



VOLUME: 3 ISSUE: 2

ILD Newsletter: Working together to improve your quality of life

Interstitial lung disease (ILD) refers to a group of diseases affecting the tissue and space around the air sacs of the lungs. Most of these diseases cause progressive scarring in this tissue. Once lung scarring occurs, it is generally irreversible. Medications may slow the damage of interstitial lung disease, but many people never regain full use of their lungs. Interstitial lung disease can be caused by long-term exposure to hazardous materials, such as asbestos. Some types of autoimmune diseases, such as rheumatoid arthritis, also can cause interstitial lung disease. In most cases, however, the causes remain unknown.



INTERSTITIAL LUNG DISEASE CLINIC -- EDUCATIONAL SUPPORT GROUP:

WHEN: Tuesday, May 22, 2018

WHERE: Toronto General Hospital, 1st Floor Eaton South Building (Elizabeth Street Entrance) Conference Room 450a

TIME: 1:30 pm to 3:30 pm

FOR WHO? ILD patients and caregivers

SPEAKER: Susan Ng, Clinical Nurse Specialist from Palliative Care at TGH

TOPIC: Dispelling the Myths of Palliative Care - Symptom Management and Advanced Care Planning

RSVP TO: alexandru.nathalie@uhn.ca

Upcoming Support Group:

The next patient-led support group will be held on June 26, 2018 from 1:30pm to 3:30 pm in Conference Room 450a



A little bit about Clinical Nurse Specialist Susan Ng!

Hello! My name is Susan Ng and I am a Clinical Nurse Specialist on the palliative care consultation team at Toronto General Hospital. I am also a mother to a toddler girl, Chinese Canadian, and an avid camper (can't get more Canadian than that eh?).

On the profession side of things, I began my nursing career 10 years on the Multi-Organ Transplant Unit at Toronto General, first as staff nurse, and later as clinical resource nurse (staff education). In 2017, I completed a Master's degree in Nursing at the University of Toronto (my third and final degree, I swear it), allowing me to transition into my current role. I discovered palliative care early in my career as a transplant nurse and found that its values and principles fit well with what nursing is all about and why I became a nurse.

Palliative care is about focusing on quality of life while individuals receive life-prolonging treatments and is appropriate anywhere along a person's journey living with chronic life-limiting conditions. It is a holistic approach to care that views people as unique persons (not diseases) and values the person and family as the center of care.

I look forward to meeting you at the upcoming ILD support group session, and maybe even busting a few myths about palliative care.

ONLINE RESOURCES:

Canadian Pulmonary Fibrosis Foundation:

<http://www.canadianpulmonaryfibrosis.ca/>

Twitter: @THE_CPFF

Facebook:

Canadian Pulmonary Fibrosis Foundation: Non-Profit Organization

Pulmonary Fibrosis Foundation:

<http://www.pulmonaryfibrosis.org/home>

Twitter: @PFFORG

Facebook: Pulmonary Fibrosis

Foundation: Charity Organization

THE LUNG ASSOCIATION:

<http://www.lung.ca/>

Scleroderma Foundation:

www.scleroderma.org

UPCOMING EVENTS:

October 21, 2018

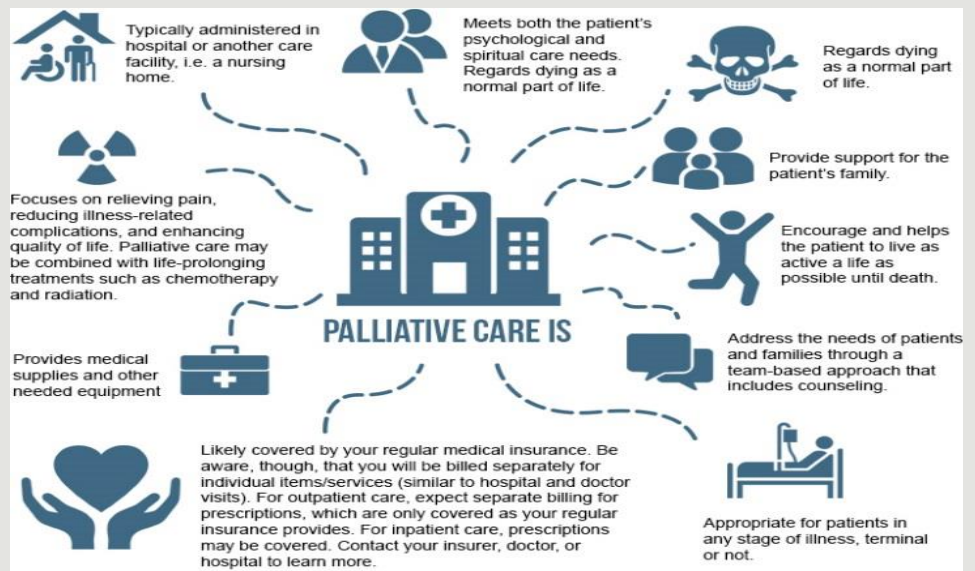
CPFF Scotiabank Toronto Waterfront Marathon – Run or walk and help raise money to fund research into causes and treatments for pulmonary fibrosis.

Register early and use these codes to get a discount!

Marathon/Half Marathon (\$80.00) = 18CPFF42K

5K (\$40.00) = 18CPFF5K

5K with stroller (\$50.00) = 18CPFF5ST



Palliating Symptoms

One of the goals of care in patients with pulmonary fibrosis is to prevent disease progression. Another goal of care is to reduce **symptoms** such as shortness of breath, chronic cough, depression and anxiety. Treating these symptoms will allow you to reach your maximum level of wellness and improved health-related quality of life.

Common symptoms of pulmonary fibrosis develop over time and tend to become severe in more advanced stages of the disease. They may include:

1. Shortness of breath
2. Breathlessness
3. Cough
4. Weight loss
5. Fatigue
6. Depression

Many respirologists and primary care physicians may already be managing these symptoms; however, you may also want to be referred to a **symptom management specialist** such as palliative care. Although there continues to be a stigma that palliative care's primary role is to support individuals around death and dying, this is simply not true. Palliative care can help with symptom burden and in many studies has shown to prolong and improve quality of life. This care does not specifically treat pulmonary fibrosis; however, it is designed to improve the quality of life for anyone dealing with a chronic illness. The individuals in a palliative care team, made up of physicians, nurses, social workers and psychologists, will work with you and your family in developing goals to improve symptoms as breathlessness or any other distressing symptoms you may experience. Palliative care will work together with you to discover your needs, expectations, hopes and fears.

Palliative care can be offered to people of every age and at any point in their illness. If you are interested in being referred or for more information, please contact your respirologist, family doctor or us in the ILD clinic.