

Life After Cancer (LACC)

The real-life impact on women living
with and after cancer



AUTHORS: Anne Nally, cancer survivor; Jennifer Blighe, cancer survivor; Eileen O'Sullivan, cancer survivor; Jacqueline Daly, cancer survivor; Dr. Helena Bartels and Prof Donal Brennan.

Women with a history of cancer often suffer with symptoms related to treatment long after their cancer diagnosis.

These symptoms are often deemed to be “less important” if a woman has recovered after cancer treatment, and a narrative often exists where women who are deemed to be disease free or in remission should almost be thankful for this and “**put up with**” whatever long term symptoms they might suffer from.

The extent to which women endure these symptoms in their day to day lives is both poorly understood and often not addressed in follow-up care.

Premature menopause, sexual dysfunction, pain and insomnia are just a small number of the many long-term symptoms women endure during or after cancer treatment.

Until recently these problems have received little attention, however a research program funded by the Irish Cancer Society and partners including the HSE, The Mater Private Hospital, the National Cancer Control Program, Breakthrough cancer Research and Pfizer Ireland aims to address some of these issues

We recently invited women with a history of cancer to take part in a survey focusing on menopausal symptoms, sleep disturbance and anxiety over a 4 week period. These specific areas were chosen as proven evidenced-based interventions exist that may address some of these issues and improve women’s quality of life.

If we can measure the existing impact that these symptoms have on women living with or after cancer, it will improve our ability to develop future services to support women and address a variety of other long-term complications of cancer treatment.

Survey Results

418 women responded to the survey, with an average age of 49.

The women who responded were mostly from Ireland, with:

- 93% of white Irish descent
- Two-thirds of women were married or in a long term relationship
- The most common cancer types were breast (63%) and cervical (17%) other cancers types included ovarian cancer, uterine cancer, haematological (blood) cancers and melanoma.

One of the most striking findings from the study was that **29% of women were unable to sleep due to pain at least 3 times per week over the previous month**. Likewise anxiety symptoms were very common and half of women reported a moderate to severe feeling of “**the worst happening**”. 1 in 3 women reported a moderate to severe “**fear of dying**”, and feeling “**nervous**” and “**terrified or afraid**”.



Menopausal symptoms

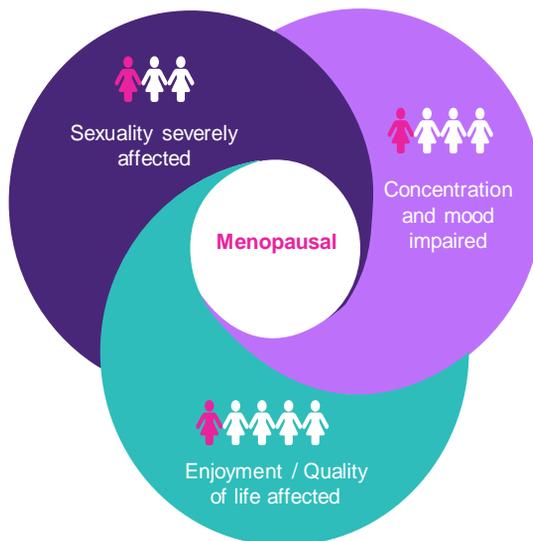
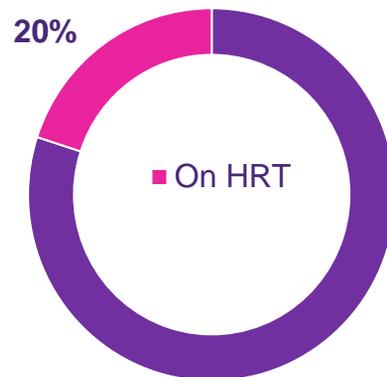
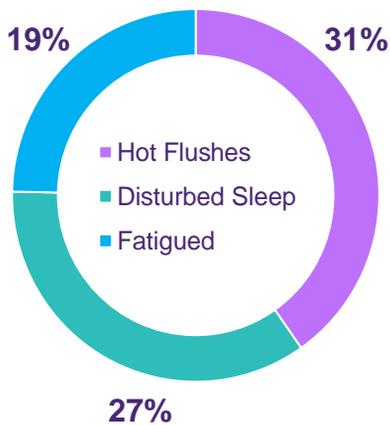
To assess which menopausal symptoms women struggled with the most, they were asked to choose from a list of common menopausal symptoms the three symptoms they would most like to be free of.

The three symptoms women would most like to be rid of were, in order:

1. Hot flushes or night sweats
2. Disturbed sleep
3. Feeling tired or worn out

Women reported sleep was the most affected activity by hot flushes. 1 in 3 women reported their sexuality was severely affected, while 1 in 4 said their concentration and mood was impaired as a result of hot flushes.

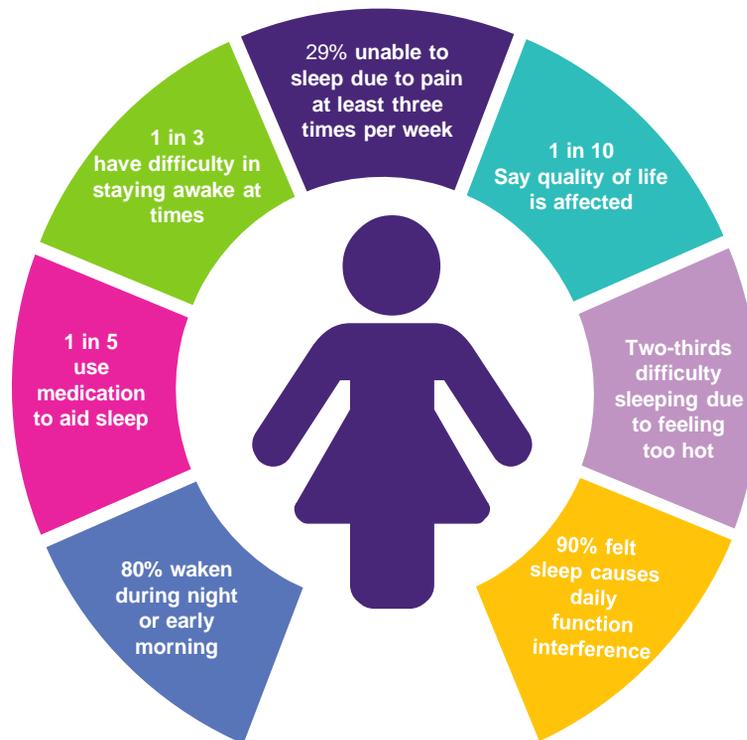
Furthermore, 1 in 5 women felt their enjoyment of life and overall quality of life was significantly affected by hot flushes. Twenty percent of women were currently using Hormone Replacement Therapy.



Sleep

Almost two-thirds of women reported difficulty sleeping because of feeling too hot, and two-thirds of women reported their overall quality of sleep as “bad”, while only 2% of participants rated their sleep as “very good”.

Many women use prescribed medication to help them sleep, with 1 in 5 using medication to help them sleep more than 3 times a week.



Feeling tired and fatigued significantly affected women’s ability to carry out daily tasks, with 1 in 3 women reporting difficulty in staying awake while driving, eating or while socialising at least once a week.

Almost 80% of women reported waking up in the middle of the night or early morning and trouble falling asleep again.

90% of women felt their sleep problem caused at least some level of interference in their daily functioning, with 1 in 3 reporting sleep affecting their daily functioning as “much or very much interfering”. Most women felt their sleep problem affecting their quality of life was noticeable to others, with 1 in 10 reporting this as noticeable”.



Current Pandemic

This survey was carried out during the Covid-19 pandemic during which severe restrictions on movement, travel and work were in place. To assess the effect, if any, on the above reported symptoms of these restrictions, women were asked to report whether they had noticed a change in their symptoms.

Two-thirds of women reported no change in their symptoms since the start of the pandemic. Just under 20% of women reported a worsening in their symptoms, with 10% reporting their symptoms were “somewhat worse”, 7% “moderately worse” and 2% that their symptoms were “much worse”.

Those women who reported a worsening of symptoms described feeling “worried about going into hospital and getting Covid”, increased “fear of dying”, feeling “anxious all the time” and overall “sleeping less and worrying more”. Worry about catching the virus and feeling vulnerable due to a history of cancer were identified as contributing factors to interrupted sleep and finding “going outside very stressful”.

Summary

This survey highlights the impact on women’s quality of life following a cancer diagnosis and living with menopausal symptoms. Sleep disturbance and hot flushes were highlighted as particularly challenging.

The purpose of this survey was to gather data from a large group of cancer survivors to better understand which symptoms are most bothersome and to develop a new service to support women in managing these.

This information will now be used as a baseline to measure the impact of any new interventions designed to address sleep disturbance and menopause in female cancer patients and survivors.

Furthermore we hope that the results of this survey will actually bring a sense of relief to many women knowing that the severity of their symptoms are common and real, experienced by others and that these are not symptoms that may have to be endured ad infinitum.

