Exploring Ways to Improve Well-Being Through Clear Communication About Ovarian Cancer

As a woman living with ovarian cancer, you and your family may have questions for your healthcare providers at any point – whether it’s at your initial diagnosis, during treatment or when you are in remission. There are steps you can take to gain more control over your experience – just by having a clear dialogue with your loved ones and oncology care team.

To better understand the needs of the advanced ovarian cancer community, TESARO, Inc. with input from the National Ovarian Cancer Coalition (NOCC) and the Ovarian Cancer Research Fund Alliance (OCRFA), conducted a national survey* of patients and healthcare providers. The survey results indicate there is uncertainty among patients about what to expect after diagnosis – whether they are initially diagnosed or actively seeking greater resources and connections to lessen the burden of the disease.

TESARO hopes to improve understanding of advanced ovarian cancer by fostering a stronger, more effective dialogue between women and healthcare providers.

THE SURVEY REVEALED IMPORTANT INFORMATION ABOUT THE DIALOGUE BETWEEN WOMEN AND HEALTHCARE PROVIDERS.

There is uncertainty among patients about what to expect when facing ovarian cancer.

49% OF THE PATIENTS who are in treatment or who have been treated admit that they find not being sure of the path forward after diagnosis to be very or extremely challenging.

47% OF THE PATIENTS who are in treatment or who have been treated admit that they find not knowing what to expect after treatment to be very or extremely challenging.

71% OF OVARIAN CANCER PATIENTS reported feeling very anxious before visits to their healthcare provider.

34% OF HEALTHCARE PROVIDERS are unsure if, or do not feel that, they give their ovarian cancer patients all of the information they need about ovarian cancer.

Patients and healthcare providers vary with regard to their perceptions of how frequently they discuss certain topics.

91% of HCPs say they discuss expectations for treatment often or at every visit.

69% of HCPs say they discuss recurrence often or at every visit.

55% of HCPs say they discuss the emotional challenges of ovarian cancer often or at every visit.

40% of patients

38% of patients

29% of patients

*The Our Way Forward survey was conducted online in the U.S. by Harris Poll on behalf of TESARO, Inc. between April 13 and May 2, 2017, among 254 women 18+ years of age living in the U.S. who have been diagnosed with ovarian cancer. Survey respondents were selected from individuals who had agreed to participate in surveys through the Harris Poll and their partners or were recruited to participate by patient advocacy organizations, NOCC and OCRFA. Results are not weighted and are therefore representative of only those surveyed. A parallel survey was conducted between April 17 and May 5, 2017, among 232 physicians who treat ovarian cancer patients in the U.S. consisting of 201 medical oncologists and 31 gynecologic oncologists. Survey respondents were selected from physicians who had agreed to participate in surveys through the Harris Poll and their partners. Weights for gender by years in practice and region were applied to align the data with the population parameters for medical oncologists and gynecologic oncologists, separately. A post weight was then applied to combine the two medical specialty groups in proper proportion for the total.
COMMUNICATION BETWEEN YOU AND YOUR ONCOLOGY TEAM IS IMPORTANT

Following are some questions to help prepare you and your loved ones for meaningful conversations with your oncology care team during the course of your treatment.

BEFORE YOUR APPOINTMENT

☐ Prepare a list of specific questions for your doctor and prioritize based on your needs at that moment – and the questions that may come up before your next visit.
  
  *We have provided potential questions below that may be relevant to you.*

☐ Consider if you want a family member or close friend to come with you to the appointment for support and to take notes.

☐ Bring this discussion guide, extra paper and a pen to write down key points from your conversation.

CONVERSATION CUES

The hardest part of any conversation is simply getting it going. It’s a good idea to keep a journal or notes about symptoms or side effects you are experiencing, including frequency and severity, and bring it to each appointment. You may also want to note any changes in your day-to-day life, personal and treatment goals, and your concerns, as all of these are important for your healthcare provider to know.

Along with your journal, and your specific questions that you bring to your appointments, the below may help to kick-off a meaningful discussion with your doctor to ensure you leave feeling that your questions were answered.

For all patients:
What is your preferred method of contact for additional questions? Email? Phone? How long will it take for you or your staff to get back to me?

If you are newly diagnosed:
What do I need to know about my treatment plan? How do my treatments work?

Should I consider BRCA testing and genetic counseling?
  * Do I need those results before I start treatment?

What side effects should I expect? How will this impact my life? What do I need to know about ongoing monitoring?

Are my treatments covered by my health insurance?

What else do I need to do to take care of myself? Why is it important that I do it?

What happens after I finish treatment? What are my chances of recurrence? What are my options if my cancer recurs?

Are there any support groups or online resources I can look into to be better informed and get peer-to-peer support?

If your treatment is ongoing:
Do I have new test results since my last appointment? What do the results mean? What will happen next?

Is my current treatment plan still the best option for me?
  * How do I know if my treatment is working?
  * Are there other treatment options I should consider?

If new options are suggested:
  * Why do I need this new option?
  * What do I need to know about this treatment? How does it work? How is it administered?
  * What side effects should I expect? How will this impact my life? What do I need to know about ongoing monitoring?
  * Is this treatment covered by my health insurance?
  * What else do I need to do? Why is it important that I do it?

Should I consider a clinical trial?
If you have recurred:
What are my treatment options if my cancer recurs?

Now that my cancer has returned, is there a recurrence pattern that I can expect?

If you are in remission:
How frequently should I come in for check-in visits to monitor my disease?

What do I do while my ovarian cancer is in remission?
- Do you have any recommendations, tips, or approaches to help me minimize or manage, any anxiety I may feel during this time when my disease is in remission, but we are monitoring the cancer’s growth?

What are my chances of recurrence?
- How long are most women in remission before the ovarian cancer might return?

Are there symptoms I should look for that would signal a recurrence?

Why would my ovarian cancer recur?

What do I do if my cancer recurs?

I’ve heard the term “watchful waiting” used – what does it mean?
- If I am not in treatment now, does it mean I get a “vacation” from my treatment? What side effects and impact on my lifestyle should I expect?

What does progression free survival mean? How is that related to remission?

What is maintenance treatment?

Should I consider a maintenance treatment during remission?
- What are my options for maintenance treatment?
- Will maintenance treatment impact my daily routine and lifestyle?
- How are maintenance treatments administered?
- Are there oral treatment options available? How frequently would I have to take it?
- What side effects should I be aware of with maintenance treatment?
- Do I need to know my BRCA mutation status to be prescribed a maintenance treatment?

Who can I reach out to for extra support during this time?

**AFTER YOUR APPOINTMENT**

Even with the best preparation, you may think of new or different questions following your appointments. Remember to write in your journal any thoughts, questions or concerns to ensure you ask at your next appointment. Or, if your oncology team offers an online communication system, secure the contact information and/or email addresses in order to reach out between visits.

**Notes:**

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**About Our Way Forward**

*Our Way Forward* is a call-to-action that encourages ovarian cancer patients, their loved ones and healthcare providers to rethink how they talk about advanced ovarian cancer. The program provides ways to partner together and navigate the physical and emotional challenges that the disease brings. For more information, visit [ourwayforward-oc.com](http://ourwayforward-oc.com), and follow us on Instagram ([@ourwayforward.tesaro](https://www.instagram.com/ourwayforward.tesaro)).