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## Survivors need aftercare most of all

### Health

#### Donal Brennan

In our rush to condemn CervicalCheck, we've overlooked the thousands of women who have survived cervical cancer and the medical and psychological aftercare they need

Cervical cancer has been to the forefront of Irish life for the last 18 months. For those of us who work in the area, the devastating impact of cervical cancer is seen daily. We all remember young mothers, daughters and aunts who have had the honour to care for who have been taken prematurely from their families and loved ones, in the upheaval of emotional discourse as the national understanding of the human impact of cervical cancer developed, some important points appear to have been lost to the discussion.

An important reality that has frequently been overlooked is the fact that over 1,000 women were diagnosed with cervical cancer in Ireland since 2008, and that 10 per cent of these women had not participated in the CervicalCheck programme.

Also overlooked is the fact that there are thousands of cervical cancer survivors living in Ireland. Throughout the CervicalCheck debate, these women have been forgotten.

In Ireland, a narrative persists that once a patient completes their treatment, they should be thankful the cancer is under control – or that they are alive.

In some cases, they may be given the "all clear", a uniquely Irish phrase which should rarely be used given the possibility

that any cancer can return. We currently place no emphasis on the management of long-term side effects, many of which are secondary to treatment.

Most cervical cancer survivors suffer long-term psychological and physical complications. These are under-reported and sometimes ignored by health care professionals.

During the disclosure meetings held after work carried out by the Royal College of Obstetricians and Gynaecologists, which I and my colleagues attended, it was clear that many of the women involved felt completely isolated. Their anger was directed towards the lack of services available to manage their ongoing symptoms rather than their oncologist results.

Madge, Madge and sexual dysfunction are daily realities for these women who have to struggle with the daily indignity of incontinence. Many had to deal with an abrupt loss of fertility and menopause symptoms. A huge number of relationships had broken down.

The ongoing stigma associated with cervical cancer contributes further to the sense of isolation many of these women experience. Some have been the victims of wholly incorrect assumptions that they are in some way to blame for developing cervical cancer.

Cervical cancer is caused by the HPV virus, which is sexually transmitted. Most sexually active people will have this virus at some stage, but the majority of us can clear this virus. Some people cannot.

At a meeting organised by my colleague Professor Mary Hogan at the Royal College of Physicians last November, after the publication of the Scully report into CervicalCheck, patient advocate Lorraine Walsh delivered a profound and moving description of the impact cervical cancer had on her life.

As a society, our approach to cancer has to mature. A mature approach to life after cancer in Irish society requires that we change our approach to cancer, which is often considered an acute disease with the emphasis on rapid access to diagnostics and treatment.

Although important, once this acute phase has been completed, the services and support for the management of chronic complications are extremely patchy, completely uncoordinated and often dependent on local voluntary cancer support groups.

Although the National Cancer Strategy highlighted this as an important issue, progress has been shockingly slow. Why? Surely providing women with a high standard of care and support should be the focus going forward. All women deserve a care plan that will improve their quality of life during and after cancer treatment, including access to dietitians, physiotherapists and counsellors. Currently they don't have basic, vital services.

Last week saw the publication of the Royal College of Obstetricians and Gynaecologists (RCOG) review of incident cancers within the CervicalCheck program. It concluded that the Irish programme appears comparable to the NHS screening program in England.

The aims of the review were to provide individual women with an independent review of their personal screening history, and to provide an aggregate report and overall assessment of the CervicalCheck program for the government.

Many will be alarmed by the fact that the

expert review disagreed with the original CervicalCheck smear report in the cases of 20 per cent of the 1,038 women included in this review. This is, however, lower than the 40 per cent discordance rate seen in the two most recent reviews performed in the NHS screening program which had been the operation for over three decades.

Such a high level of discordance is to be expected during these unblinded look back reviews, when the reviewers knew that the woman had subsequently developed cervical cancer. This sort of review does not simulate a normal screening situation.

For every 1,000 asymptomatic women who present for screening, 20 will have pre-cancerous changes, smear tests alone will pick up 15 of these.

In future, HPV screening, which we plan to introduce, will pick up 16 of the 20. Women are asked to come back at regular intervals to reduce the risk of repeatedly missing abnormalities.

There are a number of caveats to be taken from the RCOG review. Firstly, it does not mean that if a woman has a smear test there is a one-in-three chance that it will not detect an abnormality.

Secondly, of the 20 per cent of women who received a discordant result, an asset opportunity to either prevent their cancer or diagnose it at an earlier stage was missed in half of these women. Unfortunately, 12 of these women succumbed to cervical cancer, which is a devastating disease.

These cases should always be the focus of any review to identify areas of improvement going forward. As recommended by the RCOG review, it is imperative that we restart our own incident cancer review in Ireland, a process that has been on hold for the last two years.

Cervical screening will reduce the incidence of cancer by approximately 70 per cent, but unfortunately it will never be 100 per cent effective. The RCOG report explicitly states that "no single cancer as a screening failure is overly simplistic, because many of these cancers are actually screen detected."

In this review, 70 per cent of women were diagnosed with a very early stage 1 cancer

(confronted to the cervical and half of these had what we call microscopic disease – so small as to be visible only with a microscope. These should be considered a screening success, as the treatment is the same as that of pure cancerous lesions.

So where next? There were calls last week from patient advocates, whom I greatly admire, for another independent review.

We have already had an audit organised by CervicalCheck, followed by a public inquiry led by Dr Gabriel Scully. Last week the independent expert panel from RCOG published its report.

How many reports do we need? We know that this programme was clinically effective and operating to the same standards as the well-regarded English programme. It is time to move on.

For the last 20 months, cervical screening in this country has been in turmoil. That turmoil has resulted in the offer of additional smear tests, huge backlogs, and the resultant delays in women getting results. Some women will have experienced delayed diagnosis as a consequence.

The turmoil engulfing CervicalCheck has also led to a delay in the introduction of the more accurate HPV test, this means that we will continue to have more interval cancers than we would have had if the test had been introduced as planned in 2018.

Last week Drastach Levo Vastardis said he had regrets about how the government handled the CervicalCheck crisis. I have some sympathy; the government must under intense media and political pressure.

Instead of opting for another retrospective look back, it is time we moved forward and addressed not problems that women who had cancer are experiencing every day.

Continued investment in research and funding for management of long-term chronic complications of cancer treatment would be the best outcome from the CervicalCheck saga.

**Donal Brennan** is a consultant gynaecological oncologist and ICG professor of gynaecological oncology

### Quotes of the week

**"While 10,000 people are living in emergency accommodation tonight and that is terrible and shameful, let's not forget that we lifted 14,000 people out of homelessness and provided them with secure housing."**

Taoiseach Leo Varadkar defends the government's performance on housing

**"We are at a very advanced stage of refining the business. We are very close, but we don't have sufficient evidence yet for our auditors, hence they disclaimed opinion on that."**

Paul O'Connell, the FA's new executive head, explains why Dublin was unable to appoint a director in recent accounting 18 accounts

**"I am extremely proud of all that we have achieved over the years and the key role that our collective Team has played in Ireland's offshore arena."**

Tony O'Reilly on stepping down as chief executive of Providence Resources

**"What we do is what the meat processors and the retailers are making on the meat. It's like the Fourth Secret of Fatima."**

Stefan Herzig, chairman of the Irish Farmers Association's Cork division, criticises Central Bank

**"We have a tremendous amount of captured fighters who are still in Iraq and they're mainly from Europe. We should add you like some nice ISIS fighters? I could take them to you. You can take 'em, they're yours you want."**

Donald Trump poses a question about captured fighters in Iraq