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Ontario Health is committed to improving the quality of health care in the province in partnership with patients, clinicians, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, care partners, clinicians, and researchers.

This patient guide accompanies the quality standard on <u>Cancer Survivorship</u>. It outlines the top 5 areas where clinicians can take steps to improve care for cancer survivors. The patient guide also includes suggestions on what to discuss with your clinicians, as well as links to helpful resources.

WHO IS A CANCER SURVIVOR?

The term "cancer survivor" describes anyone living with, through, and beyond a cancer diagnosis. Ontario Health's Cancer Survivorship Program uses this term to describe patients from the point of their diagnosis through the end of their treatment and beyond into their life after treatment ends, highlighting the importance of early care decisions and collaborative care that addresses everyone's unique needs and preferences. Although not everyone prefers the label, it is used here to describe supportive health care for people who have had cancer.

Top 5 areas to improve care for cancer survivors



Quality Statement 1: Comprehensive Assessment at Regular Intervals

What the standard says

Cancer survivors receive a comprehensive assessment of their survivorship care needs at regular intervals. Assessments are documented in an individualized, person-centred care plan that is updated regularly. Survivors with identified needs receive or are referred to appropriate care and services.

What this means for you

You should be offered an assessment of your physical health, mental health, and overall wellbeing at least once a year. This assessment should be done by a clinician with expertise in managing cancer survivorship needs. Your clinician should use this assessment to complete or update your care plan. With your consent, they should also share this plan with everyone on your health care team so that the team has the information they need to give you the best care to meet your unique needs.

DID YOU KNOW?

"Clinicians" are health care professionals who provide care to patients. Clinicians include doctors, nurses, nurse practitioners, pharmacists, psychologists, and registered dietitians.

WHAT IS A CARE PLAN?

A care plan is a written document (physical or digital) that describes your health needs and goals, as well as the resources needed to meet them. The care plan should be based on your faith traditions, culture, values, beliefs, wishes, goals, and needs. For example, your care plan might include:

- A description of what you want your care to look like
- Plans to manage any physical or mental health concerns you have (see quality statement 3)
- Contact information of the cancer treatment team
- Contact information of the clinician or health care team responsible for your follow-up care

If you consent, your care plan can be shared with your health care team and care partners, as appropriate.



Quality Statement 2: Transitions in Care, Primary Care Use, and Care Coordination

What the standard says

Cancer survivors transition between levels of cancer care as appropriate for their needs. Transitions in care for survivors involve care coordination, shared care, and support between health care teams and settings, ensuring integration with primary care.

What this means for you

Your care does not stop when treatment ends. You may move between different types of care depending on your needs. These transitions are meant to make sure you get the right care at the right time, and that no part of your health is overlooked. To support these transitions, your primary care clinician, cancer specialists, other members of your health care team, your care partner or a designated navigator should work together and share information, as needed.

WHO IS A DESIGNATED NAVIGATOR?

A designated navigator is 1 person, possibly from your health care team or a trusted care partner, who agrees to coordinate your move between levels of cancer care and other health care services. You can help decide who your navigator is. Your navigator and their role may change over time, as needed.

LEVELS OF CANCER CARE

You may move through different stages of care, from active treatment to regular check-ups. To give the best support, your health care team should check your needs and provide care that fits where you are in the care continuum. This care can come from primary care clinicians, specialists, or survivorship clinics.

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Quality Statement 3: Psychosocial Support

What the standard says

Cancer survivors and their care partners have access to regular psychosocial screening (as part of a comprehensive assessment) to identify any psychosocial needs or barriers to accessing care. Survivors with unmet psychosocial needs receive information and support or are referred for treatment.

What this means for you

Your clinician should ask you regularly about your emotional health, mental health, and overall well-being. This includes asking if:

- You feel sad or worried a lot of the time
- You feel lonely
- You have questions about resuming or continuing your regular activities

Once your clinician knows how you're feeling, and which things you are struggling with, they can provide information or let you know about services and supports in your community that might help you.

IF YOU'RE A CARE PARTNER:

It can be challenging to help manage the care of a cancer survivor. The cancer survivor's health care team should ask you about your emotional health, mental health, and overall well-being. If you would like it, they should also offer you information and support that might help you.



Quality Statement 4: Patient Education and Self-Management

What the standard says

Cancer survivors receive comprehensive education about survivorship care, both during and after active treatment. They are offered self-management support and strategies to address their survivorship care needs, with the goal of optimizing their health and quality of life.

What this means for you

You should receive clear and comprehensive information about cancer survivorship that outlines what to expect throughout your cancer survivorship journey. This may include information on your care plan, potential long-term and late effects of treatment, and post-treatment needs. Your clinician should also identify community support services or ongoing research studies that align with your care needs and phase of life. You should also receive information on things you could do to improve your quality of life, such as practical tips about nutrition, physical activity, sleep, and healthy behaviours.

DID YOU KNOW?

There are some things you can do to take care of your health and make you feel better, such as:

- Being active
- Eating healthy foods
- Not smoking
- Protecting your skin from the sun
- Getting enough sleep

If you are not sure what steps are right for you, talk to your health care team. They can give you information, suggest support services, or help you find other resources if needed.

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Quality Statement 5: Accessible, Culturally Safe, Equitable Care

What the standard says

Cancer survivors receive care in a health care system that is accessible, compassionate, and culturally responsive to their traditions, values, and linguistic and other needs. Health care teams work to build trust, remove barriers to accessing care, and provide equitable care, giving special consideration to First Nations, Inuit, Métis and urban Indigenous people, and equity-deserving populations.

What this means for you

Your health care team should always treat you with dignity and compassion. They should be respectful of your culture, language, and traditions. You should be given the opportunity to be as healthy as possible. This means that you should be able to get high-quality health care when you need it, no matter where you seek care (for example, at your doctor's office, virtually, or at the hospital).

Suggestions on what to discuss with your clinicians

Ask your clinician(s):

- What does my survivorship care plan look like and are there any plans for follow-up?
- What tests or screenings will I need, and how often will they happen?
- Who do I contact if I have a health concern between assessments?
- How do I get back to the cancer centre or oncologist if needed?
- What symptoms should I watch out for during or after treatment?
- What long-term and late effects of cancer treatment should I expect during cancer survivorship?
- How can I manage my post-treatment needs?
- If I don't feel like myself after treatment, is this normal and what can I do to feel better?
- What supports you can refer me to?
- What can I do to reduce my risk of recurrence?
- What lifestyle changes can help me stay healthy?
- What community resources and supports are available to me?

Share with your clinician(s):

- Any concerns or questions you have about your care plan
- Anything about your care that you do not understand
- Any other health concerns you have
- If you don't feel like yourself after treatment

If you are a care partner

You might have your own questions. It can help to identify yourself as the patient's care partner to their health care team. This will make sure they know and respect your questions and concerns.

- Let them know what your role will be in helping the patient manage their condition
- Let them know if you need help

Learn more

<u>Canadian Cancer Society</u> offers services for people diagnosed with cancer. The information is available in English and French.

Ontario Health (Cancer Care Ontario) provides information on managing many of the most common symptoms of cancer and its treatments in a variety of languages.

<u>Wellspring Cancer Support</u> offers programs free-of-charge and without referral for people living with cancer and care partners to overcome emotional, physical and practical challenges.

UHN Princess Magaret Cancer Center provides <u>resources</u> specific to adolescents and young adults with cancer.

Princess Magaret Cancer Center offers <u>online cancer classes</u> about treatments, side effects, and what to expect in survivorship.

Ontario Health has developed other quality standards and patient guides on conditions related to cancer survivorship that may be useful, including:

- Opioid Prescribing for Acute Pain
- Opioid Prescribing for Chronic Pain
- Transitions From Youth to Adult Health Care Services
- Transitions Between Hospital and Home
- Major Depression
- Anxiety Disorders
- Insomnia Disorder

Need more information?

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).

Need this information in an accessible format? 1-877-280-8538, TTY 1-800-855-0511, info@OntarioHealth.ca

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