabilities and implied that this might prevent them from prescribing it to such women. Other doctors stated that they would prescribe it to women who could not consent, on a ‘best interests’ basis.

Some GPs recognised that they needed to be proactive in trying to ‘reach out’ their services to older women with learning disabilities, especially those who lived with elderly fathers.

From the staff in learning disability services

Only a small minority of staff were confident that women with learning disabilities generally understood what was happening to them during the menopause – the difference between women *describing* what was wrong and *understanding* what was wrong was emphasised by staff.

The vast majority of staff felt strongly that women with learning disabilities should be educated about the menopause and this was usually seen as a more appropriate task for residential, as opposed to day service, staff.

Staff expressed concerns about a general lack of good medical attention often experienced by people with learning disabilities and were therefore concerned that doctors may not take menopausal symptoms seriously for women.

From the parents

All the parents who took part in the research were mothers. The mothers felt they played a key role in observing and interpreting menopausal changes in their daughters. They also felt that the best person to educate their daughter about the menopause was themselves, although they recognised roles in this for medics and staff in learning disability services.

About half the mothers saw similarities in their own menopausal changes with those of their daughters. Some of the mothers clearly recognised that they had influenced their daughters’ attitudes to menstruation generally and that this had usually been to pass on negative attitudes.

Staff training

Research evidence suggests that staff in residential and day services generally recognise the role they need to play in supporting women through the menopause, but feel this job is made difficult by a lack of training and a lack of specialist resources to help them. The following are some of the important tasks for staff in learning disability services:

- Providing women with learning disabilities with information and support to understand that the menopause is a natural process; basic information about the most common symptoms will be important to pass on.
- Many women with learning disabilities will need help to alleviate some of the menopausal symptoms they find troubling. They are likely to need staff (and/or family carers) who are observant and sensitive and who can help to facilitate access to appropriate healthcare.
- The role of staff and family carers in advocating for women's access to healthcare provision is clear. Also, because some women with learning disabilities may not be able to report the beneficial effects of treatments or indeed undesirable side-effects, then this points to an additional role for staff and carers in monitoring these and reporting back to healthcare practitioners.
- An ideal model would be if staff were willing and able to attempt to work in partnership with GPs, the women themselves and their carers, where appropriate. Where there is resistance to this approach, staff in learning disability services may need to persuade GPs and family carers of its advantages.
- Staff may need to access some of the accessible health information which is increasingly being produced for people with learning disabilities and use this with their service users. In addition to information about conventional treatments, women with learning disabilities may benefit from help and advice about some of the more easily available and straightforward alternative treatments and therapies.
- It is clear that those women who had hoped to have a baby, and subsequently realise this will never happen, may need sensitive help in coming to terms with this.
- Staff may need to provide opportunities for women to talk about their experiences and feelings and learn from others. Women's groups can fulfil this function very well.

It should be clear from the points made above, that staff in learning disability services will need training and support from their organisations in carrying out these and other, related tasks. This pack makes suggestions for a variety of staff training exercises, (with accompanying materials) which may help prepare staff for this work. The training suggested here is designed to help staff recognise when women with learning disabilities might be going through the menopause and how they might help. The training also enables staff to examine their own and other people's attitudes to the menopause.

The following observations are made by the authors from their experience of running staff training sessions on the menopause in learning disability services.

The experience of older women staff

Women who were going through, or had been through, the menopause themselves were very important participants on the training courses. As you would expect, they were more knowledgeable about the subject than younger staff, but they were also more relaxed about it. It was clear that younger women had considerable anxieties about what the menopause might be like, whereas the older women could say that it wasn't as bad as they had expected. Many of the older women could see a funny side to some of the changes they had gone through and could therefore inject a welcome sense of humour into the discussions. However, both younger and older staff recognised the need for, and supported the introduction of, training in learning disability services on the issue.

Ethnic/cultural differences

Staff from Black and minority ethnic cultures were well represented on the training courses held by the authors. There were no obvious differences in attitudes or experiences compared to women from white British backgrounds. The only exception to this was women from South East Asia, who reported very few, if any, menopausal symptoms. However, the number involved was very small and it is not possible to generalise from this.

Training for male staff

All courses held by the authors were for women only. This is because we felt that women would be more comfortable discussing menstruation and menopause in a women-only group. However, in the evaluation forms (see *Templates L* and *M* for example evaluation forms) we asked the participants for their views on mixed groups for training. The overwhelming majority was of the opinion that women-only groups were most appropriate. Yet they also felt that male staff who worked with women with learning disabilities did need training on the issue. They felt this would best be done in men-only groups, or possibly with women staff who had already had the opportunity of women-only training first.

There is something of a dilemma for learning disability services here: few are likely to have sufficient numbers of male staff working with older women to make men-only training sessions viable and even if they did, the interest of male staff in the topic may not be great. Added to this is the strong preference expressed by women with learning disabilities that they should have women staff to support them in anything that was to do with their periods and the menopause. In view of the above, services may decide that training for male staff on the menopause would best concentrate on raising awareness, recognising symptoms and exploring attitudes, rather than on ways male staff can directly support women.

Facilitating women's access to primary healthcare

At the staff training sessions and during the research project itself, many staff expressed deep concerns about the attitudes and practices of GPs towards people with learning disabilities. Many reported poor practice and a lack of interest from GPs towards their learning disabled patients and there was little faith amongst staff that this could or would change in the future. Many staff also reported that it was often not possible to change

from a 'bad' GP to a new one, as doctors were generally reluctant to take on people with learning disabilities as patients. In view of this, it may be necessary to spend considerable time during staff training on devising strategies to try to overcome these problems.

The need for specialist education materials

Staff expressed very strong views that, if they were to be expected to educate women about the menopause and support them through it, then they needed the right tools to work with. Strong preferences were expressed for clear and explicit visual materials: videos and leaflets were considered most appropriate for group and individual work. The style and content of the video and leaflets contained in this pack reflect what staff in learning disability services have said they would find most useful. In particular, efforts have been made to find a balance between giving women with learning disabilities enough information so as to prepare and empower them, but not so much information that it causes unnecessary anxiety and fear.