

# LIFE AS A PRRT PATIENT

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WORLD NEN LIVES 2020

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# MY NEN JOURNEY

- Diagnosed April 2012, Age 53, psychologist
- Symptoms:
  - Bloating, abdominal discomfort, occasional bouts of vomiting and diarrhoea. flatulence!
  - colonoscopy, gastroscopy, and various other investigations. Weight loss, not-so-healthy tan. Some puffiness around my ankles doctor thought that my liver was playing up
- Abdominal ultrasound – initial finding of Pancreatic Cancer, bile duct blocked by the tumour. Initially thought it was Adenocarcinoma
- 3.5 months in hospital, stent, large secretion of ACTH – (Adrenocorticotrophic hormone) – received medication to reduce the secretion
- Low potassium, erratic calcium and magnesium

# MY NEN JOURNEY

- Started PRRT
  - Combination of Itrium and Lutatate
  - “Cytokine storm”
- 13 PRRT cycles since 2012
- Very effective in my case
- No side effects
- 2019 – one tumor was responding less to PRRT so we added Capecitabine and Temazol
  - feeling a bit off with fatigue, some nausea and hair thinning.
- Monthly Octreotide injections
- Bowel obstruction
- Biliary bypass
- Gall bladder out

# MY NEN JOURNEY

Quite a decent quality  
of life CONSIDERING 😊

Three children  
completed university

One grandchild and  
another one on the  
way

# MY NEN JOURNEY

- What Helped me:
  - Network professionals I trust
  - Oncologist, gastroenterologist, oncological dietitian, surgeons, nuclear medicine team, etc.
- Health literacy and knowledge of the disease
  - Did not consult Dr. Google much 😊
- Advocated for my own health
- Kept busy, work, gardening, walks, reading time, etc.
- Support Groups
- FRIENDS!

# MY NEN JOURNEY

- Mental Health
  - “Life is not fair” syndrome
  - What if?
  - Accept the OFF days
  - Notice that you might become a bit self absorbed
  - Accept help
- Cancer is a dynamic illness
- “My ability to control my disease is very limited”
- “Take each day as it comes” – It takes time and practice.
- Roll with the daily changes

# MY NEN JOURNEY

*“One of the most important things for me has been **NOT** to be defined by my illness”*

