

# Is it Menopause?

Julie Fraser

Pam Patterson

Marg found her own way of coping with the hot flashes



# Partnerships

- Disability Services
- Women's Health
- Women Tasmania
- Speak Out Association of Tasmania





# What does the research say?

- “Very little is known about menopause in women with intellectual disability.”
- “Studies of menopause have found that the median age at menopause was 3 to 5 years earlier in women with intellectual disability compared with women in the general population.”
- “Women with Down syndrome and women with Fragile X appear to have especially early onset of menopause.”



# What does the Research say?

- “...the frequency of estrogen or hormone replacement therapy is much lower in women with intellectual disabilities than in women in the general population, so that they do not receive the same degree of preventive and therapeutic intervention as women in the **general population.**” Healthy Ageing – Adults with Intellectual Disabilities: Women’s Health and Related Issues. Aging Special Interest Research Group of the International Association of the Scientific Study of Intellectual Disabilities (IASSID) in collaboration with World Health Organization, Geneva.



## Stage I – Education Session for Support Workers. Aim:

- Explore what is normal at midlife and how this applies to women with ID.
- Gain information and strategies to support clients through their hormonal changes.
- Get current information on lifestyle, alternative therapies and medical management options
- Provide practical resources to take away and use with clients.



## Demographic of Support Worker Session.

- 28 participants including 2 men.
- Participants represented both residential and day support workers.
- 7 participants were themselves currently experiencing menopause.
- The remaining 19 participants had very little or no knowledge of menopause.




# Outcomes of Support Worker Session


- None indicated a thorough knowledge of menopause.
- **None** had considered signs and symptoms in the context of women they support.
- All had limited knowledge of treatment and support strategies in the context of women they support ie; diet, exercise, conventional or alternative therapies.



# Requests for further topics

- Osteoporosis
- Preventing and managing post menopause health issues such as
  - Heart disease
  - Diabetes
  - Obesity
  - Incontinence
- Breast screening
- Pap smears

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- Medical management of menopause
  - Complementary therapies and menopause
  - Motivation and achieving lifestyle changes
  - Sexuality and relationships
  - Screening for Colorectal cancer



## Stage 2 – Menopause Health Forum for Women with Intellectual Disability

- Give women with intellectual disability the opportunity to share and learn more about menopause and other health related issues.
- Prepare and share healthy foods
- Water activity



# Topics covered

- What is menopause
- Signs and symptoms
- Management of menopause
  - Including exercise
  - Healthy eating / lifestyle
  - Rest and relaxation
  - Medication and therapies
  - Recommended health checks
  - What you should expect from your doctor



## Stage 3 – Physical Activity

- Through the Burnie Moves Project participants were encouraged to take part in regular physical activity over a period of 12 months (this is continuing)
- Dancing
- Bike riding
- Sock Camps
- Water activities
- Yoga/relaxation



# Outcomes

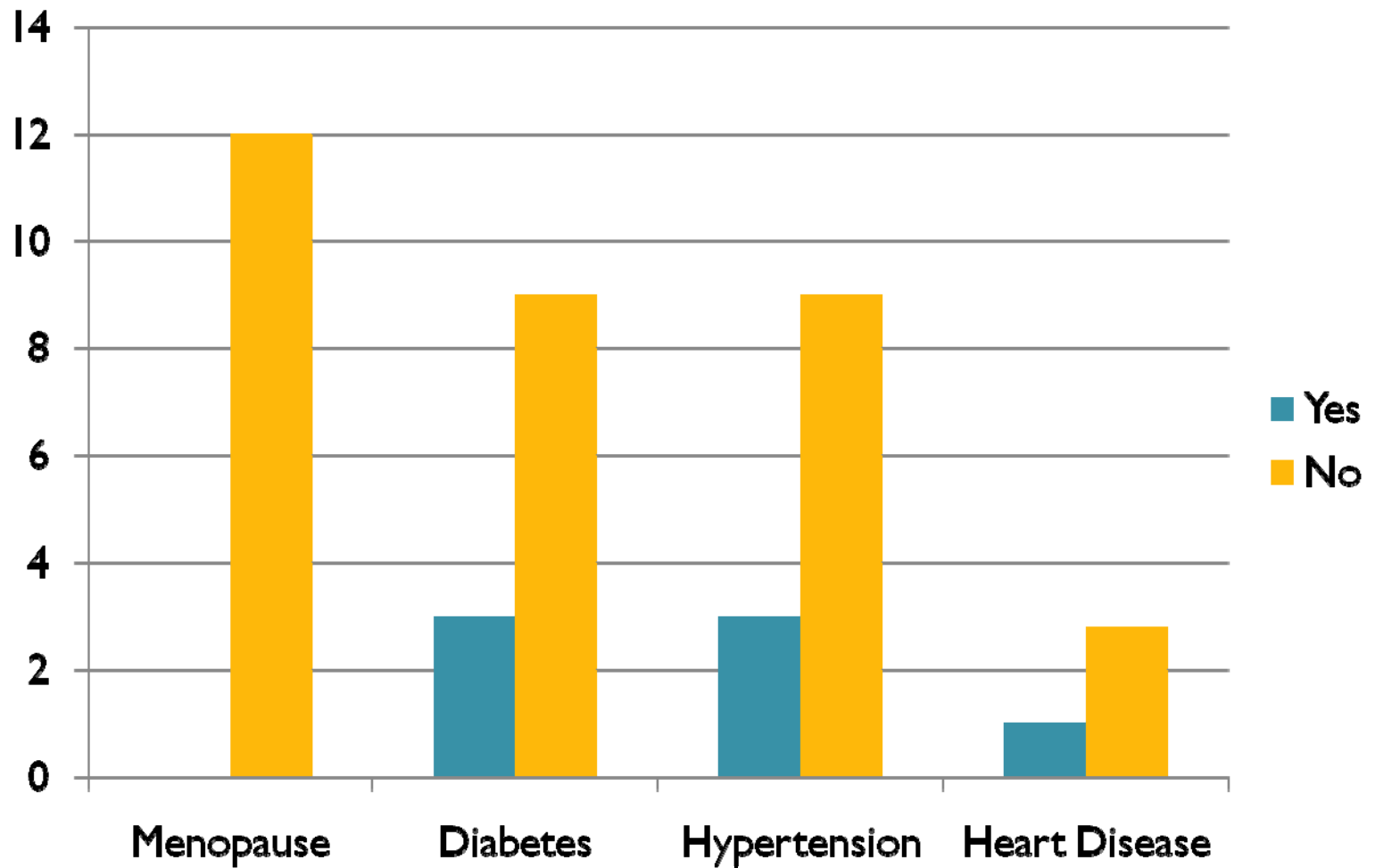
- 12 women with intellectual disability participated. Age – late 20's to late 40's
- Pre session questionnaire identified that -
  - None of the participants could identify what menopause was.
  - Knowledge of symptoms – Only one participant knew about hot flushes but thought they were related to being a mother.



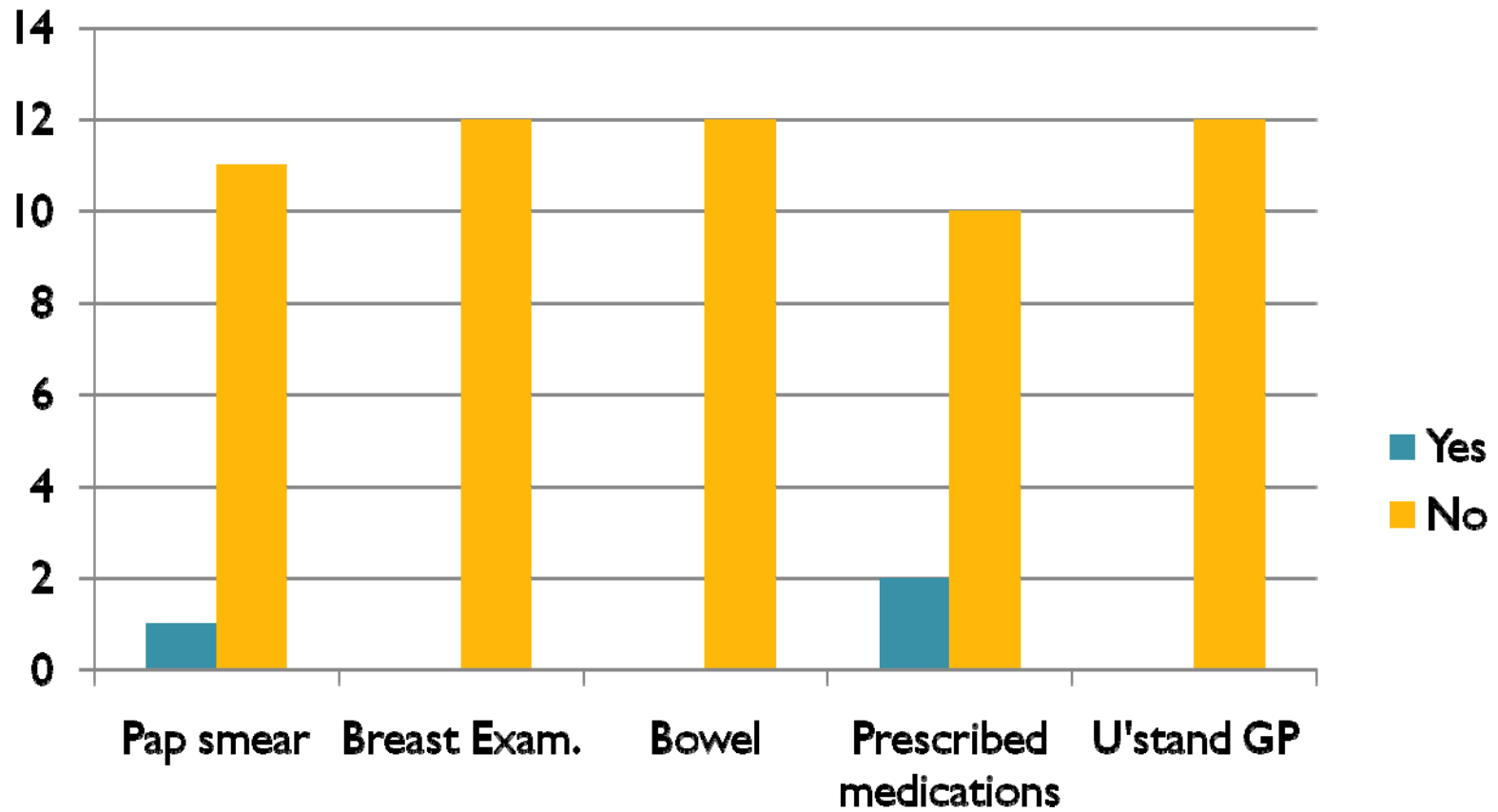
- **Treatment**


- No knowledge of treatment or support strategies ie diet, exercise, conventional or alternative therapies.
- When asked “Who could you talk to about menopause?” I indicated doctor – Living independently

# Discussions about health issues with GP.



# Contact with GP



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- Evaluations of the project concluded that not only did women with intellectual disability know very little if anything about menopause, but many support workers who were themselves experiencing menopause had significant gaps in their knowledge of menopause.



# Conclusions

This pilot study has highlighted

- The need for ongoing education for women with intellectual disability as they transition through life; including opportunities for group work
- Adequately resourced and experienced generic services to cater for the needs of women with intellectual disability.
- More emphasis on developmental and intellectual disability within health professional training.
- Health information that is accessible ie Easy English, alternative formats.
- Assertiveness and Self-Advocacy training for women with intellectual disabilities
- The need for support staff to continually update their skills and knowledge to meet the changing needs of the people they support and put them into practice.



# Resources

- **Menopause-Women in the Rhythm of Life** – Tasmanian Women’s Health Program
- **Supporting Women with Learning Disabilities through the Menopause** - Pavilion 2002
- **Screened Out** – Women with Disabilities and Cervical Screening; Pap Screening Victoria
- **Women First** – Breast Health for Women with Developmental Disabilities; Wyoming. Susan G. Komen, Breast Cancer Foundation
- **Preventative Women’s Health Care for Women with Disabilities – Guidelines for General Practitioners** – NSW Cervical Screening Program



# References

- David M. Martin et al (2008): *Journal of Intellectual Disabilities* (Eng)– *Women with Learning Disabilities and Menopause*
- Michelle McCarthy (2002): *Journal of Intellectual & Developmental Disability* (Eng)- *Going through the menopause: perceptions and experiences of women with intellectual disability*
- Dianne S. Willis (2008): *Journal of Intellectual Disabilities* (Scot)- *A decade on*
- Lynne Swanson (1998): *'Surviving the Change – Menopause and Women with Disabilities'*
- P.N.Walsh et al (WHO and USA): *Healthy Ageing – Adults with Intellectual Disabilities and Women's Health and Related Issues*
- Joanne E. Wilkinson, MD MSc et al: *Journal of the American Board of Family Medicine* , *Clinical Review– Primary Care for Women with Intellectual Disabilities*