2019

Making the Case for Better Menopause Services in Wales

FTWW

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Foreword *by Diane Danzebrink*

I am delighted to be writing a foreword for this important report. I have followed the work and progress of FTWW with great interest for a few years now, as we share many common aims with regard to improving access to, and quality of, women's healthcare services.

Having worked with, and supported, many women living and working in Wales, it has become very clear that women in the region are experiencing a loss of personal health and well-being, the loss of jobs and careers, and the breakdown of relationships, as a direct result of their menopause symptoms and a lack of appropriate care and services available to them. Those women who present with complex medical histories are particularly poorly served as there are very few specialist menopause clinics in Wales; many currently have no access to a specialist service at all.

My experience of working with women based in Wales is reflected many times over when I speak with the team at FTWW. Menopause will affect every woman, and it is high time that this phase of a woman's life was adequately supported in a timely manner to avoid the women of Wales continuing to suffer in silence.

This report will provide NHS Wales with invaluable insight on how to improve menopause services across the country, including the provision of factual, evidence-based information and skilled professionals, enabling every woman to make informed choices about how she manages her menopause symptoms. As always, FTWW has provided a broad range of service-user perspectives; I believe it would be wise to take notice of such a powerful evidence-base.

Diane is a menopause counsellor, with nurse training in menopause. She is a member of both the British Menopause Society, and the Royal College of Obstetricians and Gynaecologists' Women's Voices Involvement Panel. She is a leading figure in the world of menopause awareness, having launched the #MakeMenopauseMatter campaign in Westminster in 2018. Her campaigning has successfully resulted in the creation of a dedicated menopause forum at Westminster, chaired by Jackie Doyle Price MP and Rachel Maclean MP, as well as a UK Government commitment to include menopause in England's school curriculum from 2020. She is regularly asked to speak at events and in the media; recent appearances have included BBC's Breakfast Show, BBC Look East, and The Telegraph.

1 What is menopause?

1.1 Definitions:

The menopause is when a woman stops having periods and is no longer able to get pregnant naturally. It is caused by a change in the balance of the body's sex hormones, which occurs as women get older. The ovaries stop producing as much of the hormone oestrogen and no longer release an egg each month. This usually occurs between 45 and 55 years of age. In the UK, the average age for a woman to reach the menopause is 51.

NHS UK tells us that, ‘On average, most symptoms last around 4 years from (the date of their) last period. However, around 1 in every 10 women experience them for up to 12 years’ and, ‘About 8 in every 10 women will have additional symptoms for some time before and after their periods stop. These can have a significant impact on daily life for some women’ (1).

Peri-menopause is the time-frame in which periods hormones fluctuate, periods become erratic, and symptoms commence. This stage can begin as many as 10 years before full menopause (denoted by the complete cessation of periods).

Around 1 in 100 women experience the menopause before 40 years of age. This is known as **premature menopause or premature ovarian insufficiency**.

Premature or early menopause can occur at any age, and in many cases, there's no clear cause. However, sometimes it's caused by breast cancer treatments, chemotherapy or radiotherapy, or it can be brought on by an underlying medical condition, such as Down's syndrome or Addison's disease (2).

Surgical Menopause is when women undergo an operation to remove their ovaries, called an oophorectomy. If both are removed at the same time – a bi-lateral oophorectomy – this will cause the woman to go into immediate menopause. However, sometimes, even if only one ovary (unilateral oophorectomy) is removed, or just the uterus (hysterectomy) the loss of blood supply to the remaining ovary / ovaries can be enough to reduce their function and induce menopause.

At time of writing, these operations are performed regularly across Wales, not just for malignancies but also for benign gynaecological conditions, such as endometriosis. This is despite oophorectomy not being recommended by NICE as a first-line treatment for the disease.

Medical Menopause is when women are given hormone-manipulating drugs called Gonadotropin-releasing hormone (GnRH) analogues. Essentially, they cause the ovaries to shut down, inducing a temporary menopause. This mechanism is used to ameliorate some patients’ symptoms of various menstruation-related health conditions, such as endometriosis and pre-menstrual dysphoric disorder (PMDD).

It is recommended that GnRHa be given alongside add-back hormone replacement therapy (HRT) to reduce associated loss of bone density. However, in some instances, the ovaries do not recover full functionality post-treatment and so women can find themselves in a permanent menopause.

2 Why is menopause an important consideration for Wales?

Women make up 52% of the population in Wales. At some point in their lives, those women will experience menopause.

As of March 2019, in Wales, between 60-70% (3) of women aged between 50 and 64 (the years in which menopause is most likely to be taking effect) are in employment, resulting in their comprising almost half of Wales's workforce (4).

In addition, women at the average age of menopause are also described as being the 'sandwich generation', ie women who are providing care for both children or grandchildren, as well as older relatives. WEN Wales's report on unpaid care tells us that, 'The vast majority of women have at least one child for whom they are likely to take primary responsibility, and women have a 50:50 chance of having spent a substantial period caring for an adult by the time they are 59 years old' (5).

It isn't hard to see, therefore, that women going through menopause are also at the age where they will often be expected to perform a huge number of other duties, both within the workplace where they are likely to be at the peak of their career progression, and at home, where they may well have unpaid caring roles and be responsible for at least 70% of household chores (6).

Given the economic and societal burden upon women aged 45 and over, universal access to better menopause support and treatment would seem prudent, if only so that symptom-management can be improved, enabling the continuing fulfilment of those roles listed above. The TUC's research into working women going through menopause found that 80% experienced noticeable changes and that, of these, 45% found their symptoms difficult to deal with (7).

It isn't uncommon for women to have to leave employment as a consequence of their symptoms and / or to require many interventions from healthcare professionals in an effort to deal with its effects.

3 Symptoms of menopause

8 in 10 women going through menopause will experience symptoms in addition to heavy, erratic bleeding prior to complete cessation of periods (8).

These symptoms may include:

3.1 Vasomotor Symptoms

These are symptoms governed by the part of the brain that manages blood pressure, such as hot flushes and night sweats, considered to be amongst the most common issues associated with menopause.

Hot flushes are the sudden sensation of heat that affects the chest, neck, and face. They can also cause excessive perspiration which can be uncomfortable, embarrassing, and anxiety-inducing. They can last for a few minutes or hours.

Night sweats are episodes of extreme sweating, soaking night and bed clothes and resulting in disturbed sleep. They can occur several times in one night. The impact on mental and physical health cannot be under-estimated.

Vasomotor conditions can also cause feelings of anxiety and heart palpitations.

A woman going through menopause may experience vasomotor symptoms for 5-7 years. However, some women may have symptoms that last up to 11 years or even a lifetime.

Women with vasomotor symptoms may also be at a higher risk of heart disease, bone loss, and early atherosclerosis, a hardening of the arteries that can lead to heart disease and raised risk for heart attack (9).

3.2 Urogenital Atrophy

This is the thinning and shrinking of the tissues of the vulva, vagina, urethra, and bladder, caused by loss of oestrogen. Symptoms are multi-fold and include vaginal dryness, irritation, localised bleeding, pain, a frequent need to urinate and recurring urinary tract infections (10).

3.3 Other physical symptoms

These commonly include:
Dry skin and mucous membranes, hair loss, weight gain, peripheral neuropathy (pins and needles / numbness in hands, feet, arms and legs), headaches and / or migraines both with and without visual disturbances, joint pain and stiffness, reduced muscle mass, and altered sexual function or loss of libido.

3.4 Psychological symptoms

Many women report low mood as a result of their hormonal changes. However, in some instances, symptoms can be severe and evidence of clinical depression. Anxiety is another very common feature of menopause. For those women who experienced mental health issues during or after pregnancy, recurrence of these is not unusual.

Problems with cognition are also regularly reported, with many women experiencing memory loss, difficulties concentrating, and 'brain fog', where they struggle to express themselves clearly.

Loss of confidence and self-esteem, mood swings, and episodes of tearfulness are also not unusual.

3.5 The Everyday Impact of Symptoms

According to a May 2016 survey (11) conducted by Ipsos MORI on behalf of the British Menopause Society (BMS), one in two women in Great Britain go through the menopause without consulting a healthcare professional. This is despite those same women reporting on average seven different symptoms and 42% saying their symptoms were worse or much worse than expected.

Headline figures from that survey include:

50% reporting that symptoms had negatively impacted on their home lives;

50% reporting that symptoms had negatively impacted on their sex lives;

36% reporting that symptoms had had a detrimental effect on their social lives;

More than 33% reporting that symptoms had impacted their work lives.

3.6 In Wales, our survey respondents said…

‘I have been unable to function since becoming menopausal and experiencing every menopause symptom possible…I became isolated , crippled with anxiety and lost myself completely…It is ruining women’s quality of life and health’ (TB)

‘I have been going through the change and thought I was mentally ill for years’ (DD)

‘…Fast and debilitating symptoms (make) women leave their jobs…Women may have worked all their lives to reach those positions, or may be the sole earner of a family’ (LP)

‘There are still issues I am struggling with, the worst ones being occasionally still getting very down and tired and having period flooding. I'm reluctant to go back to the doctors to ask for more help’ (RJ)

‘(Menopause) led to me leaving my vocational job as I couldn't cope with the sleepless nights, constant brain fog, lethargy, anxiety and lack of confidence’ (LN)

‘I’ve struggled with both chemical and surgical (menopause). It’s a joke to some people when you’re a bath of sweat, boiling hot, feeling like someone is choking you and your brain feels like mush’ (DW)

4 Long-term health implications of menopause

4.1 Osteoporosis

One of the most common and widely known long-term implications of reduced oestrogen is osteoporosis.

Osteoporosis is a fragile bone disease which causes painful and debilitating fractures, mainly of the wrist, hip, and lower spine. The latter is often responsible for the ‘dowager’s hump’ seen in older women, which can make daily activities and mobility very difficult.

Women lose bone rapidly in the first few years after the menopause and are more at risk of osteoporosis than men, particularly if the menopause begins early (before the age of 45) or they've had their ovaries removed.

50% of women over the age of 50 will have osteoporosis, compared to 20% of men of the same age.

One in five women will break 3 bones before being diagnosed, despite it being so common in women aged over 50.

Early diagnosis, using a DEXA scan, and intervention, such as oestrogen-based HRT can prevent a good many osteoporosis-related fractures in women. DEXA scans should be offered as a matter of course to all menopausal women, particularly those who have a history of missed periods and / or early-onset menopause.

300,000 fractures a year can be attributed to osteoporosis

Across the UK, osteoporosis costs the NHS £6million per day (12).

4.2 Heart disease

One of the less appreciated long-term repercussions of menopause is the impact loss of oestrogen can have on women’s cardiovascular health.

Up to the point of menopause, women are less at risk of heart disease and heart attacks than men, primarily because of the protective effects of oestrogen. Once this has

diminished, women's risk equals that of men, with 3.5million women in the UK living with cardiovascular disease, the same number as men.

28,000 women die from heart attacks in the UK each year – 3 per hour – and women are also more than twice as likely to die in the 30 days following their heart attack than men partly because they are diagnosed later and partly because they are less likely to receive guideline-recommended care (13).

Twice as many women die from heart disease as breast cancer in the UK. The myths and misinformation that have led to so many (young) women, and their medics, fearing HRT because of perceived, and what are now considered to be over-stated, risks of breast cancer should be contrasted with the current evidence regarding heart disease. In particular, women who are in premature menopause should absolutely be accurately informed of the risks and benefits of HRT.

Quite simply, a great deal more emphasis needs to be placed upon both prevention of cardiovascular disease in women, as well as improved symptom awareness for both women and their healthcare providers. Fully appreciating the role of ovaries in maintaining heart health is crucial, so that they're not removed without truly informed consent. There is also growing evidence that timely administering of HRT can have a beneficial effect on women's cardiovascular well-being (14).

4.3 Dementia

New research suggests a possible link between reduced oestrogen levels and increased risk of dementia.

Whereas once it was thought that women's longer life expectancy might explain their being more likely to develop dementia, in the UK, the difference in female to male longevity has now reduced to just over 2 years. As a result, life expectancy can no longer account for the far greater numbers of women affected.

In fact, in the UK, 62% of people with dementia are women and 31,850 women die in the UK every year as a result (15).

The fear of taking HRT as a result of negative publicity around the risks of breast cancer, a risk which is now widely accepted as having been over-stated, has meant that the risk of Alzheimer's Disease has been over-looked. In fact, current estimations are that women over the age of 60 are twice as likely to develop Alzheimer's Disease as they are breast cancer (16).

Certainly, many women complain of cognitive problems during menopause which can be misdiagnosed as early onset dementia. Menopause can also have such extreme effects on physical and mental health – which in turn have been associated with future development of dementia – that it seems to make sense to intervene early to improve women's health and well-being as they go through this tumultuous time in their lives.

4.4 Suicide

Whilst it remains the case that three times as many men as women commit suicide, research shows that, actually, in the UK, more women than men attempt to end their lives each year (1 in 14 women, compared to 1 in 25 men) (17) with the highest number of completed suicides amongst women being in the 45 – 55 age bracket, the time at which the vast majority will experience menopause (18).

As described on page 2 of this report, these women are known as the 'sandwich generation', with work and caring responsibilities, at the same time as they are experiencing the effects of swingeing hormonal changes.

The Mayo Clinic comments that 'Risk of depression may increase during the transition to menopause…when hormone levels may fluctuate erratically. Depression risk may also rise during early menopause or after menopause — both times when oestrogen levels are significantly reduced' (19).

In its 2014 report, 'Preventing Suicide: A Global Imperative', The World Health Organisation calls for all countries to develop a national strategy for suicide prevention (20); it seems that Wales, with its considerable population of women over 50, should be looking at intervention in the form of dedicated, comprehensive, and easily accessible menopause-related services as a priority.

4.5 The Impact of Women's Long-term Health Issues on Wales

It is important to note that comparisons with other countries in the UK show Wales as having, overall, an older population (21).

Older women continue to outnumber men, although the difference in life expectancy has narrowed to around 2 and a half years (22).

According to an analysis by AGE UK, women in Wales are likely to spend up to 24 years of the latter part of their lives suffering a long-term illness, health problem or disability that limits day-to-day life (23).

As a consequence, costs to health and social care are disproportionately higher in Wales than elsewhere in the UK. It is vital therefore, that Welsh Government starts to consider how they can focus early intervention in women's health on the provision of gold-standard menopause care – to include HRT – as a key mechanism for prevention of long-term health issues, including osteoporosis, dementia, heart disease, and depression, even suicide.

4.6 On these issues, our survey respondents said…

'The most I've had is advice to see the GP because I'm high risk for osteoporosis, being under 50. No mention of specific, menopause support'. (SP)

‘I have a family history of heart problems, but I was still put into surgical menopause with no discussion about risks. I’m now under the cardiology team, as I am suffering with chest pains which are very frightening’. (DS)

‘I was repeatedly told by both female and male GP's I was not and could not possibly be going through menopause, my mental function got so bad they even suggested Alzheimer’s’ (CD)

‘Menopause is incapacitating…Difficulty with word finding, articulation, memory lapses, mood changes - anxiety/depression, insomnia, reduced ability to multitask or simply concentrate on a single activity…’ (WB)

‘As someone who suffered depression after childbirth and suffered much worse during peri-menopause, my doctors insisted it was not and could not relate to this…People will say, menopause is not life threatening, when actually for many women it can and has been’ (CD)

‘I am a woman who has spent the past 6 years in hell. The menopause robbed me of my sanity and life’ (TC)

5 Treatment of Menopause

In Wales, the UK, and across the globe, medical professionals are largely confused about how to deal with menopausal women. This confusion can be attributed, in no small part, to negative messages coming from the media about the risks and benefits of Hormone Replacement Therapy (HRT).

Numbers being prescribed this medication are at their lowest and this is directly linked to the huge amount of negative press following two studies undertaken in the 1990s – the Women’s Health Initiative in the USA, and the Million Women Study in the UK – which found that the use of HRT posed a significant risk to those taking it, mainly in the form of increased risk of breast cancer. Those studies have subsequently been found to be flawed, and their findings debunked.

In 2015, and on the back of many subsequent studies, including a re-evaluation of the research mentioned above, NICE published updated guidance which clearly demonstrated

the benefits of HRT. This guidance showed that HRT can, in fact, be an enormously powerful tool in helping women manage debilitating menopausal symptoms, as well as reducing those long-term health risks which come with being untreated, including cardiovascular disease and osteoporosis, both of which remain the biggest killers of post-menopausal women.

The problem is that 'good news' doesn't usually attract much media attention. As a consequence, patients and clinicians alike are still labouring under the misapprehension that HRT is something to be largely avoided. Busy healthcare providers don't have the time to read lengthy NICE guidance and, according to the many reports we have received from women across Wales, clinicians remain either unaware of the information that would enable them to support their patients to make an informed decision about how to treat their symptoms, or reluctant to prescribe for medico-legal reasons.

Likewise, aside from notable exceptions for breast and cervical cancer screening, women's health more generally isn't an area which attracts much in the way of public awareness campaigns, with menopause no exception. As a result, women themselves are often ignorant to both symptomatology and impact of menopause, as well as the potential benefits of HRT.

Online, there are a proliferation of web resources disseminating unreliable and inaccurate information so, unless women know where to look for reliable guidance, they remain unaware, unsupported, and struggling in silence.

5.1 Key Recommendations from the 2015 NICE Guidelines on Menopause:

5.1.1 Person-centred care

One of the central tenets of the NICE guidelines (24) and the BMS's follow-up recommendations (25), both of which will be examined in more detail in this section of our report, is the need to treat each woman as an individual with unique needs, 'All women are different and respond differently both to oestrogen deficiency and in their response to treatments' (26).

The BMS goes on to describe the process as follows, 'Decisions have to be made on an individual basis, taking into account symptoms, past history, family history, diet and lifestyle and individual preferences and concerns' (27).

In support of this, Wales's Prudent Healthcare Principles (28) prioritise the concept of patients and professionals being 'equal partners', with shared decision-making being vital. Where menopause is concerned, this requires the dissemination of impartial information, and dialogue around 'what matters' to the individual.

5.1.2 Blood Tests

Diagnostic blood tests should not be required to diagnose perimenopause or menopause in women aged over 45. Instead, diagnosis should be based upon discussion of symptoms – which, given the numbers of women affected, should be made a priority knowledge area for

all HCPs. This reduction in unnecessary blood testing would undoubtedly produce cost-savings for NHS Wales.

5.1.3 Information

NICE emphasises the vital role of informed choice for women affected. This means that Healthcare Providers should be both willing and able to explain the various stages, symptoms and long-term health implications of menopause to their patients. This extends well beyond paternalistic references to 'just hot flushes' which many women in Wales cite as being the only thing to which reference is ever made and, often then, a subject of comedy.

It is also noted that information for women who are about to undergo medical or surgical treatment which may lead to menopause is an absolute necessity. Huge numbers of women who contact FTWW for post-treatment support describe a total lack of discussion or literature both before and afterwards. Clearly, leaflets and online resources are helpful – but so too are extended consultations with healthcare professionals when it comes to something so life-impacting as menopause.

5.1.4 Management

Diet and lifestyle advice should be considered and discussed, as well as social prescriptions to supporting interventions and agencies provided.

HRT should be offered after full consideration of risks and benefits. It remains the most effective treatment for menopausal symptoms and has minimal risks. It improves quality of life and enables women to 'return to their old selves'.

Oestrogen-based HRT is the primary mechanism of prevention of osteoporosis and is licensed as such.

Contrary to much mythologising, according to those menopause experts in attendance at the All-Wales Menopause Summit of June 25th, 2019, there are no real contraindications to taking HRT – not migraine, not high cholesterol, not high blood pressure. In fact, there is evidence to suggest that HRT may actually reduce some of these problems, especially if they started during peri-menopause or post-menopause.

The type of HRT prescribed would be governed by the patient's medical history, including whether or not she has had a hysterectomy, her stage of menopause, family history, other medication and individual preferences.

Countless women from across Wales continue to report being offered anti-depressants over and above HRT. This despite it *not* being a NICE-recommended treatment for psychological symptoms associated with menopause *and* being more expensive. For low libido, testosterone can be considered alongside ordinary HRT.

5.1.5 Management of patients with a history or risk of breast cancer

Women who have had breast cancer or who are thought to be at high risk of breast cancer and who have menopausal symptoms should be offered a discussion about all treatment options, including HRT. These women should receive care from menopause specialists due to potential drug interactions.

5.1.6 Urogenital atrophy

Oestrogen deficiency can cause significant vaginal and bladder problems yet is hugely under-recognised and under-treated, partly because women are often too embarrassed to seek help and partly because symptoms are often dismissed or diminished as being 'a bit of dryness which can be remedied with a lubricant'. However, NICE recommends that vaginal oestrogen should be offered as a matter of course. For those women whose symptoms are not resolved, a referral to a menopause specialist is advisable.

5.1.7 Premature Ovarian Insufficiency (POI)

Women experiencing menopause (ie erratic / absent periods) under the age of 40 should, firstly, have their diagnosis confirmed by blood tests. HRT can be offered and continued at least until the average age of menopause (51 years), unless there are contraindications. This is essential for bone and cardiovascular health as well as symptom management. Once again, women with POI should have access to a menopause specialist.

5.1.8 On-going care

NICE goes on to recommend that, three months after commencing HRT, a review with a healthcare professional should be organised. Only once the patient is satisfied with their treatment regimen should these consultations be reduced to annual check-ups.

Referral to a menopause specialist should be offered to women who have a complex medical history, if there are persistent side-effects from their treatment, or if there are difficulties finding optimum treatment for symptom control.

As we will explore further in Section 6 of this report, 'The Current Situation in Wales', for most women in Wales, there are no menopause specialists or dedicated clinics available within their health board, meaning that their care is frequently not up to the standard expected by NICE, the recommendations of which Welsh Government has made a historical commitment to fulfilling (29).

5.1.9 Treatment regimens

Contrary to previously held views that HRT should be ceased after 2-5 years, or at the age of 60, the evidence explored by NICE shows that there are no good reasons to impose such limitations.

5.1.10 Long term benefits and risks of HRT

For many women, appropriate use of HRT is beneficial. However, as discussed in 5.1.1 'Person-Centred Care', it is important to discuss benefits and risks with each individual woman, taking into account her diet, lifestyle, past medical and family history.

For more detailed information on the different types and effects of HRT, we would recommend reading NICE 'Menopause: Diagnosis and Management' (30) and / or BMS 'Menopause Diagnosis and Management from Guideline to Practice' (31) as this is not within scope of this report. However, we should emphasise that the guidelines now make clear that there is no need for any arbitrary, age-related cut-off point for the taking of HRT.

5.2 In Wales, our survey respondents said…

'My GP says…if you are 53 there is no point going on (HRT) because you'll only have to stop again! No discussion of risk or patient choice' (KC)

'Menopause without HRT is unbearable, it improves quality of life so much' (JC)

'At my appointment, although I felt like someone was eventually listening to me, the health professional did not seem to be fully aware of the NICE guidelines about prescribing HRT' (LN)

'I'm 42 and…11 weeks post op from a total abdominal hysterectomy with both ovaries and tubes removed and I feel very alone. I was given HRT but…I have so many unanswered questions. There are so many symptoms physical and emotional that I am facing alone' (LR)

'The Consultant Gynaecologist told me I was possibly experiencing perimenopause symptoms and prescribed HRT - 2 months (on) and I'm starting to feel my old self again, thankfully the blackness and constant sadness is starting to go' (TB)

6 The Current Situation in Wales

Currently, in Wales, women are dependent upon GP knowledge of menopause and its symptoms to access NICE-recommended treatment, ie HRT.

Unlike other conditions which are perceived to have a large public health impact, with the onus on prevention and early intervention, such as diabetes, COPD, and heart disease,

women's health (despite comprising heavy menstrual bleeding, endometriosis, and menopause which have a similar, if not greater, 'disease / impact burden') is not incentivised as an area requiring any special attention or additional training within primary care.

This has had the unfortunate effect of making women's health a 'poor relation' in terms of early diagnosis, understanding of treatment options, and universal access to effective care. Many women report its being 'pot luck' as to whether they (ever) see a GP or practice nurse in Wales with knowledge of menopause and its associated NICE recommendations, let alone a menopause specialist or dedicated clinic.

6.1 Primary Care

Unfortunately, in primary care, many women in Wales report having their symptoms misunderstood, particularly when it comes to psychological symptoms, such as anxiety, depression, mood swings or insomnia. Too many women find that they're automatically assumed to have a mental health condition, even if there is no prior history and their age-profile or circumstances should indicate menopause as a likely cause. Instead of being offered HRT as a first-line treatment, in line with NICE guidance, these women tell us that they're being persuaded to take anti-depressants, with little to no effect. Of course, anti-depressants won't provide the same sort of health benefits as HRT – and it should also be pointed out that, on the whole, they cost the NHS more money.

A major issue with the NHS's way of providing care, including in primary care settings, is to view symptoms in isolation instead of collectively. If women's symptoms were analysed holistically, by someone with a special interest in menopause, that may well speed-up the pathway to appropriate care, improving well-being and saving money. Indeed, Welsh Government's own Prudent Healthcare programme makes clear that one of its main foci for change is to 'radically change the outpatient model, making it easier to get specialist advice in primary care settings' (32).

However, where menopause is concerned, currently, many women in Wales instead find themselves being referred to a range of consultants in secondary care, including cardiology, rheumatology, and neurology, each one with a waiting list of up to 6 months. It isn't hard to see how this can lead to women being shuffled around, from department to department, with no clear answers as to how to proceed.

Nevertheless, when the GP suspects menopause as a cause of symptoms, and where there are assumed contraindications to HRT, the option to refer to secondary care, ie the local gynaecology service is available.

6.2 Secondary Care: Gynaecology

In Wales, the referral-to-treatment time should not exceed 24 weeks. However, gynaecology services are stretched across the country and so, women can be waiting in excess of 6 months for a first appointment with a gynaecologist to discuss their potential menopause symptoms.

According to the British Menopause Society's map (33) most gynaecologists in Wales have not undertaken the specialist menopause training offered by the BMS or FSRH. This means that many women will be waiting long periods to see a consultant who, in most cases, has limited knowledge of menopause or how best to treat it.

Often, women will require several appointments to try various types of HRT, combinations, and strengths. With each gynaecology appointment attracting a 6-month wait, this can potentially add a couple of years to the patient journey in Wales, with symptoms progressively and negatively impacting on patients' lives in the meantime.

6.3 Tertiary Care

Recognising the need for longer appointments and shorter waiting times to discuss various physical and psychological symptoms of menopause with an accredited specialist, some health boards in Wales have set about providing a dedicated menopause clinic for their population, particularly those patients who have struggled to access accurate information or treatment locally, or who have more complex needs.

Aneuryn Bevan UHB and Cwm Taf Morgannwg UHB both offer a specialist service but, due to patient demand, they are only available via a GP / consultant referral and have waiting lists of around 4 months each. In North Wales, and with FTWW's support and assistance, Betsi Cadwaladr UHB is in the process of assessing a business case for a pilot specialist menopause clinic, which would run in North-East Wales and similarly require a GP / consultant referral. The problem, of course, with such a triage system is that it presumes knowledge in primary care both of the existence of such a clinic and that symptoms may be attributable to menopause in the first instance. A significant number of women in Wales have made it clear that, in their experience, this knowledge is lacking.

With only 2 - potentially 3 - health boards in Wales providing some form of tertiary care for its menopause patients, this inevitably results in variation – and possible harm - being experienced by women across the country.

The NHS system in Wales demands that patients ordinarily be seen within their own health board's borders so, if a service isn't available, women lose out. For those wishing to be seen 'out of area', there is the option of an Individual Patient Funding Request (IPFR) but this is rightly perceived by HCPs and patients alike as being long-winded, complicated, and with no guarantee of success. As a consequence, many GPs / local consultants are reluctant to spend time completing one and patients are often not aware that they can attempt to complete one themselves – nor do they have sufficient support to be successful.

6.4 Outside of Healthcare

In short, women report to us that the system of menopause care in Wales is beset with problems, starting with their own lack of awareness of what constitutes menopause and the multifarious ways in which it presents.

Like many menstruation-related conditions, menopause is subject to both taboos and normalisation, which means that many women feel that they have to struggle on in silence,

fearful of derision, mockery, and a lack of understanding from those around them, including, on occasion, their healthcare providers.

Whilst puberty and periods are touched-upon briefly in schools in Wales, the vast majority of women report never being formally taught anything about the time at which periods will end, including what to expect, or the long-term implications. Increasingly, as more girls go on to become healthcare professionals themselves, this perpetuates the knowledge-gap.

Women across Wales report being left to fend for themselves during menopause, a struggle compounded by little understanding of what is happening to them in the first instance, and then being forced to navigate the medical landscape themselves, often whilst at their lowest ebb.

As this campaign and report indicates, many have found their way to FTWW, whose remit is to provide evidence-based information and support within the Welsh context. However, despite an increasing reliance on the third sector to provide such services, or 'social prescriptions', there is very little funding available for patient-led organisations like ours to deliver what has become a life-line for so many women. Welsh Government needs to do a lot more to support organisations like FTWW, so that we can continue to share our breadth of experience with both women themselves, empowering them to manage their own health and advocate for themselves, and service-providers.

6.5 On this topic, our survey respondents said…

'I am 1 year + into surgical menopause and was given no after care, support or guidance after my operation (total abdominal hysterectomy)! Things need to change…' (EJ)

'I visited (the) GP on numerous occasions with totally debilitating symptoms…severe panic attacks, sleeplessness, horrendous anxiety, all came from nowhere. (I was) given…anti- depressants, sleeping tablets, beta blockers and counselling and appointments with mental health team. (I) ended up paying private as genuinely thought I was going mad!' (TB)

'I received little help from health professionals as doctors do not recognise many symptoms of menopause. I therefore researched and put in place my own menopause care' (TC)

'I don't want my daughters to reach 40 and feel isolated if they start going through the menopause at that age too. I found doctors telling me I was too young, even though I told them my mum had gone through menopause by 48, difficult to deal with…' (RJ)

'The reluctance of GP's to prescribe HRT is costing the health service a fortune in overprescribing of antidepressants and other medications (as well as) unnecessary appointments' (TB)

'I have tried to get help with my symptoms from 3 different doctors now and each one of them just basically shrugged their shoulders' (MS)

'I believe that more specialised centres are the way forward. Staff also need to be knowledgeable and educated in natural, complimentary therapies to help women who suffer with a variety of menopausal symptoms' (LM)

7 Menopause as a Public Health Wales Issue

7.1 The inclusion of Menopause in Public Health Wales's Sexual Health Specification (34)

The inclusion of menopause in the Sexual Health service specification seems rather arbitrary, given that it wouldn't ordinarily fit with the Public Health remit around 'protecting the public from infection and environmental threats to health' (35).

Typically, Public Health Wales's sexual health responsibilities will focus on issues where prevention and / or early intervention is either possible or conventionally desirable, such as Sexually Transmitted Infections (STIs) and contraception. It is for this reason that FTWW didn't respond to Welsh Government's consultation on the specification. Indeed, in the document's 'Summary of Service Requirements', the focus – as one would expect – is on STIs, contraception, and abortion. Menopause isn't mentioned once probably because, generally-speaking, there isn't the same appreciation of early intervention and prevention (of longer-term health problems) as part of any conversation about the issue.

7.2 Concerns about Menopause within the Sexual Health Specification

Whilst we welcome menopause being given this platform, ensuring that it does, at least, garner health boards' attention, there are still some issues around its placing within Public Health that we would like to address.

a) Unlike other Public Health Wales campaigns or strategies, there is currently no 'screening' programme in place to alert women and their healthcare providers to symptoms, treatment, or location of services;
b) As far as we know, no numbers are being collected on women requiring intervention or support for menopause; the same would apply to the collection and evaluation of any agreed outcome measures;
c) Currently, there aren't any Public Health Wales-produced resources, such as leaflets, available to women themselves or clinicians;
d) Unlike other components within the Sexual Health Specification, such as cancer screening, contraception, abortion, or sexually transmitted infections, there wouldn't seem to be a 'prevention / early intervention' strategy for menopause, in line with Public Health Wales's stated aim of 'supporting the development of a sustainable health and care system focused on prevention and early intervention';
e) Currently, health boards are under no obligation to provide a specialist menopause service, despite NICE recommendations that there be one-such for every patient requiring one;
f) In relying on GP triage to secondary or tertiary services, the Sexual Health Specification provided fails to consider a lack of symptom awareness on the part of both women themselves and their healthcare providers. It also fails to provide any sort of description as to what kind of services should be available within a specialist menopause clinic, thereby building in the potential for variation across Wales;
g) If menopause is to be considered a Public Health issue, what funding is being made available to ensure it is the subject of a dedicated, pan-Wales campaign to combat taboos and myths, and improve awareness of symptoms and treatment options, in line with other issues / health conditions under the Public Health Wales umbrella?

Despite our concerns, as mentioned, we do welcome the inclusion of menopause in the Specification, if only so as to ensure that every health board is required to examine its current menopause provision, or lack of, and report back to Welsh Government on its intentions.

The key now, we would argue, is to make sure that menopause has the same level of attention and expertise as other Public Health Wales campaigns. Given that it will affect around 52% of the population, and that early intervention can make an enormously positive difference to prognoses, well-being, productivity, as well as save public monies, this needs to be prioritised as a matter of urgency.

7.3 On this topic, our survey respondents said…

'I started early menopause at 26 due to cancer. There's no help and support out there for us' (LS)

‘I wish that I had been able to talk to someone about this when I was young, No one talked about it and I really suffered in silence’ (AJ)

‘I wish I’d been educated from a young age about menopause. I felt like it was a total shock. I’m frustrated at ‘losing time’. We shouldn’t just have to wait it out. It would be nice to be treated with the same level of care as when pregnant’ (HW)

‘The menopause has such an impact…it would be so helpful to have guidance…I’m big on helping myself but often unsure as what to do for the best’ (FH)

‘Women need a menopause (and peri-menopause) service, preferably one that provides a general health screen/check at age 50. This would help identify, treat and prevent future health conditions from impacting unduly on the women and the NHS’ (JA)

‘I had to have a GP's signature to have support for menopause but a 16 to 17 year old can easily access contraception’ (PR)

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8 Recommendations

In light of our report's findings, we are pleased to be able to offer the following recommendations to Welsh Government:

1 Make *'Menstrual Well-being Throughout the Life Course'* a mandatory element of the Health and Well-being Area of Learning & Experience in the new school curriculum from 2022, ensuring that girls, women, and future healthcare professionals are introduced to menstruation-related issues, including menopause, in an accurate, evidence-based, age-appropriate way. This will go a long way to combating taboos, as well as empowering individuals through raised awareness and knowledge. It is also important, however, that girls / women see menopause as a natural part of the life-cycle, rather than a health 'problem' per se.

2 Make menopause the subject of a dedicated Public Health Wales campaign, to include awareness-raising events and resources, such as CCTV video / animation for use in GP surgeries, posters, and leaflets, and online information.

3 In line with other Public Health Wales screening programmes, devise and disseminate a formal letter to women aged 40 or earlier, signalling onset of menopause, symptoms, and useful resources, as well as signposting to appropriate local services, including healthcare, with expertise in menopause.

4 Incentivise and make menopause a priority for Wales-based nurse / GP curriculum and continuing professional development, to include demythologising HRT.

Every GP practice in Wales should have at least one GP formally recognised as having a 'special interest and training in Women's Health, including menopause'. This should have the same sort of funding and training allocated to it as do other 'specialist' health conditions perceived to be public

health priorities with considerable economic and disease burdens, such as diabetes, heart disease, COPD.

5 Consider adding 'menopause' to diagnostic toolkits for mental health conditions / illness, so that it is considered as a potential cause in women presenting at the relevant age and history.

6 Invest in specialist women's health nurses across Wales, with training in menopause, and hosted by health boards. These could be a resource shared by individual primary care clusters, making them easily accessible to all women in Wales and therefore meeting the Prudent Healthcare Principles of 'care closer to home', 'early intervention and / or prevention'.

7 Consider developing specialist nurse provision to include more general 'Well Woman' sessions, incorporating other elements of the Public Health Wales Sexual Health Service Specification relating to women's health, ie breast screening, cervical screening, contraception, prevention / treatment of STIs, as well as ultrasound scanning for gynaecological conditions like endometriosis, access to pelvic physiotherapy, and prescribing. These shoudn't be referral-only but also incorporate drop-in sessions and Menopause Café-style self-management and support.

8 Ensure ease of access for all women. Clinics should be held at community hospitals or local healthcare centres / hubs, with information provided on subsidised transport links. Developing a 'Well Woman' bus, a resource which might be shared with other, possibly pre-existing services, could be another alternative enabling care closer to home for those living in more rural locations.

9 Initiate funding for relevant 3rd sector organisations to deliver patient-led training and resources for healthcare professionals and employers, provision and facilitation of support / support sessions for women themselves.

10 Ensure that every health board in Wales is able to offer a least one dedicated, specialist menopause clinic for its population. Clinics should be consultant and specialist-nurse-led, with BMS and / or FRSH training, and appear on the BMS's map of recognised menopause specialists. Ideally, such clinics should be able to offer regular drop-in facilities as well as GP triage and referral. The Specialist Nurse should have prescribing authority, as well as the consultant. The clinic should incorporate a multi-disciplinary approach for more complex patients, and also offer DEXA scanning.

11 Work with employers, and women themselves, to develop a health and well-being focused charter mark for employers who take steps to improve experiences of their employees going through menopause.

12 Ensure the co-production of service design and delivery, including information and resources, at every level across Wales, in line with the precepts of both the Social Services & Well-being Act Wales 2014, and the Well-being for Future Generations Act Wales 2015. Including menopause in the remit of Welsh Government's Women's Health Implementation Group (WHIG) would be a useful way forward.

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