FTWW Full Statement

Covid-19 and the Impact on Women's Health in Wales

16th April 2020

Throughout this crisis, FTWW has continued – as ever – to provide its online support services 24/7, via a dedicated forum for women living with chronic, recurrent, often invisible health conditions across Wales. This mechanism has enabled our community to share their experiences and discuss those most pressing issues facing them as lockdown continues. Many report feeling that they're 'slipping through the net' and don't have the support they feel they should have from Government or local authorities

Key Points:

- **Women make up 52% of the population in Wales**
- **More women than men are living with chronic illness, both physical and mental**
- **Women are more likely to be care-givers and single parents**
- **Many 'women's health' conditions incur significant diagnostic delay**
- **Women require more clinical interventions as a consequence of pregnancy and childbirth**

Why are these things particularly significant during the Covid-19 pandemic and what can Welsh Government do to ameliorate their effects?

FTWW explores the issues facing those women in Wales living with chronic and / or recurrent health conditions and offers up patient-led solutions

1 Diagnostic delay

80% of those living with auto-immune conditions are women, with a diagnostic delay of 5 or more years; endometriosis, a condition which affects 1 in 10 women mainly of reproductive age takes an average 8.5 years to diagnose in Wales. As many women as men are living with cardio-vascular disease and yet research shows that women are more likely to die from heart attacks due to delayed diagnosis and poor treatment. In everyday life, the issue of diagnostic delay can pose very real problems not only for health but also for financial security, including accessing benefits.

Without a confirmed diagnosis, women in employment find it difficult to argue for reasonable adjustments in the workplace; without a confirmed diagnosis, women who incur additional costs to cope with their symptoms can encounter significant barriers to the financial support provided by Personal Independence Payments (PIP). Equally, women who are either seeking work or are too unwell to try can find a lack of official diagnosis hinders their efforts to claim benefits like Employment Support Allowance (ESA) or Universal Credit (UC).

Now, during Covid-19, women are finding it also prevents their being formally recognised as 'vulnerable' with which comes additional support during Lockdown, including special slots for supermarket shopping, and home delivery of supplies or medications. Even more startling however, is the fact that some women are now relieved at their lack of a diagnosis – because it means they may be deemed worthy of resuscitation should they be unfortunate enough to contract CV19.

Another significant issue is that, due to lack of clarity over how women present with conditions like heart attacks, they may see concerns over contracting or spreading Covid-19 as another reason to delay help-seeking. Inevitably, this will have implications both for survival and / or long-term prognoses. It is vitally important that the NHS in Wales is prepared for an influx of unwell patients following the lifting of lockdown and that women's symptoms are not dismissed.

FTWW recommends:

- **Clarity and transparency around the criteria used to establish who is considered 'vulnerable', and who should be shielding**
- **An easily accessible mechanism to enable patients to challenge the current decision-making process around vulnerability**
- **Consider – as in England – implementing a mechanism which enables self-registration as vulnerable, with scope to include details on individual needs during lockdown**
- **Consistent, clear guidelines be made public to reassure those women living with physical and mental health issues that their lives are of value, and that care will be provided to them on an equal footing to those without pre-existing**

conditions, ie by examining individual needs, preferences, and efficacy / benefit of treatment

- **Provide and publicise clear guidance on presentation of conditions like heart attack and stroke and what to do during the Covid-19 crisis**

2 Access to clinical interventions, including medication

Those women who would ordinarily have regular clinical reviews, whether they be appointments to adjust pain medications, procedures such as hormone injections to manage gynaecological conditions, or iron transfusions for anaemia, for example, are now finding it incredibly difficult to access these interventions.

Understandably, in-person appointments can, in large part, no longer be accommodated; however, tele-conferencing, whether it be via the telephone or other applications, such as Skype / Zoom should make it possible for regular – and essential – medication reviews to take place, whether they be with a medical professional or pharmacist.

Without these discussions, women are finding that they're now expected to manage their health conditions with sub-optimal or no medication. Some are trying to eke out existing supplies; others are being forced to withdraw from medical management altogether; still others may be forced to pay privately for their medications, sourcing them from suppliers whose legitimacy cannot be guaranteed. This will inevitably have a significant and detrimental impact on prognoses.

Rather than keeping these patients safe from clinical settings, it seems that, without some form of routine access to medical input, they may well end up having to access emergency treatment instead, with all of its incumbent risks. Patients whose long-term conditions have been safely and effectively managed up to now may well experience dangerous exacerbations, with long-term negative impacts for future health and well-being.

It is worth mentioning that not everything can be done remotely. Some medications / interventions ordinarily require in-person appointments, so that the patient can be examined, provide samples, or undertake procedures etc. Many patients now find themselves unable to have these essential appointments, whether that be because they're no longer available as healthcare providers are redeployed or as the NHS seeks to reduce in-person contact, or because patients themselves are vulnerable and self-isolating. Either way, patients are finding themselves having to make a choice between no intervention / medication, continuing with medication without any form of review (thereby putting themselves at risk of harm), or entering a communal clinical setting.

The vast majority of patients are sympathetic to the unprecedented challenges posed by the current crisis. However, perhaps most crucial and yet lacking is consistent information or guidance being provided to patients in this situation – and for patients to be assured that this guidance will be followed by their healthcare providers, in terms of accessibility of

services. Given the numbers affected by issues of this nature, a public statement and / or advice line would be a sensible way forward, enabling patients to make informed choices about how to proceed and / or who to contact for further support.

Understandably, routine or elective hospital procedures and operations have been cancelled. For many of our members, for whom such interventions are required in the management of their health conditions, this has put essential treatment on hold. With specialist services scarce in Wales, for a not inconsiderable number, this means waiting times now extending into years. Patients appreciate the prioritisation of those affected by Covid-19, however, a lack of information about how to manage symptoms in the interim or where this leaves patients in terms of waiting lists is proving highly problematic and compounds what is already a very stressful situation.

At FTWW, our chief concern is that the longer patients have to go without being able to consult with their medical team(s) or consultants, particularly in terms of evaluating medications, accessing essential interventions, or interim self-management, the more likely it is that individuals will need to be admitted to hospital in an emergency situation unrelated to Covid-19. Emerging from the lockdown, we also envisage those with chronic illness requiring expedited access to specialists as a result of worsening symptoms / prognoses.

FTWW recommends:

- **flexibility on the part of all GP practices, specialists, and pharmacies, to include teleconferencing facilities and available to those who are new to the area and requiring an initial medical appointment to register and access medication**
- **allowing patients to send data (collected using apps, blood pressure monitors etc) over email**
- **a collection service / drop-off facility for those samples which can be carried-out at home**
- **those whose operations / procedures have been cancelled should have a follow-up call or conversation to discuss interim management**
- **patients affected by cancelled procedures should be expedited for care once the lockdown is lifted.**

3 Availability of Hydroxychloroquine

Most people with auto-immune conditions, such as Lupus, Sjogren's, Undifferentiated Connective Tissue Disease (UCTD) or Mixed Connective Tissue Disease (MCTD) are women. Indeed, it's estimated that 80% of those living with an auto-immune condition will be

female. Many of these are taking hydroxychloroquine; it is often the basic building-block of a long-term drug regimen for such patients.

In the midst of Covid-19, we now see it being posited by politicians as a possible cure for Coronavirus, despite there currently being little scientific evidence to back that up. There are limited supplies of the drug under normal circumstances; it is now being bought up in large quantities, depriving those patients who have an established need for it. Long-term, this could have disastrous consequences.

FTWW recommends:

- **Welsh Government issues assurances guaranteeing supplies of hydroxychloroquine to those who take this medication for auto-immune disease.**

4 Pregnancy

i) Early Pregnancy Units (EPUs)

For those women experiencing bleeding, pain, or reduced foetal movement, EPUs are already a challenge to access, with many women using A&E as an entrance point. Reluctance to utilise emergency services and, indeed, active discouragement from attending A&E during this crisis means, sadly, that increased numbers of women will be left to miscarry at home, some of whom may well require urgent medical help for ectopic pregnancy, infection, and / or severe bleeding, for example. The potential harm inherent in this situation is clear.

Current restrictions on partners accompanying pregnant women to clinical settings means that those being seen in EPUs will have to go alone, essentially forcing them to experience any potential loss of their baby/ies by themselves. In some instances, where babies are of 20 weeks' gestation, this will result in women having to give birth by alone, without a partner's support, at what will inevitably be a hugely traumatic time.

ii) Foetal Monitoring

Non-essential maternity appointments are being cancelled or conducted over the phone, including 16-week appointments where baby's heartbeat is monitored. In all likelihood, this will mean problems, such as infections, are missed, possibly resulting in baby loss. For those who have had previous losses, the reassurance of the 16 week 'listen-in' is vital in reducing anxiety levels and preventing mental health implications.

Additionally, whilst understandable, women now need to attend scans on their own. For those who have experienced recurrent or previous baby loss, a scan can be a terrifying

prospect and facing it alone may only exacerbate those fears. There will be women receiving bad news at their 12 or 20-week scans with no emotional support.

iii) Birth and Birth Trauma

During Spring/Summer 2019, MakeBirthBetter conducted a survey which showed that 30% of new mums suffer from mental and/or physical trauma following their birth and aren't given adequate support to enable them to cope. With birth partners now only allowed to attend during actual labour, a lack of intervention or support prior to or post-birth, birth plans being abandoned, and the added complexities brought to the delivery suite by Covid-19, it seems inevitable that pregnancy and birth-related trauma and related mental health issues will increase exponentially for families and staff. Some women may choose to have their babies at home, without midwife support, even if an independent labour is contraindicated for them. It is vital that measures are taken now to prevent trauma as far as possible, recognise it when it occurs, and have mechanisms in place to deal with and treat it.

iv) Post-Birth

Current guidance dictates that midwives do not carry out home visits. Instead, women will receive a phone call on day one and take baby to the midwife on day 5 for a weight check. The possible impact of this for the well-being of both mother and baby is huge, including missing out on breastfeeding support, missed opportunities to spot domestic abuse, and not picking up on any maternal mental health issues.

v) Maternity-related issues outside of clinical settings

Social distancing for pregnant mums has significant financial implications. Currently, government guidance makes it a choice for mums rather than an obligation for employers to protect the health and jobs of their employees. As a result, many pregnant women are on Statutory Sick Pay (SSP) instead of being furloughed. This could impact on their eligibility for Statutory Maternity Pay (SMP) if it coincides with the calculation period for SMP. It is also forcing many expectant mothers to choose between their economic security and their own / babies' health.

vi) Fertility Treatment

As with all elective procedures, fertility treatment has been cancelled. For those women who are nearing the cut-off point age-wise, any such delay may mean that they're not able to access treatment and have a family once the lockdown is lifted. The mental health impact of this cannot be under-estimated.

FTWW recommends:

- **Local maternity services be ring-fenced, with government / health boards to consider and publish plans to prioritise trauma prevention now, as well demonstrate investment in trauma-focused treatment later**

- **Peri-natal mental health services and related bereavement support should be prioritised coming out of the Covid-19 crisis. There needs to be significantly more investment and services provided throughout Wales, ensuring easy and equitable access and including specialist mother-and-baby mental health beds**

- **Develop a social media campaign giving women guidance and a number to call if they experience early pregnancy complications**

- **'FaceTime' and / or similar facilities should be permitted during scans, so that partners can hear what is happening and see the scan even if not present in-person**

- **Extra provision for support for women who get bad news at a scan**

- **Prioritise first time mums for extra checks and support with issues such as feeding and confidence / coping, ideally before leaving hospital; FaceTime and similar could be utilised after leaving hospital**

- **GP practices to consider organising drop-off / collections for pregnant women's urine samples to ensure adequate checks for infection**

- **Consider facilitating 16-week check-ups for those who have experienced a previous loss**

- **Devise and implement legislation which indicates pregnant women be allowed to work from home or furloughed rather than utilise SSP**

- **Temporarily suspend the age-related cut-off point for women whose fertility treatment has been cancelled during the Covid-19 crisis**

5 Daily Living during Covid-19

i) Childcare

With women making up the vast majority of people responsible for looking after children, the impact of lack of childcare or schooling could have significant health-related repercussions for those who are already disabled / living with significant health conditions. For those who have domiciliary helpers who are now self-isolating, it's vital that Government does all it can to ensure these women can take advantage of mechanisms put in place to support vulnerable individuals

ii) Bills

Disabled women / women living with chronic illness tend to be amongst the poorest in our society. The current crisis inevitably means that utility and food bills will rise as people are expected to use more water, electricity, and gas to do increased amounts of washing and cooking. Thus far, there has been little to no recognition of how these increased costs will

be met by those people who can least afford them. As we write, there are still some local authorities in Wales not providing food vouchers or funds to cover the costs of free school meals, expecting parents on low incomes and with reduced access to public transport to travel to schools to collect a packed lunch, irrespective of the parent's health status.

iii) Shopping

Government has compiled a list of vulnerable people which, when eventually disclosed to supermarkets, meant that those people could be added to a priority delivery list. The list is fraught with inconsistencies and gaps, with some health conditions not being included despite treating medical professionals advising otherwise. Given the diagnostic delay that so many women's health conditions incur, it seems inevitable that women in particular will be affected by how such a list is being drawn-up. Thus far, it has resulted in a significant number of people not being able to utilise the benefits of being on the list when, clearly, they should be able to do so.

Whilst local, independent shops are stepping up to the mark and making home deliveries, the likelihood is that they are more expensive than the supermarket and with limited choice for those on restricted diets due to their health needs. At a time when money is tighter than ever, it is crucial that those people on low incomes and with specific health-related needs are able to access affordable groceries and have them delivered to their homes. For those who would ordinarily use food banks, access to deliveries is proving similarly problematic.

There is currently no visible or patient-facing mechanism in place to enable unwell people in Wales to self-register their needs on a national database or list, even if advised by their medical professionals to 'shield'. One of our members described a roundabout situation where, in pursuit of a letter to enable her to access grocery deliveries, she had been sent between a host of medical professionals and the local authority with no success. This is unacceptable. Efforts must be made to avoid both paternalism and the expectation that doctors, already under considerable pressure, should spend time on administrative tasks when processes could be implemented to allow patients to register themselves. Self-registration would also reduce the numbers of vulnerable patients using up limited resilience to queue for shopping at a time when the risks to them of doing so are exceptionally high.

It is also important to be aware that the current limits imposed on purchases of individual items, whilst understandable and logistically possible for the 'well', pose considerable challenges for those on restricted diets as a consequence of their health condition(s). Limiting items to 2 or 3 of each means that those with particular needs can't buy enough to last more than a few days and, when home deliveries are taking up to 3 weeks to arrive, this can result in significant suffering for the person affected.

iv) Exercise

For those with impairments that affect mobility or cause fatigue, 'exercise' can be a problematic term. It would be more inclusive to refer to 'fresh air and exercise', thereby reducing the likelihood of those with invisible illness being targeted should they need to

stop and rest during any outdoor periods, or wheelchair-users facing comments about 'not needing exercise'.

v) Clarity of information re 'shielding'

As described in the section on 'shopping', the lack of UK-wide consistency around 'shielding letters' and 'vulnerability lists' is proving extremely problematic for those living with significant health issues and multi-morbidities, the majority of whom will be women.

Letters from the Welsh Assembly Government / Chief Medical Officer for Wales, to those who are vulnerable or very high risk, commenced on 23rd March 2020. All letters were supposed to be received by 6th April. As we now know, at least 13,000 of those were sent to the incorrect address, leading to a significant data breach. Irrespective of this, one Lupus Support Group in mid-Wales reports that only one-fifth of its members have this far received their letters, despite lupus being a serious auto-immune disease for which patients will ordinarily be taking immune-suppressant drugs.

As already outlined, Government's own list of conditions to be considered 'high risk' is not comprehensive; GPs and hospital clinics have therefore been asked to check patient records to find all vulnerable patients in their care. Understandably, this is taking time and those patients seeking advice from their GP practice are finding it difficult to access the information they need. These letters are essential documents, not least required to show employers, some of whom are questioning their employees' need to self-isolate for 12 weeks. Some of these employees may be key-workers and called into work, despite their health condition(s) making them vulnerable to infection.

Furthermore, the UK media can sometimes misrepresent the situation, unintentionally reporting England-only interventions as being applicable to all; this confusion is harming patients in Wales and the other devolved nations. Depending on the local authority in which they live, there has been no clear pathway communicated to Welsh patients on who to contact for help if they need it. Patients in Wales report feeling disenfranchised and disempowered.

FTWW recommends:

- **A public statement providing clarity on how the those deemed 'vulnerable' and 'shielding' be drawn-up – the current criteria doesn't appear to include all of those who should be included and whose healthcare providers have recommended they shield**
- **A Welsh Government glossary of terms to ensure clarity and consistency around terminology, such as 'vulnerable', 'high risk', 'shielding', 'isolation', 'quarantine' etc**
- **Consider allowing people to self-register, including those not yet registered with a local GP, on a 'Vulnerability Database', outlining their specific needs, with the facility for it to be formally printed out or sent to individuals, so that it can be**

used as evidence of need for shops, employers, the police, etc.

- **Future recognition of the implications of diagnostic delay in accessing services, an issue that will predominantly affect women**

6 Mental Health impacts

Whilst women, particularly disabled / unwell women, are isolated and without access to their usual forms of support, medication, or intervention, it seems inevitable that the numbers experiencing mental health issues will rise.

We already know that women are more likely than men to be living with a mental health condition. For example, young women are at an increased risk of self-harming behaviours, including eating disorders, whilst specialist services to treat them are lacking in Wales. We already know that women of menopausal age, predominantly responsible for household chores and care of relatives, are at increased risk of suicide and that HRT has, up to now, been in short supply. We also already know that women in Wales tend to experience longer waits for diagnosis and treatment of gynaecological disease than their counterparts in the rest of the UK, resulting in consequent depression and anxiety. It is vital that Government and service-providers begin considering and exploring measures now, to ameliorate the long-term mental health consequences of Covid-19

FTWW recommends:

- **Welsh Government begin exploring now how to best invest in the training of future and existing mental health practitioners and provision of services coming out of this crisis, so that women experiencing any of the aforementioned issues know that there will be an easily accessible and navigable pathway of mental health interventions and support in place for them**

- **Look at expediting any surgical procedures which have been cancelled post-lockdown**

- **Ensure increased communication and reassurance for those affected**

7 Going forward

Many of our members expressed similar sentiments about the impact of Covid-19 on themselves, the population at large, and its implications for society going forward.

It was hoped that the newly developing concern for people being isolated within their homes would continue for those permanently housebound by illness once ‘normality’ resumes. Others noted employers’ acceptance and accommodation of reasonable adjustments, including remote working, when, previously, disabled people were often

denied these measures. Members were united in hoping that positive changes to general perceptions, attitudes, and practises would continue beyond Covid-19.

Members commented on the massive increase in online leisure activities, exercise, and educational resources, from school to cookery classes. One remarked that she would, 'never want things to go "back to normal" if we lose all of those things'.

Still more remarked that they would wish for their friends, families and employers to now appreciate how challenging life is for people with chronic illnesses and impairments, and to make more effort to be inclusive when 'normal life' resumes.

FTWW Final Thoughts:

- **It is important to note that, whilst most people living with chronic or recurrent illness / long-term health conditions are pragmatic enough to appreciate the unprecedented situation in which we find ourselves and do their best to self-manage this change in circumstances, we must be mindful also of avoiding harms being done to current and future generations**

- **It is women who carry the majority of responsibilities where child-rearing is concerned; it is they who must be supported if we are to avoid the well-established long-term implications of adverse childhood experiences. This is particularly pronounced for those women who are both living with health conditions and who may be at risk of developing / worsening mental health conditions. For both them and their offspring, we must listen to those being impacted and act now**

- **We would ask that our recommendations throughout the body of this text be enacted as far as possible, to include disaggregation of data according to sex and gender and also other protected characteristics, so as to explore – and learn from - the intersectional impact of Covid-19.**