

# *The Menopause and Women with Learning Disabilities*

## **SUMMARY**

This research project was undertaken by Michelle McCarthy and Lorraine Millard as part of the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities. The purpose of the research was to investigate what women with learning disabilities understood about the menopause, how they experienced it and what support they needed and got. The attitudes and practices of GPs, staff in learning disability services and parents of older women with learning disabilities were also explored.

## **BACKGROUND**

Despite it being an experience common to all women, very little attention has traditionally been paid to the menopause as it affects women with learning disabilities. The reasons for this are varied, but include: a traditional lack of attention paid to gender specific needs in learning disability services; a lack of attention to reproductive health care needs of women; and a lack of attention to age related concerns generally, although all these factors are clearly changing. The cumulative effect however, has been that older women with learning disabilities have not been adequately prepared for, or supported through, what for most women is a significant 'change of life'.

What little literature there is on the topic is mostly from a medical perspective and is aimed at establishing whether women with learning disabilities (including women with Down's Syndrome as a specific sub-group) reach the menopause at roughly the same time as other 'ordinary' women (e.g. Carr & Hollins 1995). In more recent times, some practice based materials have also emerged (e.g. Cooper & Welsh 2001).

## **THE RESEARCH**

Semi-structured interviews with 30 women with learning disabilities in their 40s, 50s and 60s were conducted. The attitudes and practices of GPs, staff in learning disability services and parents of older women were investigated through postal surveys. Two advisory groups of women with learning disabilities helped the researchers to formulate research questions and with the development of specialist education materials, including video, pictorial and accessible leaflets. Staff training materials were also developed and piloted with several staff teams.

## THE 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 (i.e. that it signifies the end of a woman's fertility).

In light of this it was not surprising that the women did not appear to attach emotional feelings about the end of their opportunity to have children specifically to this event. The restrictions on their fertility is likely to have been a pervasive feature of their lives.

The vast majority of the women did not know anything about other women's experiences of the menopause (e.g. 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.

We did not find any significant 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 e.g. church groups.

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 (e.g. 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 difficult menopausal symptoms. Some recognised the problems of obtaining informed consent to this treatment and some suggested that they were willing to prescribe it on a best interest 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 just with their 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 more appropriate task for residential, as opposed to day service, staff.

Staff expressed concerns that about a general lack of good medical attention people with learning disabilities often experience 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.

**THE IMPLICATIONS**

- Women with learning disabilities have the right to information about what is happening to their bodies and to learn about experiences they have in common with other women. This suggests that those who support them have a responsibility to do so proactively, but this is not necessarily an easy or straightforward task. The use of pictures and other visual resources is strongly recommended. Menstruation and menopause related vocabularies in symbol and signing systems are also important.
- Women with learning disabilities expressed very clear and strong views that they wanted other women to support them through the menopause. Male carers and staff therefore need to be sensitive to this. Women staff who take on a direct support role may need training, specialist resources and good support from managers and colleagues. Older women staff who have personal experience of the menopause could usefully share their experiences and feelings with women with learning disabilities to help 'normalise' the experience.
- It is important for staff and carers not to impose their own agendas on women with learning disabilities, especially regarding the emotional or psychological impact of the menopausal changes. Because of their different life experiences (particularly opportunities to have children), the psychological impact is likely to be different for women with learning disabilities.

- Finally, and importantly, staff and carers in learning disability services have a clear role in encouraging women to live healthily (e.g. to have a calcium-rich diet) and in ensuring women get good access to primary health care. In turn, GPs and other primary health care professionals need to consider how they can make their services responsive to the ordinary and special needs of women with learning disabilities.

## REFERENCES

Carr, J. and Hollins, S. (1995). *Menopause in women with learning disabilities*, Journal of Intellectual Disability Research, Vol.39,2, pp. 137-139.

Cooper, E. and Welsh, R. (2001). *Making the Change*. Brighton: Pavilion Publishers.

McCarthy, M. (in press). *Going through the menopause: perceptions and experiences of women with learning disabilities*, Journal of Gerontological Social Work.

McCarthy, M. and Millard, L. (in press) *Discussing the menopause with women with learning disabilities*, British Journal of Learning Disabilities.

McCarthy, M. (2001). *Responses to women with learning disabilities as they go through the menopause*, Tizard Learning Disability Review Vol.7,1, pp. 4-12.

McCarthy, M. and Millard, L. (in preparation). *The Menopause and Women with Learning Disabilities: A Resource Pack*.

For Further information about the GOLD programme contact David Thompson, Project Manager, The Foundation for People with Learning Disabilities.

**The Foundation for People with Learning Disabilities is part of the Mental Health Foundation.**

---

*This Update was written by Dr Michelle McCarthy, Senior Lecturer in Learning Disabilities, Tizard Centre, University of Kent at Canterbury.*

The Foundation for People with Learning Disabilities is very grateful to all the companies and charitable trusts supporting the GOLD programme, in particular the Baily Thomas Charitable Fund, the Hayward Foundation, Comic Relief and the Bartley Trust.

For information on subscribing to **Updates**, please call 020 7802 0300

**The Mental Health Foundation**  
83 Victoria Street London SW1H 0HW  
Tel: 020 7802 0300 Fax: 020 7802 0301

**The Mental Health Foundation Scotland**  
5th Floor, Merchants House,  
30 George Square, Glasgow G2 1EG  
Tel: 0141 572 0125 Fax: 0141 572 0246

E-mail: [mhf@mhf.org.uk](mailto:mhf@mhf.org.uk)  
Website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

Registered Charity No. 801130