

Managing the menopause in women with Down's syndrome – a review of the literature

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Why look at the menopause?

- People with intellectual disabilities (ID) and Down's syndrome (DS) are living longer
- Few studies concentrate on the menopause in women with ID or DS
- Those that do focus on general life-cycle research than focusing on the menopause
- Few talk directly to women with ID or DS

What is the menopause

- Cessation of menstruation (periods) usually defined as post menopause a year after your last period.
- Symptoms usually start a few months or years before menstruation ceases: the perimenopause.
- Most symptoms last around four years from the last period.
 - Around 1 in 10 women experience them for up to 12 years.
- Experience of a sudden menopause for example, cancer treatment – symptoms may be worse.

Common symptoms include:

- Hot flushes: sudden heat / sweats - face, neck and chest
- Night sweat – hot flushes that occur at night
- Difficulty sleeping– feel tired and irritable during the day
- Reduced sex drive (libido)
- Problems with memory and concentration
- Vaginal dryness and pain, itching or discomfort during sex
- Headaches
- Mood changes, such as low mood or anxiety
- Palpitations– heartbeats become more noticeable
- Joint stiffness, aches and pains
- Reduced muscle mass
- Recurrent urinary tract infections (UTIs), such as cystitis
- It can also increase your risk of developing other problems e.g. Osteoporosis.

Literature review

The aim: to assess current knowledge in the area and outline best practice in managing the menopause

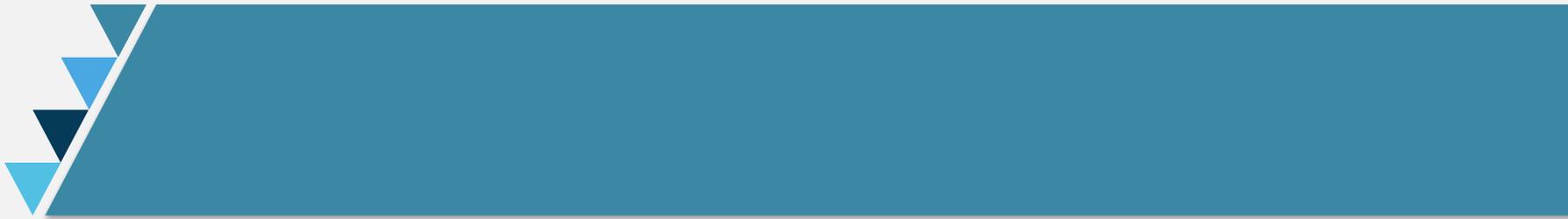
- The literature between 1980-20018.
- **Search terms:** learning disability(ies), intellectual disability(ies), developmental disability(ies), mental retardation and included, Down('s) syndrome as a separate term. Menopause, menstruation. Cessation
- **Databases:** Ebsco data bases were interrogated: British Nursing Index, The Cumulative Index to Nursing and Allied Health, Psychology and Behavioural Sciences Collection, and Med-line.
- **Inclusion/exclusion criteria:** written in English, no children, & women
- Total of 31 papers

Main literature

- Fragile X and premature ovarian failure (Kenneson *et al.* 1997; Vianna-Morgante *et al.* 1996)
- Other syndromes experiencing early onset of menopause e.g. Bloom's syndrome (Sanz *et al.*, 1993)
- Some work on mouse modelling ...
- More on menopause, oestrogen and dementia in DS (Schupf *et al.* 2003; 2018; Coppus *et al.* 2010)
- Schupf *et al.* (2018) - role of estrogen-related factors in age at onset and risk for Alzheimer's disease in women with Down syndrome

Papers on symptoms and DS

- Osteoporosis: Milberger, et al (2002) examined osteoporosis in postmenopausal women with Down syndrome – note 87% had osteoporosis in at least one of the three sites measured.
- Epilepsy: O'Brien & Gilmour-White (2005) – note changes due to menopause... Note bone density as well.
- Cognitive performance Patel et al (2001) identified post menopause women with DS showed significant declines in cognitive function. ... Suggested an associated with oestrogen deficiency
- To date, no clinical trials of oestrogen or hormone replacement therapy have been published for women with Down syndrome (Schupft et al 2018)
- Ejksjaer et al (2006). A cross-sectional study of 11 women with DS (26-40 yrs) looking at menstrual cycle – more work needs undertaken in this area



Work on the menopause



Carr & Hollins (1995) UK

- Explored the menstrual history of 45 women with DS (aged 18-61) and 126 women with intellectual disability (ID) of diverse/unknown aetiology
- Postal questionnaires completed mainly by carer informants.

Findings:

- 87% of the women with DS had stopped menstruating by the age of 46 and all had ceased by the age of 54.

Conclusion

- Women ID reach menopause earlier than women in the general population, and that women with DS had earlier menopause still.
- **Limitations:**
 - 70% response rate, but only around 4% of questionnaires completed by women themselves.
- Reliability of the data: were the responses based on the women's own knowledge or the views of their carers?

Schupf (1997) USA

- 157 women with DS and 187 women with other intellectual disability, all 40+ yrs of age.

Findings:

- age-adjusted likelihood of menopause twice as high in DS than other women with ID
- Treated thyroid conditions no influence menstrual status

Conclusion

- Supports work - women with DS experience the menopause at an earlier age and may be associated with accelerated aging.

Limitations:

- Reported: incorrectly classifying some women as menopausal due difficulties identifying menstrual status – corrected their analysis.

Cosgrave et al (1999) Irish

- 143 Irish females with Down's syndrome (DS) from on going study
- A semi-structured interview was administered to subjects, family members or care staff by one of the authors about menstrual issues
- **Findings:** age menopause established for 42 = (44.7 yrs).

Conclusion: menopause earlier than expected

- Manifestation of accelerated ageing in DS?
- Oestrogen deficiency being a factor for dementia

Seltzer et al (2001) USA

- 92 women with DS (aged 21-70) -hypothyroidism and mopause
- Statistical means top establish distribution and median age at onset of menopause:
- **Results:** similar estimates of the median age at menopause =46 years.
- **Conclusion**
- The presence of hypothyroidism did not influence age at menopause.
- The earlier-than-expected age at onset of menopause suggests that women with DS are at an increased risk for post-menopausal health
- **Limitation:** unable to define menopausal status

Schupf, et al (2003)

- Dementia and menopause.
- 163 postmenopausal women with DS (aged 40 to 60 years) based in the community identified through a Disability service system.
- **Data collection:** cognitive assessments, medical record review, neurological evaluation, and caregiver interviews to establish ages for onset of menopause and dementia.
- **Findings** support early onset of menopause. Also hypothesis that reductions in oestrogens after menopause contribute to dementia.

Findings

Life cycle research consistently reports:

Menopause is earlier in women with ID than the general population and earlier still in women with Down's syndrome (DS).

(Brambilla and Mackinlay, 1989; Schupf et al. 1997; Seltzer et al., 2001; 2003; Cosgrove et al., 1999; Willis et al 2010;2011)

Problems encountered in the evidence

- no record of the date of the last period
- unable to ascertain whether a woman had menstruated
- difficulty defining menopausal status

Asking the women

This has been limited but more work has appeared....

Carr and Hollins (1995)

But there were limitations as already discussed

McCarthy (2002)

Postal questionnaires sent to: **Carers, family carers and GPs**

- 60% of GPs never treated a menopausal woman with ID
- Care-staff felt the women were confused and anxious about the menopause but were key to reporting menopausal symptoms
- Family carers felt they would know when changes were happening

BUT

Poor response rate -GPs (23%), day service carers (24%), residential carers (16%) and family carer (40%)

Not clear whether the women's actual carers or GPs were surveyed

McCarthy & Millard (2003)

One to one interviews with 30 women with ID

- Generally had a poor understanding about menstruation, menopause and other health-related issues
- Little or no understanding of the psychological aspects of the menopause
- Ethnic minority women – no difference

BUT

Only 5 women were from ethnic minorities

(McCarthy, 2002 & McCarthy & Millard, 2003)

Chou, Lu, & Pu (2013)

Taiwan - larger study

- 117 women aged 35 years or older and their carers participated in a survey study.
- 65 (56% response rate) primary carers & 7 women with ID took part

Interviews

- 10 carers and four women with ID semi-structured interviews

Findings

- Few gynae interventions
- Lack of access to services and HRT
- Few women had been told about the menopause
- Traditional medicine used to control menstruation .
- Carer education poor

Willis (2007 & (2008)

Investigated the information and resources available to women with ID including DS and their experiences of the menopause

Semi-structured interviews

18 women (age range 46-77 yrs) approached with mild - moderate ID

3 women were not included

Topic areas

- demographic
- keeping healthy
- menstruation/menopause
- signs and symptoms of the menopause and
- sources of information/education

Findings and conclusion

- None of the women had been married or had children
- 10 were postmenopausal 5 were peri-menopausal
- There was little understanding of the menopause or menstruation

I talked to my sister and asked if it was all right..... I just [thought] it was something terrible I did

- The women didn't like their periods and were happy they had stopped

Oh I was happy mind you...I dinnae like them.....they were terrible get pain and headaches

- Few resources existed for these women on the menopause

Conclusions

- Supports previous work:
 - Little understanding about menopause
 - Lack of appropriate resources on the menopause

Willis et al (2010 & 2011)



Explore any differences in experiences of the menopause and menopausal understanding in women with and without DS.

Identify carers' knowledge and understanding of the women's menopausal experiences and problems.

Inform training and health education programmes for women with ID and for their carers.

Methods

One-to-one semi structured interviews (piloted)

40 women with severe to mild ID -
20 DS & 20 without DS

Mild – severe ID

Aged between 35-65 years

Included women across the menopausal spectrum: i.e. pre, peri and post

Inclusion criteria

- Enough communication skills to be interviewed and give consent
- Experienced menstruation
- No diagnosis of dementia
- No hysterectomy

The women's carers

The main carer, & 2 other carers (1 male, 1 female)

Inclusion criteria - 18 and over

The women

77 women were accessed

45 women to part (aged 38-63 years)

17 DS, 28 Non-DS

But

11 women did not wish to be interviewed

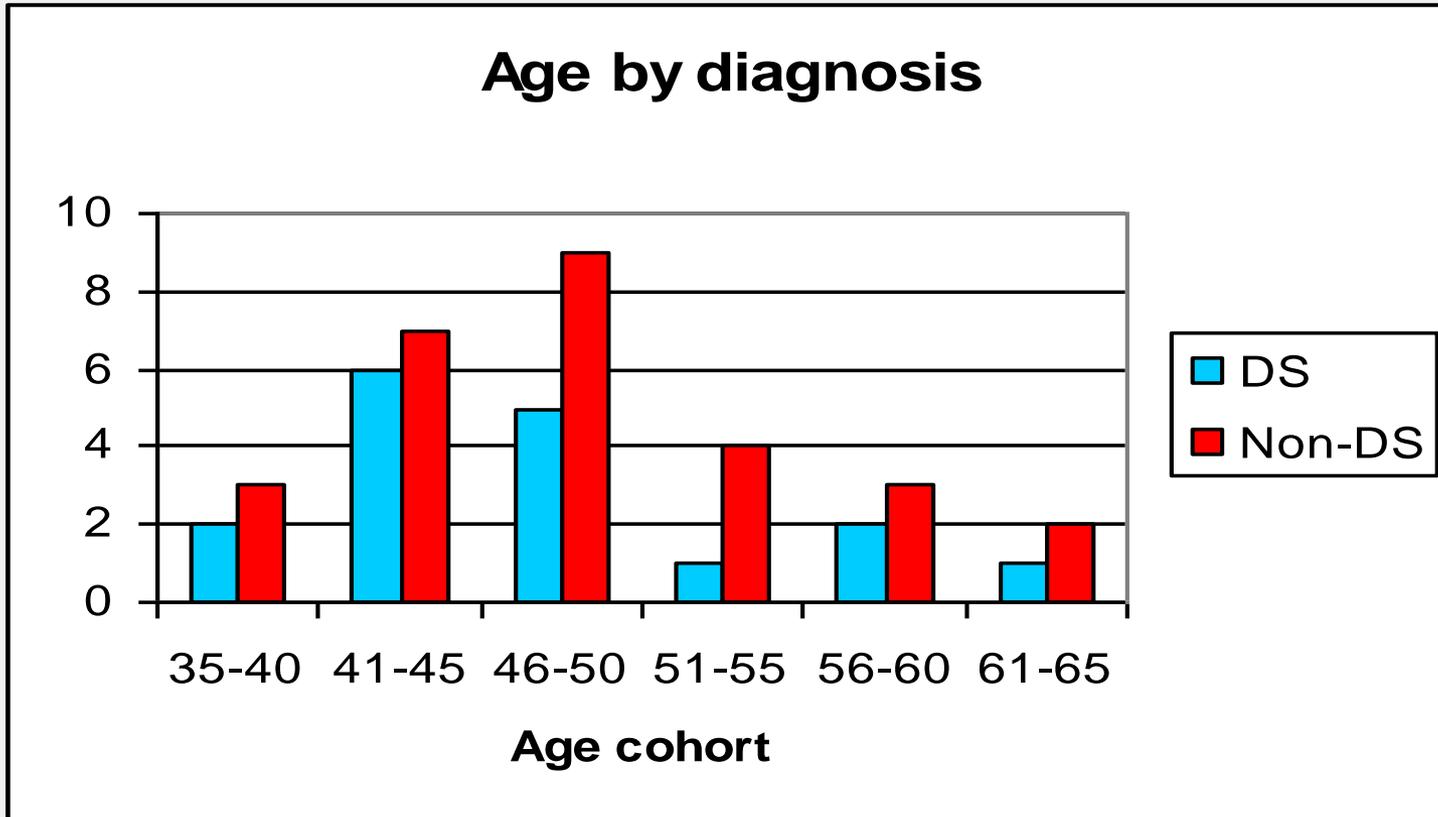
6 women were excluded due to communication difficulties

10 carers refused access

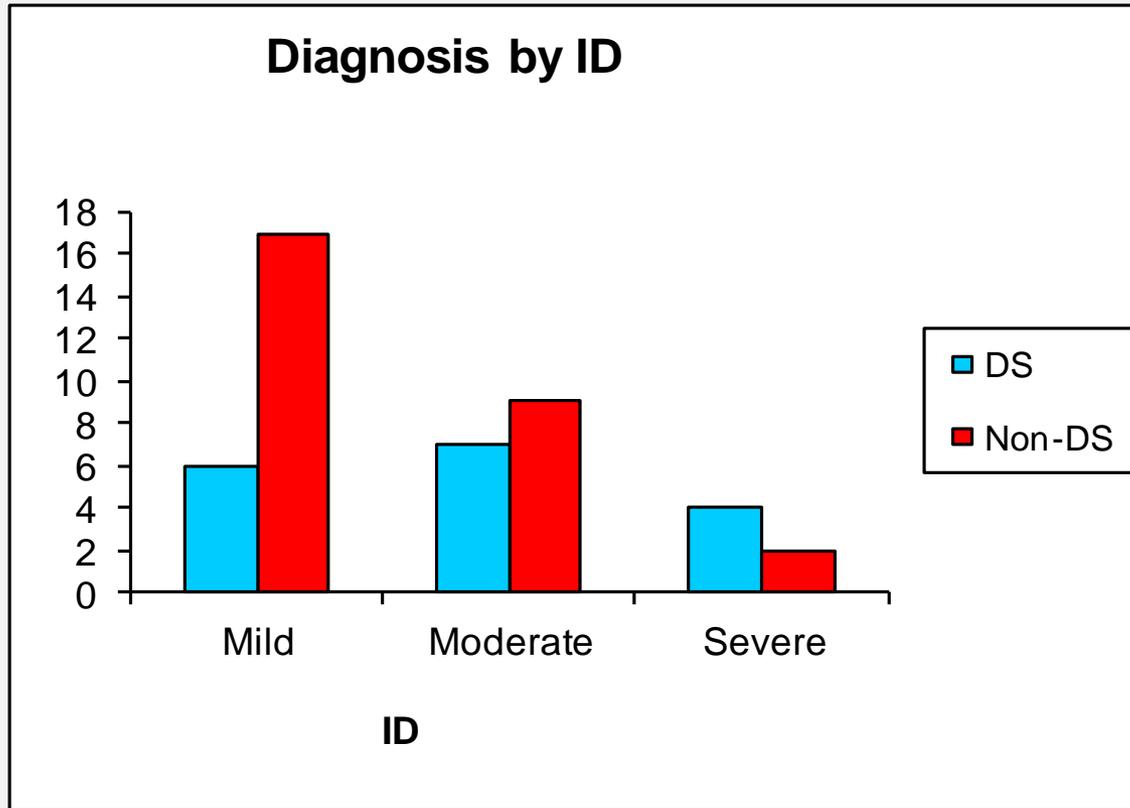
4 found to have hysterectomy post-interview

1 had diagnosis of dementia

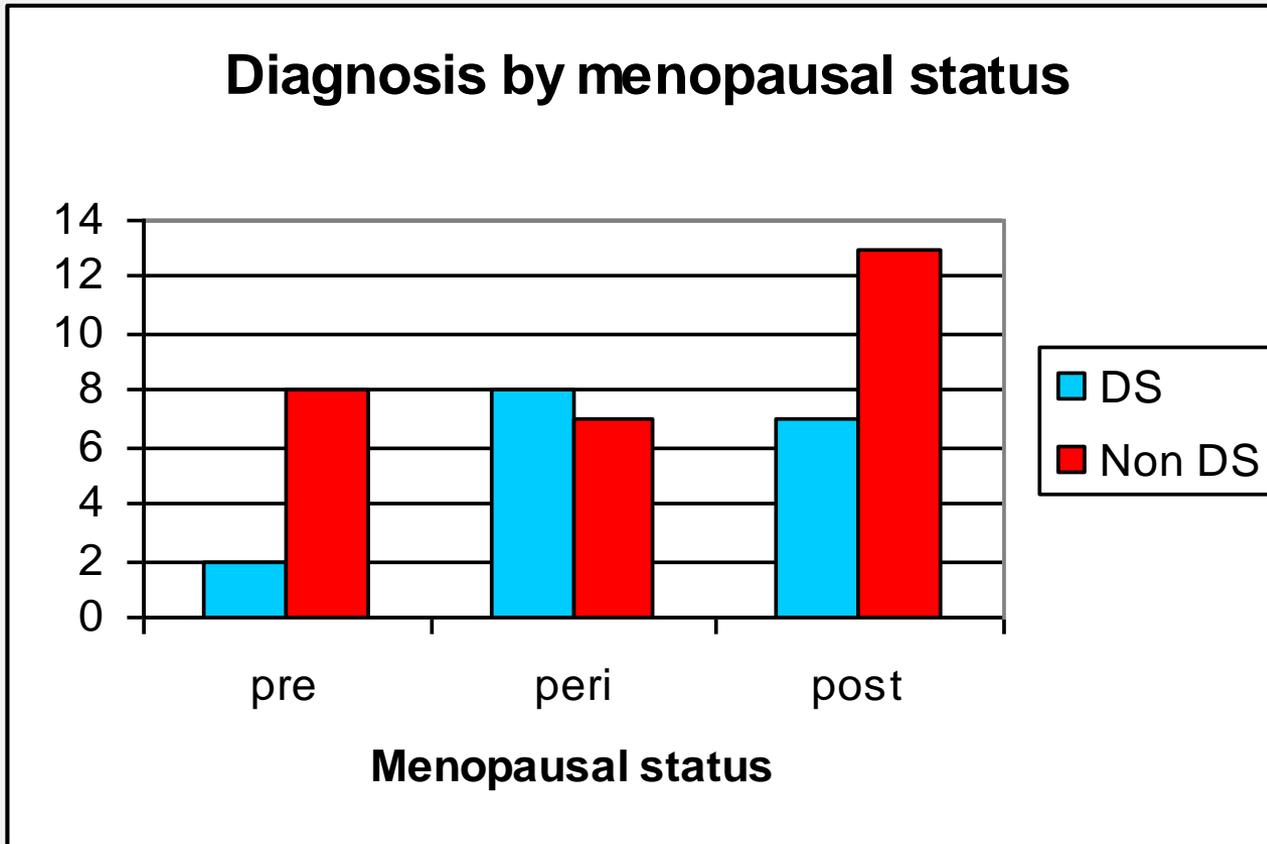
Age by diagnosis



Level of ID of the women

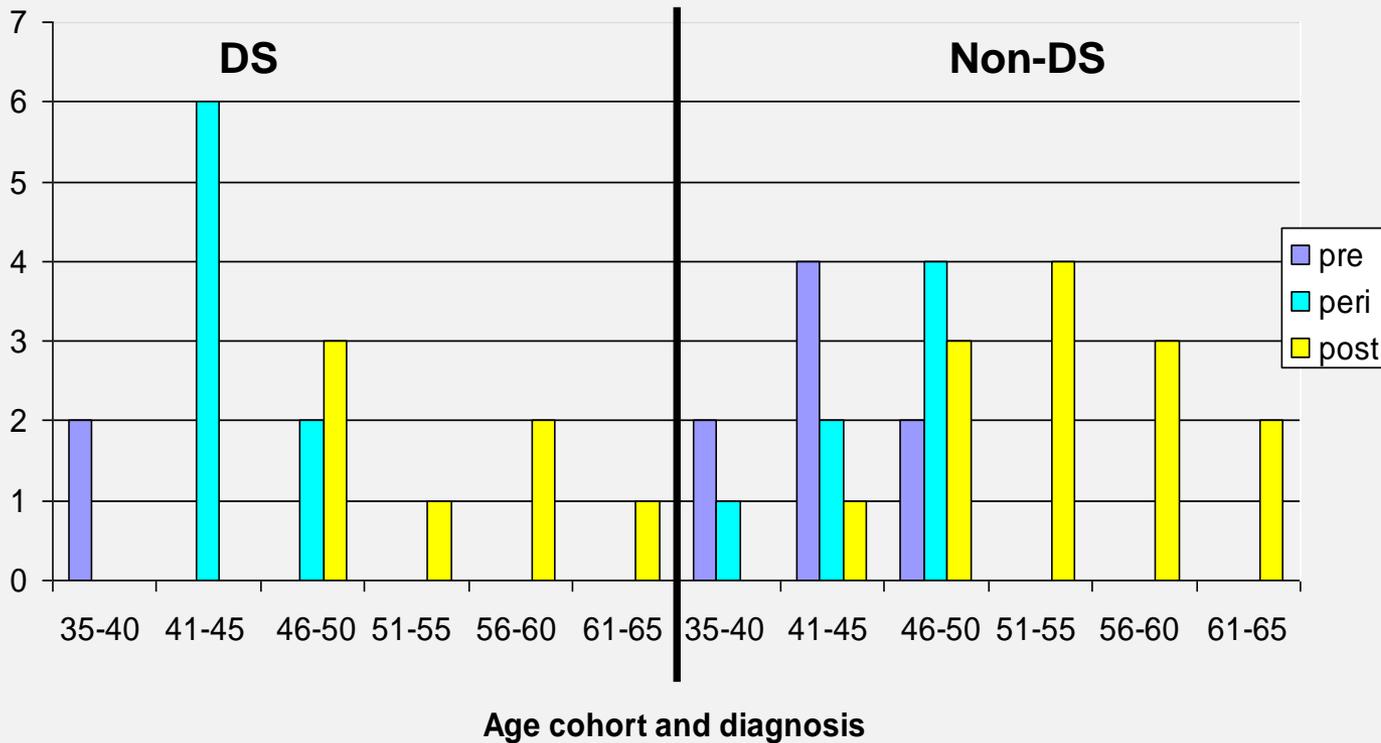


Menopausal status



Age, diagnosis & menopause

Menopause status by age



Findings

Few women:

had relationships or children, smoked or drank alcohol regularly, noticed their body aging.

Menstruation:

- Little understanding of why they have periods & were generally painful and disliked
- Relief and happiness when their periods finish for good

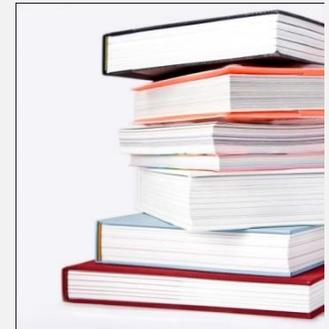
Menopause

- Few had heard of the term menopause/change of life/change
- There was awareness of other women who were going through/had been through the menopause
- Few realised they could no longer have children

Information/training



- Most women reported having someone to talk to
- Preferred another woman to talk to
- Few had received information but would like to learn
- Preference for an illustrated book – but some suggested women's groups



Carers

- 78 carers interviewed (10 male, 68 female)
Age ranged from 19-65 years (14 bands)
- 6 carers did not wish to be interviewed
- 11 women did not want their carer to be interviewed

Other facts

Time the carer had known the woman - 3 wks - 34 yrs
Amount of experience - ranged from 3 wks - 44 yrs

Findings

- Few said the women reported noticing hot flushes
BUT supporters said it was difficult to differentiate menopausal symptoms / mood swings etc from their usual behaviour.
- Few had tried explaining it and reported they wouldn't know where to start.
- Most thought the women would accept it to find it difficult.. Others would only notice if it interfered with something else
- Carers generally report feeling comfortable about the prospect of talking to the women - older carers were open about their menopause
- Most reported wanting more information on health problems generally“

Conclusions

Menopause is earlier in women with DS but problems with some of the evidence

Asking the women : Few women understood the menopause or acknowledged it was the end of their reproductive life

Generally the women hadn't spoken to staff

Staff: Also sometimes lacked knowledge

Definite need for more: Co-ordinated training and information for supporters and health and social care professionals on the menopause and on more general health issues related to the menopause.

Accessible information for the women and greater provision of appropriate health education opportunities.

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