

The Shock of Diagnosis

(Although the Storywork and Dialogues videos and guides were developed with First Nations people, they may also resonate with experiences of Inuit and Métis people.)

A cancer diagnosis can be a very traumatic time for both the individual receiving the diagnosis and their families. Often it is described as shocking and numbing; some say they don't hear anything else the care provider has said at the time of diagnosis beyond the word cancer.

“Cancer mean to me is something really dangerous, and you know cancer kills people, so as soon as you hear somebody got cancer already you think of death to the family so it's really scary. Had it really badly in Fort Good Hope so you're living every day thinking of who's going to be next, it might be you. So it was really scary and the word cancer is really scary. And right away if someone, if a nurse or a doctor says someone has cancer right away you think of death, the story gets around really fast in a town.” – Vicki, Fort Good Hope, NT

“One thing that came clear from the videos was the long shadow of the residential school program on our Elders and how that impacts of subsequent generations, the long term and long shadow that the residential school experience has wrote in the terms of cancer care is the effect that it has made people more hesitant to self-advocate and to interact with what they perceive as authority figures from different systems.” – Dr. Fourier, Terrace, BC

What you should know

- The impact of a cancer diagnosis may lead to an even greater sense of fear and isolation for the individual receiving the diagnosis, especially if they are away from their home community and family.
- It is important that care providers understand that due to the impacts of historical trauma experienced by many First Nations people that there may be a pre-existing mistrust of the medical system. Therefore the individual receiving the diagnosis and their families may be fearful and remain silent.
- It is vital at the point of diagnosis for a care provider to take the time necessary to meaningfully connect with the individual receiving the diagnosis and their families to ensure that they have the information they need and they know who they can connect with to talk about any questions that may arise after they leave. This requires the care provider to have acquired an understanding of the person, their experiences, their family, and their community.

- An individual receiving a cancer diagnosis from a rural, remote or isolated community may choose not share this with their families and others in the community due to fear and misconceptions around cancer.

To think about and act on

- What was interesting about the video and this discussion?
- Do the stories and reactions reflect what you already know from your primary care or oncology practice?
- What ideas are in the video to help a person and families better?
- Are other ways people and families should be helped?
- What could you do to help a person who hears they have cancer? What could your primary care or oncology practice do?
- Who else could make things better where you are?

Wise Practice: How primary care and cancer care organizations can make sustainable changes to improve cancer journeys

- **National Health Service Sustainability Model:** <http://online.ideasontario.ca/wp-content/uploads/2015/08/NHS-Sustainability-Guide.pdf>

Suggested Practice: Consider including this check list when a person's transition to a cancer centre or back home occurs

1. I took my patient's family and culture into account when helping him/her plan to go to [the cancer centre/his or her community].
2. When my patient left [the community/the cancer centre], I helped him/her plan who would be involved in my health when I arrived.
3. When my patient arrived [in the community/at the cancer centre], the plan I helped him/her with worked out.
4. I believe that I communicated well with my patient's health care providers in his/her community and in the cancer centre.

About the Transition Support Resources

Eight Transition Support Resources were produced to promote dialogue and discussion about the cancer journey by families, communities, primary care providers, and cancer care providers in cities. They come from stories from 28 individuals representing the First Nations patient and family perspective and from responses from 17 primary and oncology care providers in British Columbia, Alberta, Manitoba, and Northwest Territories.

About the project

The Government of the Northwest Territories Department of Health and Social Services and Cancer Control Alberta, Alberta Health Services, were the lead implementing partners working with CancerCare Manitoba, the British Columbia Cancer Agency Centre for the North, and Saint Elizabeth Health Care, as well as First Nations communities in the Northwest Territories, British Columbia, Alberta, and Manitoba. The project was funded by the Canadian Partnership Against Cancer.

