

# IBC Storytelling Talking Points

## Tell your story!

**7** Tips to get your started writing your own story. Because your story matters.

[TheIBCNetwork.org](http://TheIBCNetwork.org)

**IBC**  
THE  
NETWORK  
FOUNDATION

# 1. Before Diagnosis

- What symptoms did you first notice?
- Did you know about IBC before this?
- How long did it take for you to be diagnosed?
- Were you misdiagnosed at first? What was that like?



# 2. Diagnosis

- What were the exact words your doctor used?
- How did you feel emotionally and physically at that time?
- Did you have to advocate for yourself to get answers?



# 3. Treatment Journey

- What treatments did you go through? (chemo, surgery, radiation, clinical trials, etc.)
- How did your body respond?
- What was the hardest part of treatment?
- Were there any unexpected moments—good or bad?



# 4. Emotional & Mental Impact

- What helped you cope on the hardest days?
- Did you have support from family, friends, or other patients?
- How did you deal with fear, anger, or uncertainty?



# 5. The Invisible and the Unexpected

- What's something people don't see or understand about IBC?
- How did it impact your relationships, career, body image, or finances?
- Did you face judgment or misunderstanding because IBC doesn't form a lump?



# 6. What You've Learned

- What has IBC taught you about yourself?
- Is there a moment or experience that changed your perspective?
- What do you wish more people (and doctors) knew about IBC?



# 7. Messages to Others

- What would you say to someone newly diagnosed?
- What do you want the world to understand about IBC?
- Why is it important to you to share your story?





1. You don't have to answer every question—just the ones that resonate with you.
2. You can write your story, record a voice memo, or even speak it into your phone.
3. There's no “right way” to tell your story—raw and real is better than polished and perfect.