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Collaborative Efforts to Improve Cancer Survivor Quality of Life

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NOTES FROM THE FIELD

Collaborative Efforts to Improve Cancer Survivor Quality of Life

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An individual is considered a cancer survivor from the time of diagnosis through treatment and beyond. In Michigan, there are about 526,100 survivors (American Cancer Society, 2016). Survivors are living longer with the support from advancements in cancer care and treatment. However, they may still experience the effects of their cancer for years to come.

Survivorship Care Plans (SCPs) are one way to support survivors during the transition from oncology care to the primary care setting. The Commission on Cancer established Survivorship Care Plan Standard 3.3 in which cancer programs are to, “Develop and implement processes to monitor the formation and dissemination of a SCP for analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy” (Commission on Cancer, 2016). The SCP provides a record of treatment, follow-up care recommendations, referrals to support services, and additional community resources (Commission on Cancer, 2016). SCPS support survivor quality of life by encouraging adherence to follow-up care and healthy lifestyle recommendations.

In 2016, the MCC Board of Directors selected SCPS as the 2016-2017 priority under the *Cancer Plan for Michigan’s Quality of Life Goal*. The priority focuses on increasing the number of Michigan adults diagnosed with cancer who report receiving instructions on where to return or who to see for routine cancer check-ups after completing treatment. The MCC Survivorship Priority Workgroup, tasked with developing a project to support this effort, consists of professionals from different backgrounds with extensive knowledge on the needs of survivors.

The MCC Survivorship Priority Workgroup determined their project would involve creating five SCP resource documents for post-treatment survivors. These documents would accompany SCPS and provide education and resources on healthy behaviors that can improve quality of life during survivorship. Between July 2016 and August 2017, document topics were selected by the workgroup based on common survivorship questions or concerns and important public health interventions. These topics were physical activity, nutrition, tobacco cessation, fatigue, and healthy lifestyle choices. The documents are not intended to replace consultation with a health care provider; survivors should see their health care provider for regular medical care. The goal is for providers to share these documents with survivors who would benefit from learning more about the specific topic.

Since the cancer survivor population is diverse, it was determined the documents would be written with plain language and a reading level to accommodate survivors of various education levels. Plans were also set to translate the documents into two additional languages widely spoken in Michigan, Spanish and Arabic. The workgroup collaborated with partners in the Michigan Department of Health and Human Services, including the Tobacco Control Program, Division of Immunization, and Disability Health Unit, to review the documents that pertained to their content areas.

To test the resource documents for readability and usability, Institutional Review Board approval was received for a focus group with post-treatment cancer survivors. The focus group was organized in collaboration with St. Joseph Mercy Health System. Participants were asked to provide feedback on whether the five documents contained information beneficial to post-treatment survivors and were formatted in a manner they would find appealing and easy to read. It was concluded from focus group feedback that resource documents of this type should include:

- Additional resources related to the topic
- Citations for information provided
- Colorful pictures
- Plain language
- Bullet points

Focus group feedback was helpful to ensure the documents were meeting the needs of those individuals their use was intended for.

The five resource documents were approved by the MCC Board of Directors in November 2017 and made available for download on the [MCC's website](#) (see Appendix A for an example of the documents). The MCC Survivorship Priority Workgroup has promoted the documents at the MCC Annual Meeting and through various MCC communication channels. To evaluate use of the documents, metrics associated with document downloads from the MCC website will be monitored in 2018.

As the MCC Survivorship Priority Workgroup concludes their work on the SCP resource document project, they remain committed to improving the quality of life of Michigan cancer survivors. Over the next two years, the workgroup will focus on a new *Cancer Plan for Michigan* priority to reduce the percent of Michigan adults with cancer who report physical pain. Their project will involve creating a shared-decision making document for survivors that provides education on physical pain management. The workgroup and MCC are dedicated to meeting the unique needs of survivors as this population continues to grow.

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2. Commission on Cancer (2016). Cancer program standards: Ensuring patient-centered care. Retrieved from, <https://www.facs.org/quality-programs/cancer/coc/standards>

Appendix A: Fatigue Resource Document

LIVING HEALTHY AS A CANCER SURVIVOR: FATIGUE

A cancer survivor is a person who has been diagnosed with cancer. They are considered a survivor for the rest of their life.

- There are both physical and emotional side effects of cancer and its treatment. These side effects will impact survivors in different ways.
- Choosing healthy behaviors is important. You can lower your risk of getting cancer again through exercise, eating healthy foods and not being overweight.
- This document provides survivors with information on ways to live healthy after treatment ends. The document should not replace consultation with a health care provider. It is important that all survivors see their health care provider for regular medical care.

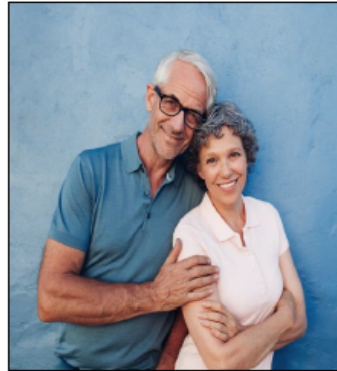
Handling Fatigue as a Cancer Survivor

Fatigue is a common side effect of cancer treatment. Cancer related fatigue is not linked to recent activity. It does not always get better if you rest.

Physical fatigue- The body feels tired and a person may not feel they have energy to do activities.

Mental fatigue- A person has difficulty concentrating, solving problems, reading, and holding conversations. They may also experience anxiety and irritability.

Cancer treatment, pain, and other factors can cause fatigue. Talk to your health care provider about different ways to treat it.



Managing Your Fatigue

1. **Be active.** Being physically active can help you gain energy and lower stress.
 - American Cancer Society guidelines for physical activity include 150 minutes of moderate-intensity exercise per week, like fast walking.
 - Exercise using a DVD or YouTube video if it is hard to leave the house.
 - Consider yoga, biking, or other types of exercises.
 - Ask your health care provider and physical therapist about activities that are best for you.
 - Physical activity is the BEST way to decrease fatigue and increase energy.
 - For some individuals, it may take time to overcome fatigue.

2. Eat healthy. Drink Lots of water.

- Eat 2 cups of vegetables and 1 ½ cups of fruit every day.
- Try eating 5 or 6 small meals spaced out over the day, instead of 3 large meals.
- If you drink coffee or tea with caffeine, only drink them in the morning.
- Drink at least 8 to 10 glasses (8 ounce) of water each day. Check with your health care provider if you have heart or kidney problems.

3. Create time during your day to rest.

- Go to bed at the same time every night, even on the weekends.
- Relax before going to bed by reading or listening to quiet music.
- Get up at about the same time every morning.
- It is ok to take 1 or 2 short, 30-minute naps during the day. Try to be active after.



4. Distract yourself with fun activities.

- Volunteer in your community.
- Take time to visit with family and friends.
- Read a book, meditate, listen to music or enjoy a hobby.

Helpful Resources for Survivors

- Call The American Cancer Society's National Cancer Information Center at 1-800-227-2345 for more information and resources.
- For more information on cancer related fatigue visit the [National Cancer Institute website](https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq): <https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq>



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2. National Cancer Institute (2015). Fatigue (PDQ®) – Patient Version. Retrieved from <https://www.cancer.gov/about-cancer/treatment/side-effects/fatigue/fatigue-pdq>