



WENDY S. HARPAM, MD, FACP, is an internist, cancer survivor, and author. Her books include *Healing Hope—Through and Beyond Cancer*, as well as *Diagnosis Cancer, After Cancer, When a Parent Has Cancer*, and *Only 10 Seconds to Care: Help and Hope for Busy Clinicians*. She lectures on “Healthy Survivorship” and “Healing Hope.” As she notes on her website (wendyharpham.com) and her blog (wendyharpham.com/blog/), her mission is to help others through the synergy of science and caring.

Patient Handout: Late Effects in Adult Cancer Survivors

Dear Patient,

After cancer, understanding late effects enables you to take steps that minimize their negative impact on your life whenever possible.

What are “late effects”?

Late effects are health problems that first appear months or years after completion of cancer therapy. These delayed aftereffects arise when cancer and/or cancer treatments injure normal tissues in ways that impact future health. A late effect can be a sign, such as scarring on an X-ray; a symptom, such as hearing loss; or an increased risk of a condition, such as heart disease.

Why learn about late effects?

Ignorance is not bliss when it means missing opportunities to improve the outcome. Knowledge about late effects helps you avoid regret (“I wish I knew *then* what I know *now*”) and empowers you to (1) pursue available measures to decrease your overall risk of certain late effects; (2) recognize and report problems early, when many are more treatable; (3) interpret in healing ways what you hear and read.

Do all survivors develop serious late effects?

No. Adults treated for cancer can expect detectable changes, but most long-term survivors do not develop late effects that seriously impair or threaten life. Keep risk in perspective. Imagine your risk is nine times higher of a specific problem that occurs in 1 out of every 1,000 people. Your risk is still relatively small: only nine of every 1,000 survivors like you will develop that problem—and 991 survivors won’t.

What determines your risk?

Ongoing research is helping us understand the many factors involved. Your known risk is based on key factors, such as...

- Specifics about your cancer treatments (e.g., which drugs or type of radiation; dose frequency; total dose; radiation field).
- Other medical conditions and therapies during and after completion of cancer treatment (e.g., hypertension; hormone replacement therapy; obesity).
- Genetics (e.g., BRCA positivity).
- Health behaviors (e.g., smoking; diet).

Persistent problems that began during treatment, so-called long-term effects, may increase the likelihood of certain late effects. Also, they may affect the timing and/or severity of a late effect.

Why the lag between the end of treatment and the appearance of late effects?

If healthy tissues suffer permanent injury that is mild, the damage may remain silent unless unmasked by additional injury and/or age-related change. In some cases, cancer treatment triggers undetectable changes that keep progressing for years before becoming evident.

How do treatments lead to late effects?

Surgery

- *Scarring (fibrosis)*: e.g., internal scar from abdominal surgery may cause bowel obstruction
- *Altered/removed body parts*: e.g., a single healthy kidney that ages normally may become unable to handle the workload

Chemotherapy and radiation therapy

- *Depleted stem cells*: e.g., decreased blood-forming stem cells may cause anemia, immune deficiency, or bleeding problems in the setting of additional bone marrow changes

- *Scarring (fibrosis)*: e.g., radiation and certain chemotherapies may cause scarring of lung tissue

- *Reproductive organ damage*: toxicity to the ovaries or sperm-producing cells may cause infertility

- *DNA damage*: e.g., certain alterations in the DNA of healthy cells predispose them to developing benign and malignant tumors

Hormone Therapy

- *Altered metabolism*: e.g., decreased mineralization of bones may cause premature osteoporosis

- *Altered blood*: e.g., increased coagulation may cause blood clots

- *Increased risk of certain other cancers*

Less is known about late effects of immunotherapies. Changes in the immune system and/or injury due to an attached drug or radioactive isotope may lead to immune deficiencies and other medical problems.

What can you do to help?

You can work with the healthcare team to control some factors that influence your *overall* risk of serious late effects. For example, the risk of a second cancer is greater in people who smoke. The risk of blood-vessel disease in a radiated field is lower in people who maintain good blood pressure control. Behaviors known to improve health and longevity may delay or prevent the development of many late effects. Vital steps after cancer treatments include:

- *Quitting smoking, limiting alcohol, and abstaining from illicit drugs and risky sexual behaviors*
- *Optimizing blood pressure and cholesterol levels*
- *Preventing infections with vaccinations and good hygiene*
- *Developing physical resilience through healthful diet, physical conditioning, and high-quality sleep*

How does the risk of late effects change your role at doctor visits?

The risk of late effects impacts many methods of disease prevention, screening, evaluation, and treatment. For example, breast cancer screening for a 35-year-old woman who received chest irradiation as a teenager is different than if she’d never had cancer. You play a vital role in making sure *all* your physicians consider your cancer history.

A tactful approach is to ask: **How does my cancer history affect these decisions?** You can follow up by sharing your understanding that long-term survivors may experience (1) an earlier than usual development of age-related changes and (2) an increased chance of developing certain problems.

What if “late effects” is new to you?

Common reactions include surprise, anger, disappointment, and heightened anxiety. The distress will likely fade as you learn which late effects don’t apply to your situation and, more important, what you can do to optimize your long-term health.

Your oncologist weighed both the risks of late effects and the chance of controlling your cancer before recommending treatment. You can learn about late effects now to move forward in healing ways.

What now?

We won’t minimize any difficulties associated with late effects. While researchers keep exploring ways to prevent and treat them, let’s nourish hope by working together to minimize your overall risk of serious late effects and to make today the best it can be. **OT**