London Health Sciences Centre

South West Regional Cancer Program
Ontario Health (Cancer Care Ontario)

2025 PATIENT EDUCATION SYMPOSIUM REPORT

HOSTED BY THE SOUTH WEST REGIONAL CANCER PROGRAM

Prepared by
South West Regional Cancer Program

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What is one-word that describes your experience with patient education?



EXECUTIVE SUMMARY

The South West Regional Cancer Program (SWRCP) hosted the first Patient Education Symposium on April 5, 2025, at Grayson Mills in Stratford, Ontario. The event brought together 42 people, including patients, caregivers, healthcare providers and community organizations.

The goal of the symposium was to listen to the voices of patients and caregivers to help shape the 2025/2026 patient education strategy. Attendees took part in small group discussions, heard from guest speakers, and shared ideas about what is working well and what could be improved in cancer patient education.

Key Insights

Patients often feel overwhelmed with too much information at the start. The timing and delivery of information needs to be improved.

After treatment ends, many patients feel alone and not sure about what happens next. Patients would like more support and clear written plans to guide them.

Many patients did not know about helpful community programs early on in their journey. They feel that healthcare teams should share this information sooner.

Patient education should be more culturally sensitive and translated to different languages. Patients also want education in different formats (like print, video, and in-person).

95% of attendees rated the event as excellent or very good, and feedback indicated a clear desire for the event to recur annually.

26	2	100%
Patients and Caregivers	Expert Speakers	Attendees Felt Heard

Patient Partner
What was the most valuable thing you learned today?

> *That I am not alone in this journey through life and cancer.*

Symposium Overview

KEY THEMES AND FINDINGS

Theme 1: Navigating Cancer and Healthcare Information



Patients and caregivers shared how it can be hard to find the right cancer information at different points in their journey. They talked about how important it is for information to be clear, timely, and trustworthy.

Timing and Information Overload

Many patients and caregivers said they received too much information all at once, especially at the time of diagnosis. This caused stress and confusion. They suggested having a follow-up or "check-in" appointment a few weeks later to go over the key information again.

Preferred Learning Formats

Patients and caregivers liked having different ways to learn, such as written brochures, websites, videos, and one-on-one conversations. Everyone learns differently, so it's important to offer a mix of options. They also said education should be tailored to age, diagnosis, and personal learning preferences.

Trust and Accessibility

Patients and caregivers said it helps to be pointed early to trusted sources like Myeloma Canada, CancerConnection.ca, and local libraries. They would like healthcare teams to spend more time talking to patients and caregivers about the available resources for them. Some preferred emailed links over QR codes, and others suggested more plain-language materials. Some patients and caregivers found the medical language in brochures and pamphlets hard to understand. They suggested that all educational materials should be written in plain language to be more helpful.

Navigation Tools

Patients and caregivers suggested having "starter kits" for newly diagnosed patients and clearer guidance on where to go for help. Patients recommended virtual or in-person tours of treatment areas, like chemotherapy or radiation suites. They also shared that things like parking stress, confusing signage, and lack of orientation videos added to their anxiety before appointments.

> *"The timing of education is everything. Too much too early is overwhelming."*
>
> **Patient Partner**

> *"The quantity of information patients forget at their first appointment is huge. It reinforces how important caregiver support is right from the start."*
>
> **Patient Partner**

> *"I would have liked a session just on what to do after finishing treatment."*
>
> **Patient Partner**

KEY THEMES AND FINDINGS

Theme 2: After Treatment and Survivorship

Patients and caregivers said that finishing cancer treatment and moving into survivorship was one of the hardest and most vulnerable times.

Emotional Impact

Patients and caregivers shared that they felt relieved and anxious. Some were scared the cancer might come back, and others felt like they had lost a part of their identity. Many felt isolated after treatment, missing the support they received from care teams.

Gaps in Survivorship Education

Patients and caregivers felt that there was not enough clear information about what to expect after treatment, both physically or emotionally. Some patients did not know who was responsible for follow-up care, if it was their oncologist or family doctor.

Need for Survivorship Plans

Patients and caregivers said it would help to have a written survivorship plan that explains follow-up care, symptoms, and who to contact if they need help. They also asked for support with long-term side effects and mental health check-ins.

Peer Support

Peer support programs helped patients and caregivers feel understood and guided after treatment. It was validating hearing from others with similar experiences.

Theme 3: Community Resources and Partnerships

Patients and caregivers talked about how important community organizations are in providing education and support.

Low Awareness of Services

Many patients and caregivers said they did not hear about services like Wellspring until much later in their cancer journey. They feel that they would have benefitted from knowing about these services earlier.

Visibility of Resources

To help more people learn about these supports, patients and caregivers suggested showing information on TV screens in waiting rooms, handing out flyers, and having healthcare providers mention them during appointments. Campaigns like "Did you know?" in newsletters or websites were also recommended.

Value of Community Programs

Patients and caregivers said that programs that offer things like meditation, financial help, exercise, peer support, and symptom management were seen as very important for healing and coping. Patients wished for more caregiver events, mastectomy bras in wig shops, and better clarity around who qualifies for financial help.

KEY THEMES AND FINDINGS

Theme 4: 2025/2026 Patient Education Priorities

Patients and caregivers shared several key priorities to help shape patient education.

Health Equity

Patient education materials should be culturally sensitive, trauma-informed, and easy to access. This is especially important for minority groups, including Indigenous patients, people living in rural areas, and marginalized communities. Patient education should also be available in multiple languages and adapted for different learning styles.

Financial Navigation

Patients and caregivers need clearer information early on about out-of-pocket costs and what financial supports are available to them.

Flexible Education Delivery

Patient educational materials should be offered in a variety of formats such as print, video, audio, digital, and in-person to meet different learning needs. Many patients also preferred peer-led workshops and small group sessions. Some suggestions from patients and caregivers include staff pocket guides listing resources, joint resource fairs, and better promotion of the Patient Resource Centre (Building A, Level 1, near the Tim Hortons) and Patient Information Zone. They also suggested that staff be regularly updated on hospital and community programs so they can refer patients more effectively.

Patient and Caregiver Voices

Patients and caregivers should be included from the beginning as equal partners in planning, creating, and reviewing patient education materials. They should not be brought in only at the end for feedback. Patients recommended diverse representation, clear recruitment pathways, and promoting the value of patient voices through education campaigns for staff.

REFLECTIONS

The 2025 Patient Education Symposium reaffirmed the essential role that patient and caregiver voices play in designing effective cancer patient education. Their lived experiences, ideas, and recommendations will serve as the foundation for the patient education strategy in 2025/2026.

By building on these insights, the SWRCP will continue advancing health equity, improving patient outcomes, and strengthening the patient and caregiver experience across the cancer journey.



2025/2026 STRATEGIC PRIORITIES

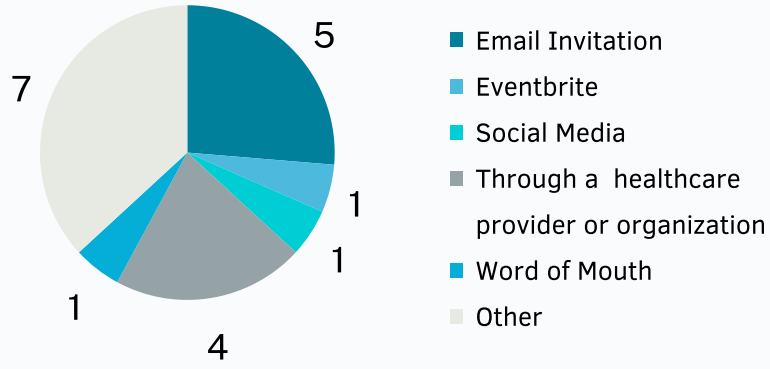
These strategic priorities were highlighted based on what patients, caregivers, staff, and community members shared during the group discussions and in the post-event survey. This report and the priorities outlined below will help guide the development of the South West Regional Cancer Program's 2025/2026 Patient Education Strategy. The ideas and suggestions shared for each of these priorities will be considered as we build the larger patient education strategy.

01	**Improve Timing, Delivery, and Personalization of Education**	• Implement staged education across the cancer journey to reduce information overload at diagnosis. • Offer “pre-admit” orientation tour before chemotherapy or radiation to prepare patients for treatment. • Provide more clear information on navigating financial resources and what is available to the patient.
02	**Expand Education Formats and Tailor to Learning Styles**	• Develop materials using the four learning types: visual, auditory, reading/writing, and kinesthetic. • Offer content in multiple formats: brochures, videos, podcasts, apps, peer-led sessions, and small-group workshops.
03	**Advance Health Equity and Accessibility**	• Ensure all education is culturally sensitive, trauma-informed, and translated into multiple languages. • Address specific needs of marginalized and minority communities.
04	**Improve Awareness and Use of Community Resources**	• Promote supports like Wellspring, HopeSpring, CancerConnection.ca, and local palliative services. • Launch resource awareness campaigns using posters, newsletters, and TV screens in waiting rooms. • Increase the presence of SWRCP staff across the region (London, Stratford, Owen Sound) to build visibility.
05	**Support Survivorship and Emotional Recovery**	• Provide written survivorship care plans outlining follow-up schedules, symptoms to monitor, and mental health supports. • Normalize topics like end-of-life preparation and how to talk to family and friends about one’s cancer journey.
06	**Embed Patient and Caregiver Voices in All Stages**	• Use a co-leadership model where patients and caregivers help plan, design, and evaluate materials. • Recruit a diverse range of patient partners, especially from underrepresented groups.

POST-EVENT SURVEY RESULTS

Total Respondents: 19/26 (73%)

How did you hear about this event?



Other:

- Patient and Family Advisory Committee (PFAC)
- Verspeeten Family Cancer Centre
- Myeloma Support Group
- Online Newspaper Notice

What was the most valuable thing you learned today:

- Feelings of connection, belonging, and shared experience.
- Learning about resources and community programs
- Realizing the emotional and practical burden of cancer.
- Importance of caregivers and support for appointments.

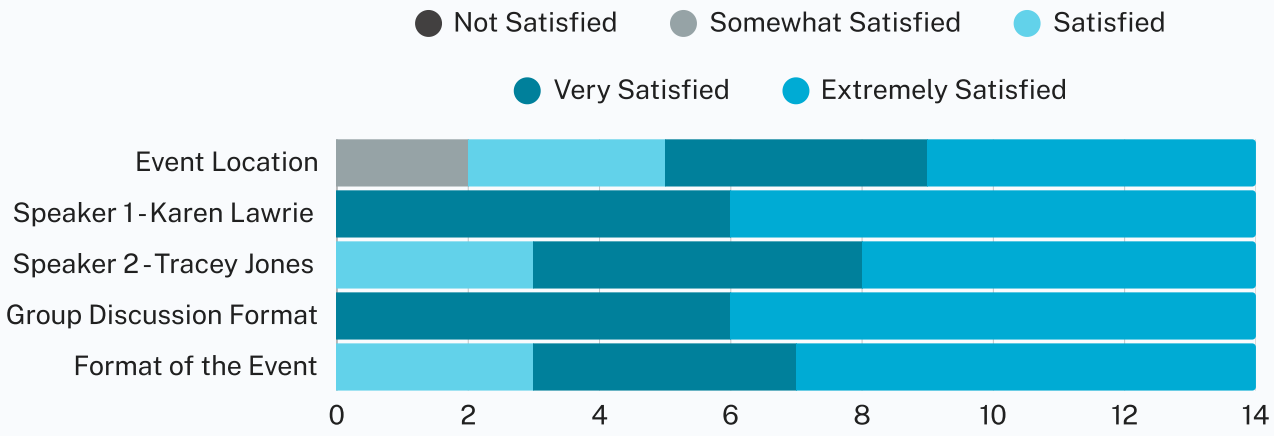
> *"It was wonderful to be in a room together to experience the warmth, sincerity and intelligence of everyone involved."*
>
> **Patient Partner**

100%
felt that their thoughts and perspectives were acknowledged

90%
said that this symposium should be a yearly event

95%
rated the event as excellent or very good

How satisfied were you with the following:



Do you have any other feedback about today's event or discussions?

- Patients and caregivers valued the opportunity for in-person connection
- There was mixed feedback on Stratford as the event location. Some liked the regional setting, while others noted that London would have been more accessible.
- There are opportunities to improve advertising and promotion for events like this.
- There was positive feedback for the facilitators, group discussions, and overall atmosphere.