

Eating & Beyond - My Story  
by Michael Baptiste

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# Welcome & Introduction

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- Michael Baptiste
- Age 31
- Duchenne Muscular Dystrophy
- Enjoyed Food
- Since 2006 Nutrition via PEG Tube



# Today's Menu

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- My Journey from Eating to Not Eating
- Dietary Options
- Getting a PEG
- Enlighten Members and Doctors about Life with a PEG

## Eat to Grow Big & Strong

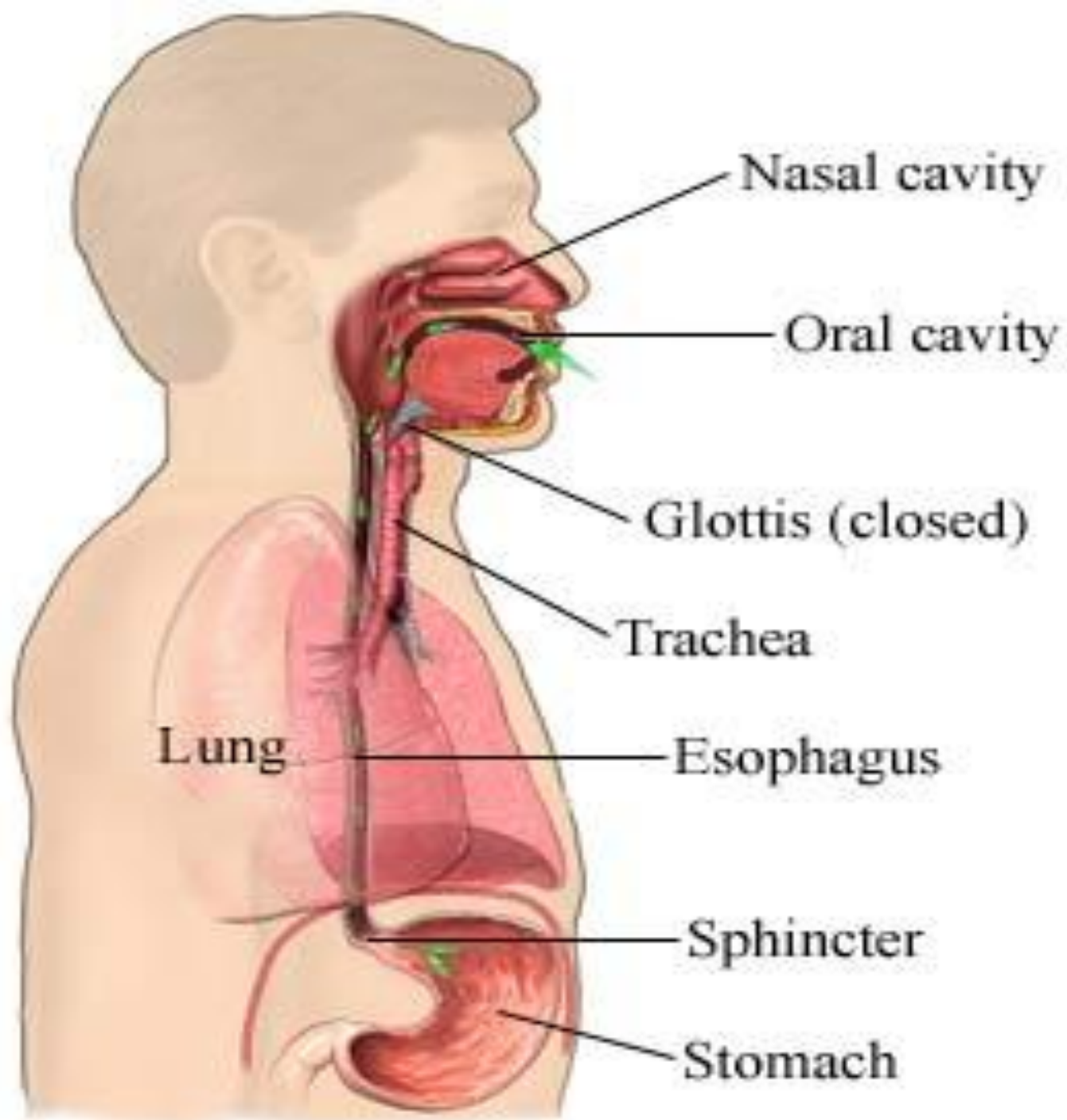
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- Eating is also for enjoyment & part of our social lives
- My favourite foods were Indian cuisine & pizza.
- At age 18 I weighed 70kgs, used a wheelchair, had mild respiratory & cardiac problems.
- I was generally healthy.

## The Beginning of Weight Loss

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- Weight loss for people with MD is partly related to muscle wasting
- BMI not as useful for MD and weight loss
- Illness will increase weight loss and further progression of Muscular Dystrophy
- Respiratory illness most common cause
- My first major illness occurred in 1997



# The Beginning of Weight Loss

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- Assessment of swallowing by Speech Pathologist
- Particles of food or fluid which enter the lungs cause ASPIRATION
- Aspiration is very dangerous and causes severe pneumonia and is life threatening
- In 1997, my swallowing was considered fine
- I now weighed 60kgs

## Next Phase of Weight Loss

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- Hospital admissions in 1999 for pneumonia & congestive cardiac failure
- Swallowing appeared to be weakening
- Intensive Speech Pathology assessment
- Recommendation to eliminate some foods which may cause aspiration, such as nuts, crunchy foods & salad leaves
- I now weighed 55kgs & had fluid restriction



# Disaster in the USA 2001

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- Went to USA for PowerHockey World Cup in Minneapolis, Minnesota
- Got unwell in Minneapolis but released from hospital
- Flew to Las Vegas but was unwell on the plane
- Second day in Las Vegas rushed to hospital with breathing difficulties

# Disaster in the USA 2001

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- Respiratory failure, intubation and placed on life support
- Extubation and re-intubation
- US doctors gave no hope of survival
- My sister & brother arrived and arranged for medical evacuation to Westmead Hospital
- An American evacuation team brought me home

# Disaster in the USA 2001

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- Arrived at Westmead Hospital ICU on 29<sup>th</sup> August 2001
- I had a central line, naso-gastric tube, arterial line, fully ventilated, both lungs collapsed and weighed 47kgs
- Successfully extubated 48 hours later and out of ICU within 6 days
- Introduced to BiPap

# Learning to eat again

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- Intubation caused impaired swallowing & further muscle weakness
- Speech Pathologist involved again but this time to assess whether I could swallow anything
- Started with thickened fluids, progressed to pureed, then minced food, soft diet and finally with almost full diet

# Learning to eat again

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- Could eat & drink most things again but needed to be careful with thin fluids
- Could not eat crunchy or hard food & could no longer eat beef or pork, unless minced
- Achieved almost full diet within 4 months of leaving hospital
- I now weighed about 48kgs

# The skeleton boy

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- By 2004 I began to lose weight regularly & had another serious battle with pneumonia
- Dietitians were involved to help increase protein & fat intake and introduction to Ensure Plus
- Low energy with more calories used to chew than were being produced by food

# The skeleton boy

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- No longer enjoyed food & respiratory problems were making it harder to eat
- Doctor suggested that a PEG may be needed shortly
- I was now afraid to eat
- Met my friend in Perth who does not eat and inspired me to get a PEG
- Get a PEG or die!



# The skeleton boy

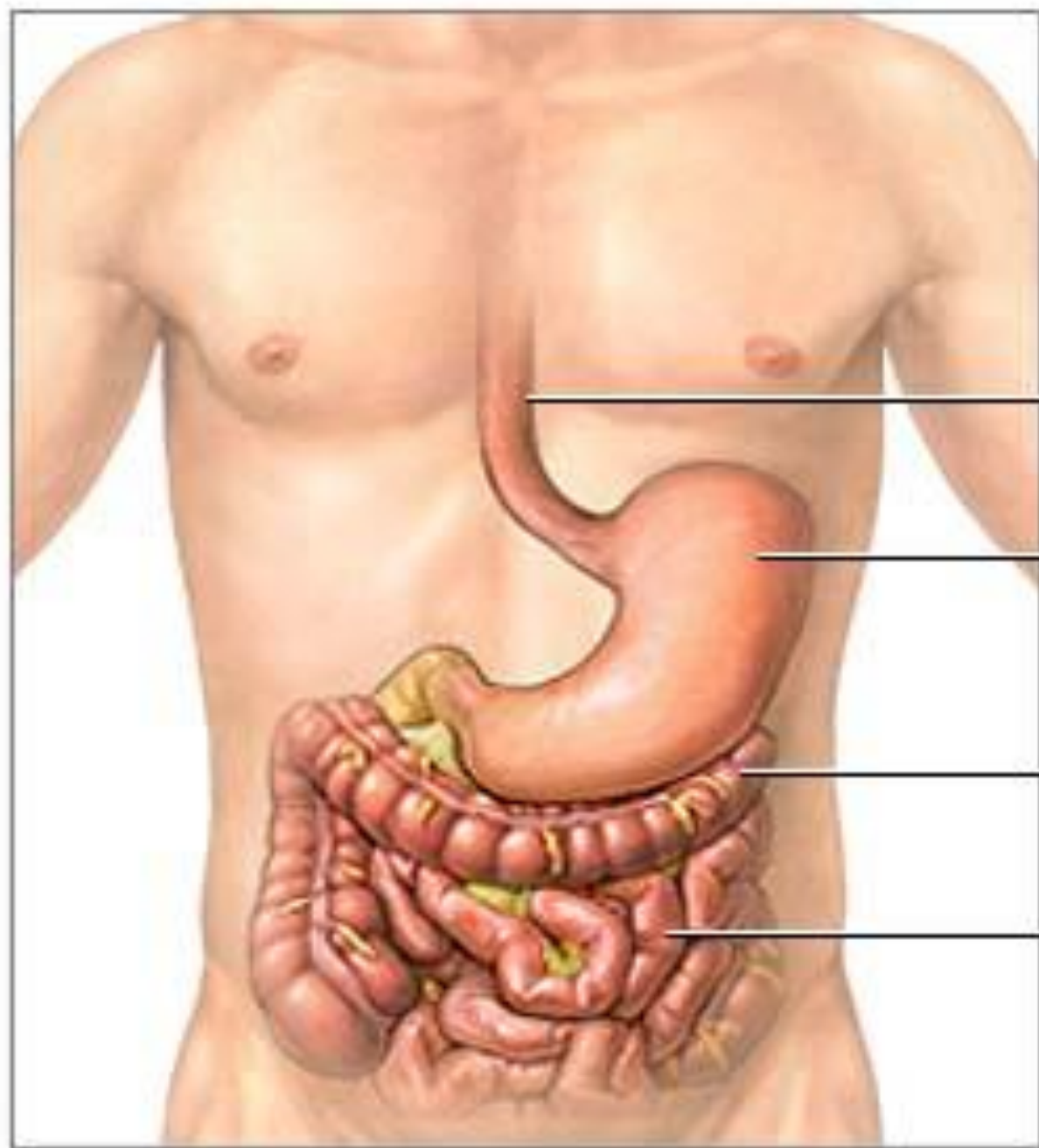
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- I was severely underweight & only weighed 37kgs
- I was skin & bone
- Impaired Immune System
- Developed bowel problems
- I called myself the Skeleton Boy

# A Good Stabbing

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- Inserting a PEG is a surgical procedure
- It is usually done under sedation & not general anaesthetic
- The procedure is done via the use of an endoscope
- The procedure takes approximately 20 minutes



Esophagus

Stomach

Large intestine

Small intestine



# A Good Stabbing

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- Post Operative pain is moderate
- It is like a stab wound
- I was given a small dose of morphine
- First feed through the PEG after 4 hours
- The site will ooze over the first couple of weeks
- A tract will grow over 4 to 6 weeks



## A Cautionary Tale

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- If you are having trouble with your swallowing and ability to maintain weight, speak to your Doctor about a PEG tube
- If you are considering a PEG remember that you can still eat once the PEG is inserted
- If it is left too late the device might not be able to be inserted

# Living with a PEG

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- Wash PEG site with normal soap and water
- No creams, lotions or dressings
- PEG needs to be turned 360 degrees twice daily
- Tube does not need sterilisation
- PEG tubes are designed for formulas and some medications



# Living with a PEG

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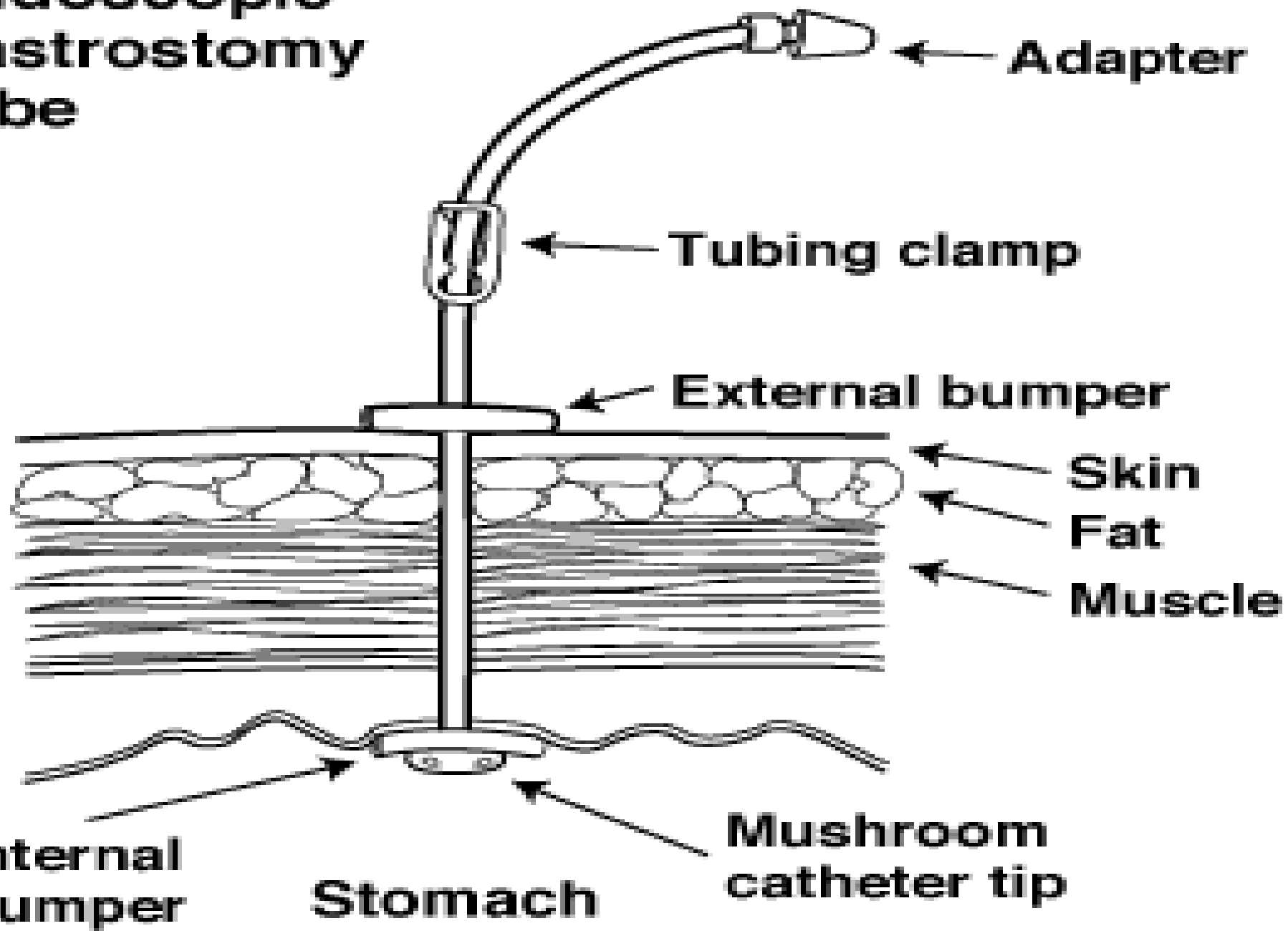
- PEG should be flushed with water 4 hourly
- Medications should not be crushed but rather dissolved
- Some substances can block or corrode the tube
- Chemists can assist by ordering appropriate brands of medication

# Living with a PEG

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- The PEG site is sometimes sore
- After 12 to 18 months the original PEG device needs to be changed and if necessary replaced with a long term device
- I now have a skin level device

# Percutaneous endoscopic gastrostomy tube



# Getting Fat

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- Jevity HiCal is the feeding formula
- It is the equivalent of a balanced meal
- It has 1.5 calories per mil
- My nutrition improved significantly in a short period
- Within 12 months I now weighed 48kgs
- I am officially fat!

## Life without eating

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- While I cannot eat solid food, I can have some things, like thickened soup, coffee and some thickened juices.
- Amazingly I can drink Gatorade
- I have less chance of tooth decay but oral hygiene is more important now that I don't eat



# Life without eating

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- I still crave food
- Sometimes sad about not being able to eat my favourite foods
- Having a PEG is a positive choice to improve quality of life

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**THANK YOU**