Engaging Patients to improve Success in Cancer Treatment and Outcomes

The *Employers Cancer Care Summit*

King Edwards Hotel, Toronto, Ontario

March 5, 2013

A diagnosis of cancer affects the entire family, not just the person being diagnosed
The Dynamics of the Health Care Team versus the Employer

What do I tell my employers. Will my job still be secure? What about my family?

We have to move quickly with the treatment plan, this particular cancer is treatable but we have to act quickly.

Cancer affects the co-workers and those who are close to the employee

Let’s find someone else to handle that project. Joe is a bit preoccupied now.

I can’t juggle more work. I am away from my family too much.

I wonder why I wasn’t invited to the meeting this morning?
Patients Need to be Engaged to Manage the Dynamics

Or someone else will manage the dynamics for you…..

“You can't always get what you want, but if you try sometimes, you might find, you get what you need.”
— Mick Jagger

In business, you don't get what you deserve, you get what you negotiate.
- Chester L. Karrass

Your Health is YOUR business!

A Success Story of Patient Engagement

• CML - orphan disease, affecting 1 in 100,000
3,200 Canadians living with CML

• Chromosomal translocation – chromosomes 9 & 22 exchange some genetic material and form a new chromosome – the Philadelphia Chromosome

• Cancer causing gene was identified – excellent candidate for targeted therapy
Patient Engagement Success Story

• Suzan McNamara – 31 years old, failing Interferon, no great matches for a bone marrow transplant – doesn’t want to die!
• Learns from searching on the internet that there may be a “miracle” pill from Novartis Pharma
• However, patient group is so small it may be too expensive to bring it to market
• McNamara starts a petition, gets 4,000 signatures in 3 weeks, presents it to the CEO of Novartis
• Clinical trials are expanded to allow everyone failing therapy to get a chance with Gleevec
• She starts the trial in January 2000, Complete Molecular remission in less than a year.
• Goes back to school full time – graduates from McGill University, Phd Leukemia Research – focus - resistance genes in Leukemia.
• Scientific Advisor for The CML Society of Canada

Patient Engagement Success Story

• Just 15 years ago a diagnosis of CML came with a prognosis of a 50% chance of dying within three to five years after diagnosis
• In 2001 2,300 patients in the US died of CML – 230 patients in Canada
• 2013 - 450 Canadians will be diagnosed with CML this year, while 50 Canadians will die of CML
What Can an Employer Do?

• Develop an atmosphere of trust with the employee to help them become engaged in their treatment and develop negotiation skills
• Pay attention to co-workers who may complain about being asked to pick up the slack for a fellow employee (team-manship?)

What Can an Employer Do?

• Allow Flextime for the employee
  • Extra vacation time (repayable when the employee recovers)
• Create and promote a healthy work environment encourage all employee’s to
  • Develop good nutritional habits
  • Exercise
  • Balance work and personal life
  • Illness prevention programs
What Can Insurance Programs do?

• Develop programs for employees living and working with cancer:
  • Link the patient with effective patient support groups that teach the patient about their specific disease and help them become engaged.
  • Lifestyle management programs, with access to nutrition exercise and stress reduction programs specifically geared for cancer patients
    • Consider extending access to the spouse or children

What Can Insurance companies do?

• Provide innovative solutions to ensure timely access to treatments while managing costs to the employee health plans/benefits programs.
• Provide “transition” programs to help the patient become re-integrated into the work force.
What Can “We” Do?

• Governments, Pharmaceutical companies and health care institutions should engage the cancer patient throughout all levels of the decision making process.

Example of Successful Equal Partnering

• A drug for CML, very effective, HPB/FDA approved dose 100mg
  • After 6 months side effects at this dose – severe
  • Most doctor know that doses can be lowered considerably without compromising the patient, yet no clinical studies available.
  • Patients switched to competitor drug as a result
  • Patient’s addressed the Pharma co, explained the problem – Clinical trial launched
  • Major $$ savings for patients to switch to reduce dose without compromising health
Example of Successful Equal Partnering MUHC - TCAB

Before

Sharps Collector

Cancer Pamphlets

The Family Room – through the eyes of a patient

A « real » Family Room

After
What Can “We” Do?

• Engage the patient throughout the process!
• Contact the patient group for the specific cancer project – they will put you in touch with the patient expert
• Bring the Patient Expert in from the beginning of the idea/plan/project

What Can “We” Do?

• Listen to the cancer patient, engage them.
• Take some time to learn about their specific type of cancer
• Resist the urge to encourage the patient to try “alternative” cancer treatments, with the exception of yoga and meditation, they may be more harmful than good.
• If you are not informed about the type of cancer, how can you help/suggest?
We Must All Work Together

Coming together is a beginning; keeping together is progress; working together is success.

Henry Ford

It's when we start working together that the real healing takes place... it's when we start spilling our sweat, and not our blood.

David Hume

Thank You!