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31st March 2023

Deputy Cairns Dáil Éireann, Leinster House Dublin 2

PQ Ref 13234/23: To ask the Minister for Health the steps he is taking to provide the staff and resources to treat individuals diagnosed with deep endometriosis in a timely manner.

Dear Deputy Cairns,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response. I have examined the matter and the following outlines the position.

Endometriosis is one of the most common gynaecological conditions in Ireland and approximately 1 in 10 women may have endometriosis. The HSE's National Women & Infants Health Programme (NWIHP) acknowledges that endometriosis is a difficult condition to diagnose and treat because of the variation of presentations, impacting the physical and mental wellbeing of patients at varying levels.

The time to diagnose endometriosis also varies by patient due to its varying and ambiguous symptom presentation. However, the exact prevalence of endometriosis in Ireland is difficult to ascertain. Part of the reason for this ambiguity is due to the fact that some women with endometriosis may never present as they are largely unaffected by the disease, coupled with the likelihood that many cases of this condition go undiagnosed.

The key aim of treatment is a relief from the onset of symptoms so that the condition does not interfere with day-to-day life for patients. Treatment may include pain medications, hormone treatment and /or surgical interventions.

With a view to addressing the needs of women in this area, NWIHP is leading on the development of a National Framework for Endometriosis Care. This Framework due to be published this later this year, will be implemented on a phased basis and will identify how care for women in this area needs to be delivered, with this care spanning primary care to local hospital care to specialist complex care at regional level to supra-regional complex services.

Investment in the area of endometriosis care commenced during 2021 and has continued under Budget 2022 and 2023 with two supra-regional complex endometriosis services in the process of being established in Tallaght University Hospital (TUH) and Cork University Maternity Hospital (CUMH).

Services in the supra-regional sites will be multidisciplinary in nature, with a focus on a holistic approach to care and with access to specialised surgery as and when clinically indicated. These supra-regional services are being designed to offer specialised care to severe and complex cases of endometriosis, which may incorporate surgery for deeply invasive endometriosis involving the bowel, bladder, and ureter or outside of the pelvis. NWIHP working with specialists in this area has estimated that approximately 250 severe cases per year would need treatment through the supra-regional endometriosis services.

Under the Framework being finalised, these two supra-regional, complex endometriosis services will be supported by five specialist endometriosis hub services located across the country. It is envisaged that each Hub will be positioned to provide interdisciplinary care to women experiencing endometriosis at a mild to moderate stage or up to Stage III of the disease i.e. the cohort of women whose symptoms cannot be managed appropriately in primary care or those local hospital based gynaecology services but who do not require the expanse of highly specialist services within the supra-regional services.

Allowing for a holistic care package for women in this area, which NWIHP has identified as critical, additional personnel being invested in include not just additional medical specialists, but clinical nurse specialists, pain specialists, dietitians, physiotherapists and psychologists.

To support the implementation of the Framework, NWIHP has established an Endometriosis Professional Network to help drive a standardised approach to endometriosis service delivery and care. In addition, an Endometriosis Quick Reference Guide (QRG) is currently in development, by the ICGP. Once developed this QRG will be disseminated amongst GPs to promote awareness of endometriosis and the increase the ability of GPs to recognise endometriosis. Furthermore, the HSE National Clinical Guideline for Management of Endometriosis is also in development and is due for completion in the coming months. The availability of this evidence-based guidance will support the management of endometriosis in both the primary and acute sector.

I trust this clarifies the matter.

Yours sincerely,

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Mary-Jo Biggs, General Manager, National Women and Infants Health Programme

