



# Menopause & Me

WAVE workshop

EACS 2019 Conference

Sophie Strachan

Lived Experience

Co Chair – Sophia Forum



# Brief history

- Diagnosed HIV + in May 2003
- First attended Royal Free ICDC in 2004
- Started ARV around 2009/10
- After initial diagnosis started losing my hair due to stress
- 2011 treatment change due to interaction of steroid and PI Ritonavir
- Developed Cushing's and amongst other side effects started losing hair



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# My health over the years

- Low mood / depression/ PTSD (with years of good mental health too)
- Impact of stigma – psychological, emotional,
- Long term chronic stress
- Long term chronic pain due to multiple prolapsed discs in back and neck
- Fatigue
- Muscle aches pains



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# 2016

- Lower back surgery August 2016 – Result!
- Car crash December 2016 – back in pain with added whiplash injury two months off work
- Long term relationship, wanting children, discussions for the last 2 years.
- No where on my radar was the menopause and no conversation had ever taken place with any health professional including my HIV consultant. I'm 44 years old
- My focus was wanting children ( amongst other life events)



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# Is this the menopause ?

- First conversation with HIV consultant April 2017– no cycle for 4 months, low mood,
- ? Is it stress related? Post car crash ?
- Is low mood linked to increased pain from car crash ( very likely) but is it also linked to menopause?
- How old am I ? 44
- Could be peri-menopausal – refer to specialist for blood tests



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# Time is not on my side

- Told by specialist you need to get pregnant now
- IVF, sperm donor, egg donor options on the table – none possible as no money to be able to afford any of these processes.
- Increasing symptom's, hot flushes, brain fog, loss of libido, irritability, mood swings, insomnia, loss of confidence
- Facing a reality
- The unexpected



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# Worsening Symptoms despite HRT

- Cognitive changes
- Psychological
- Lack of motivation
- Insomnia
  
- Latest addition.. Hair loss ☹️ ☹️



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# Recommendations

- We need to develop strong life course models of care and programs for women living and ageing with HIV, looking beyond the biomedical lens.
- Start conversations around the menopause with women in their reproductive years, including the needs of trans men
- Training for all health care professionals around the menopause including effective management
- Do not under estimate how debilitating and devastating the menopause can be for some women
- Invest in and support organizations who are developing resources with dissemination in your health care settings and beyond



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# Just a few more

- A personal ask..
- Please don't use language like 'complex'
- Sensitivity during consultations
- I never knew a specialist menopause clinic even existed so please help your patients by finding out where they may exist locally
- Reduce the age range to below 45 on studies for women, for those entering the menopause early
- Twitter has been one of my main sources of getting information,



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# Current Initiatives

- Sophia Forum has partnered with Chelsea & Westminster hospital to run a support group for both women living with HIV and some groups for non positive women
- WISEUP Women and Ageing weekend including the menopause.
- Next steps from WISEUP weekend
- FB live event in February with a trans male focus



# Thank you

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