

Reaching the masses: using Facebook to explain palliative care

Dr Leeroy William, Dr Michael Franco, A/Prof Peter Poon
Monash Health
Palliative Care Australia Conference - September 2015

Educational challenges

- Recognition of specialty
- Understanding of palliative care
- Integration into Medicine
- Generalist versus Specialist
- Societal and cultural taboos
- End-of-life care – Liverpool Care Pathway
- Euthanasia

How are we doing?

- Love AW & Liversage LM
- Barriers to accessing palliative care: A review of the literature. *Prog Palliat Care* 2014; 22: 9–19
- Poor knowledge of palliative care
- Poor communication about palliative care
- Patients and families
- Healthcare professionals

Traditional approach

- Lectures
- Placements
- Case by case education
- Consultative model
- Examinations
- Online courses

How we began...in a day!

- Undergraduate lectures
- Laptops
- Engagement?

- “One chance to make a difference”

- Facebook and Twitter
- June 2012
- <https://www.facebook.com/PallMedEd>



Palliative Medicine Teaching

Health/Medical/Pharmaceuticals



Publish



Photo



Video



Event



Very responsive to messages
100% response rate, 3-mins res...



Boost Your Post
"RIP Oliver..." is performing better than 85% of your recent posts.

4,085
likes

Social media

- Facebook – 1.35 billion active monthly users
 - Twitter – 284 million active monthly users
 - Instagram
 - Pinterest
-
- Ability to reach large numbers of people
 - Immediate
 - Interactive
 - Networking

Concerns & Solutions

- Privacy
- Inappropriate use of media
- Bullying

- Screening of content
- Self-moderation
- Freedom of speech

Target groups

- Final Year Medical students
- Medical Students in other years
- Nursing and Allied Health students

- Healthcare Professionals nationally
- Healthcare Professionals internationally

- Relatives
- Friends
- Patients

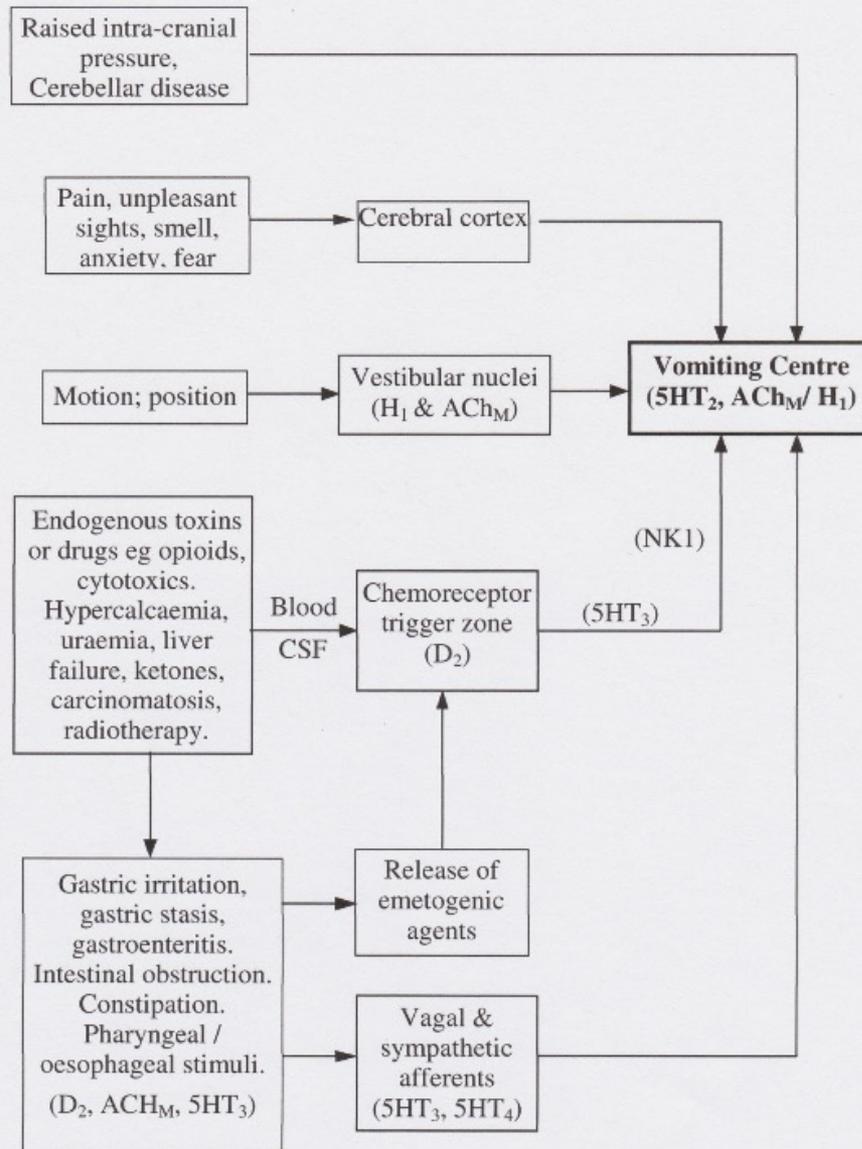
- EVERYONE!!

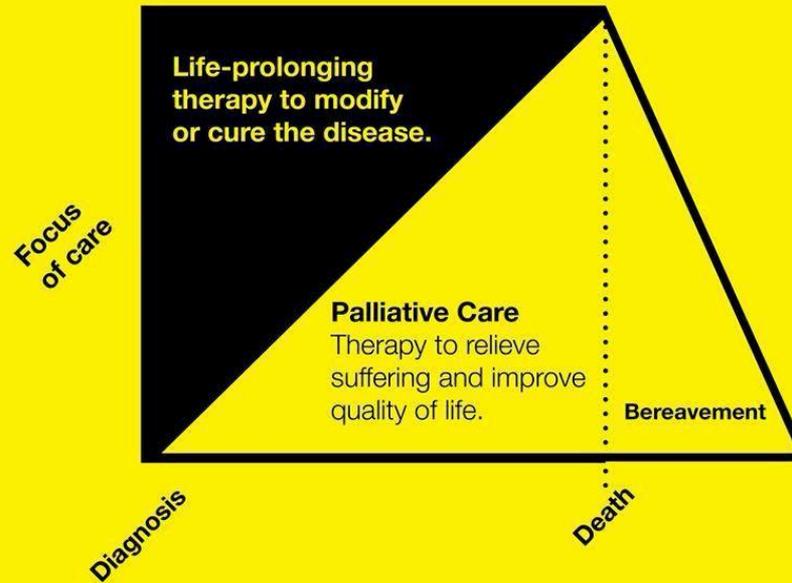
Posts

- Teaching material
 - Quotations
 - Links to articles – media and academic
 - Infographics
 - Posters
-
- Provoke thinking and reflection
 - Humour
 - Societal

NAUSEA AND VOMITING

Mechanisms





Living Well.

Palliative care should be an active part of patient care from diagnosis through treatment and beyond. Not limited to patients who have no hope of benefit from treatment of their disease.

Source: Frager G. J. Palliat Care, 1996; 12(3):9-12.



Palliative care is still widely misunderstood by many Canadians. Here are 10 common myths we often encounter.

10 MYTHS ABOUT PALLIATIVE CARE

MYTH 1: Palliative care hastens death.

FACT: Palliative care does not hasten death. It provides comfort and the best quality of life from diagnosis of an advanced illness until end of life.



MYTH 2: Palliative care is only for people dying of cancer.

FACT: Palliative care can benefit patients and their families from the time of diagnosis of any illness that may shorten life.



MYTH 3: People in palliative care who stop eating die of starvation.

FACT: People with advanced illnesses don't experience hunger or thirst as healthy people do. People who stop eating die of their illness, not starvation.



MYTH 4: Palliative care is only provided in a hospital.

FACT: Palliative care can be provided wherever the patient lives – home, long-term care facility, hospice or hospital.



MYTH 5: We need to protect children from being exposed to death and dying.

FACT: Allowing children to talk about death and dying can help them develop health attitudes that can benefit them as adults. Like adults, children also need time to say goodbye to people who are important to them.



MYTH 6: Pain is a part of dying.

FACT: Pain is not always a part of dying. If pain is experienced near end of life, there are many ways it can be alleviated.



MYTH 7: Taking pain medications in palliative care leads to addiction.

FACT: Keeping people comfortable often requires increased doses of pain medication. This is a result of tolerance to medication as the body adjusts, not addiction.



MYTH 8: Morphine is administered to hasten death.

FACT: Appropriate doses of morphine keep patients comfortable but do not hasten death.



MYTH 9: Palliative care means my doctor has given up and there is no hope for me.

FACT: Palliative care ensures the best quality of life for those who have been diagnosed with an advanced illness. Hope becomes less about cure and more about living life as fully as possible.



MYTH 10: I've let my family member down because he/she didn't die at home.

FACT: Sometimes the needs of the patient exceed what can be provided at home despite best efforts. Ensuring that the best care is delivered, regardless of setting, is not a failure.



Aussi disponible en français.

The most precious gift we can offer anyone is our attention.

Thich Nhat Hanh

True
God's
Patience





People who are dying should be able to count on excellent end-of-life care and support.

Dame Judi Dench, Patron of the National Council for Palliative Care

687 Likes 9 Comments

TOP 5 REGRETS OF THE DYING

FROM THE GUARDIAN NEWS REPORT: TOP FIVE REGRETS OF THE DYING

1
I WISH I'D HAD
THE COURAGE TO
LIVE A LIFE TRUE TO
MYSELF, NOT THE
LIFE OTHERS EX-
PECTED OF ME.

2
I WISH I HADN'T
WORKED SO HARD.

3
I WISH I'D HAD THE
COURAGE TO EX-
PRESS MY FEEL-
INGS.

4
I WISH I HAD STAYED
IN TOUCH WITH MY
FRIENDS.

5
I WISH THAT I HAD
LET MYSELF BE HAP-
PIER.

IF YOU
CHANGE
NOTHING,
NOTHING
WILL
CHANGE

Palliative Medicine Teaching

Posted by Leeroy William

24 August at 11:10 · 🌐

"In not fully explaining Pedro's prognosis to him, I simply hadn't done my job. Or was it my job?"



Who's Responsible For Talking to Patients About End-of-Life Decisions?

www.theatlantic.com

31 Likes 4 Comments



Catherine Ann Bearsley

Such an important, reflective article. I wonder if: Robert Buckman's "How to Break Bad News" or his "I don't know what to say... " are still in print. ?

24 August at 12:18 · Unlike ·  1 · Reply



Catherine Ann Bearsley

"Or was it job" that is a vital question.

When a patient is being looked after by a "team" i.e. a GP, a surgeon, an oncologist and a radiation oncologist who only communicate by emailed procedure reports, it is often a visiting palliative care nurse who sits at the kitchen table for that gentle, truthful conversation.

24 August at 20:57 · Edited · Unlike ·  1 · Reply



Michelle Rothwell

Great article - thank you for sharing 😊

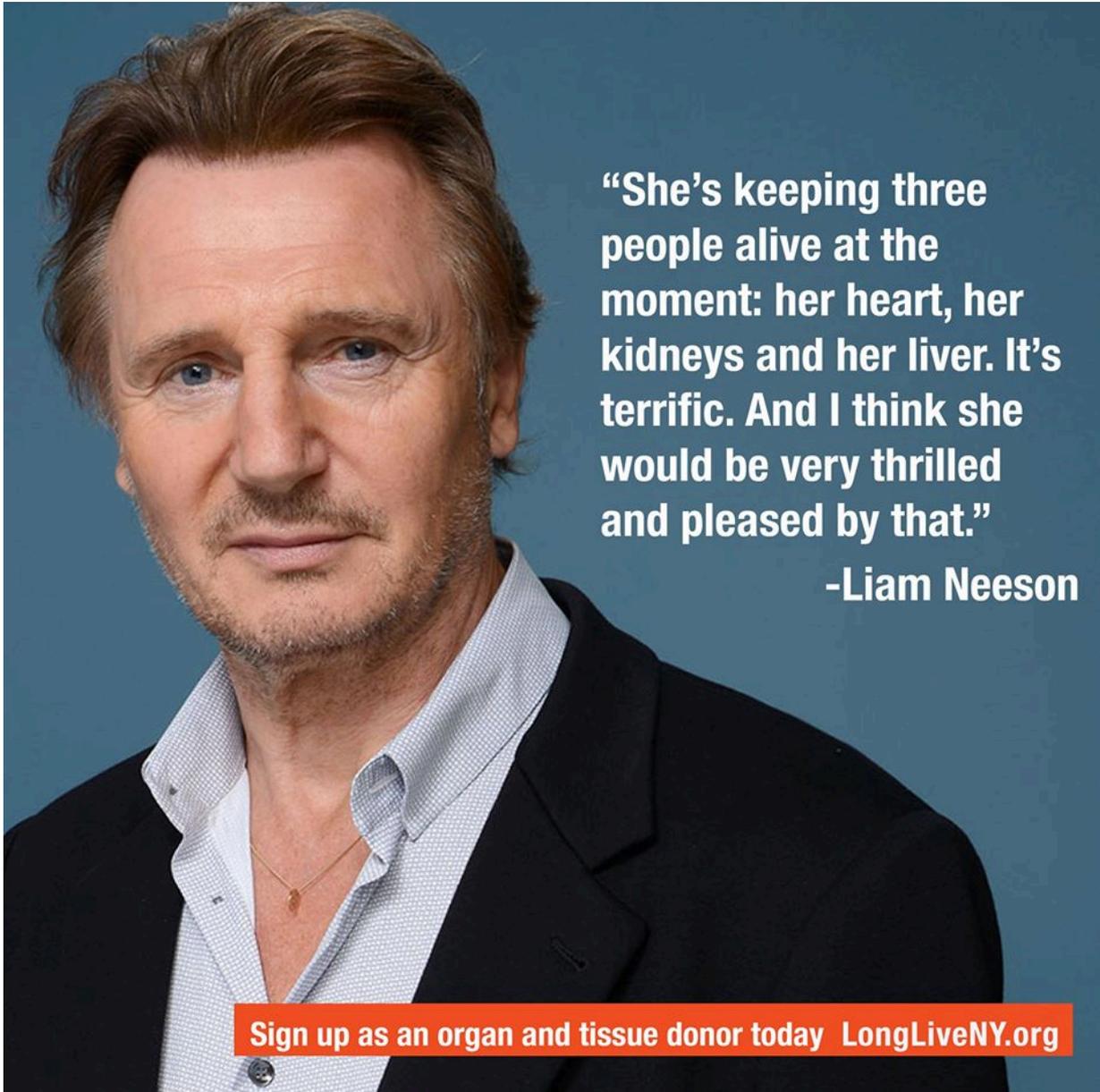
24 August at 12:49 · Unlike ·  1 · Reply

Thanks to **Push For Palliative** for this post!!

Until we can get across to the public and health professionals that palliative care is about living as well as possible for as long as possible with a serious illness, patients will continue to suffer unnecessarily.

– Dr Diane Meier
Director of the Center to Advance Palliative Care

218 Likes 6 Comments



“She’s keeping three people alive at the moment: her heart, her kidneys and her liver. It’s terrific. And I think she would be very thrilled and pleased by that.”

-Liam Neeson

Sign up as an organ and tissue donor today LongLiveNY.org

Facebook Metrics

- **Reach** – number of people who have seen the post
- **Clicks** – number of people who have clicked on the post
- **Engaged** – number of people who have liked, commented on or shared the post

Post Metrics

Your 5 Most Recent Posts



■ Reach: Organic/Paid
 ■ Post Clicks
 ■ Likes, Comments & Shares

Published	Post	Type	Targeting	Reach	Engagement	Promote
31/08/2015 08:56	 Thanks Rod!			846 	44 4 	Boost Post
31/08/2015 01:53	 RIP Oliver Sacks - neurologist and brilliant author			2.7K 	74 160 	Boost Post
29/08/2015 01:10	 "Let's not pretend this 'personal choice' is unaffected by wider economic realities. Our rapidly expanding			2.1K 	140 26 	Boost Post
28/08/2015 08:16	 "Over two thousand years ago the Buddha said just as the elephant leaves the biggest footprint in the			2K 	76 23 	Boost Post
28/08/2015 06:41	 Palliative Medicine Teaching shared LiveOnNY's photo.			9.5K 	157 350 	Boost Post

Reach in last 28 days

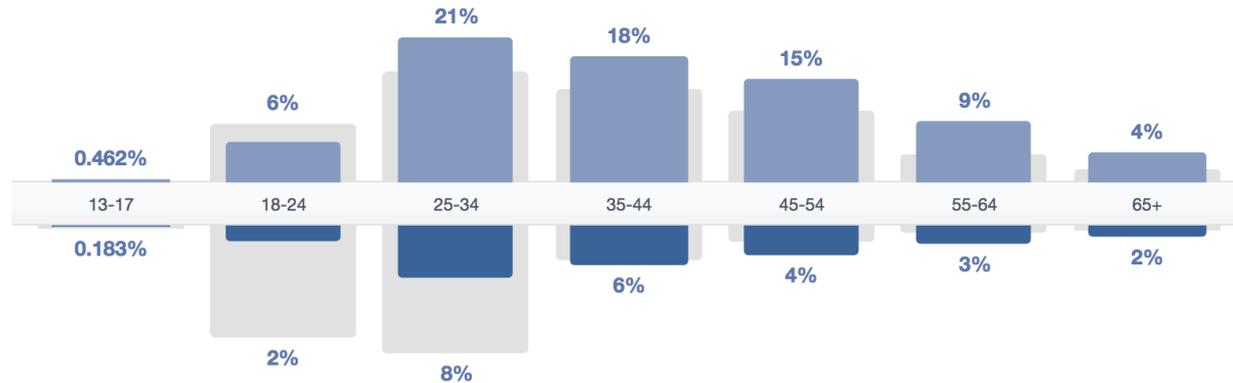
The number of people your post was served to in the past 28 days.

Women

74% People Reached | **55%** Your Fans

Men

24% People Reached | **44%** Your Fans



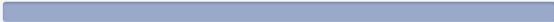
Country	People Reached	City	People Reached	Language	People Reached
Australia	27,717	Melbourne, Victoria	8,916	English (US)	43,858
United Kingdom	13,108	Brisbane, Queensland	2,594	English (UK)	20,753
Canada	6,506	Sydney, New South Wales	2,575	Czech	3,062
United States of America	5,954	Perth, Western Australia	2,050	Portuguese (Brazil)	714
New Zealand	4,791	Prague, Prague	1,718	Dutch	371
Czech Republic	3,357	London, England	1,376	Spanish	354
India	2,163	Auckland, Auckland Region	1,100	French (France)	332

Effectiveness of posts

The success of different post types based on average reach and engagement.

Show All Posts ▾

Reach Post Clicks Likes, Comments & Shares

Type	Average Reach	Average Engagement
 Photo	5,353 	346 268  
 Link	2,096 	151 40  

Most popular post

Post Details

Reported stats may be delayed from what appears on posts ✕



Palliative Medicine Teaching added a new photo. ▼

Published by Leeroy William [?] · 19 June ·

FOREVER AND ANON

DUST IF YOU MUST

Dust if you must, but wouldn't it be better
To paint a picture or write a letter,
Bake a cake or plant a seed,
Ponder the difference between want and need?

Dust if you must, but there's not much time,
With rivers to swim and mountains to climb,
Music to hear and books to read,
Friends to cherish and life to lead.

Dust if you must, but the world's out there,
With the sun in your eyes, the wind in your hair,
A flutter of snow, a shower of rain.
This day will not come around again.

Dust if you must, but bear in mind,
Old age will come and it's not kind.
And when you go – and go you must –
You, yourself, will make more dust.

159,138 People Reached

9,379 Likes, Comments & Shares

6,493

Likes

709

On Post

5,784

On Shares

1,007

Comments

47

On Post

960

On Shares

1,879

Shares

1,860

On Post

19

On Shares

9,614 Post Clicks

3,803

Photo views

2

Link clicks

5,809

Other Clicks i

NEGATIVE FEEDBACK

98 Hide Post

40 Hide All Posts

0 Report as Spam

0 Unlike Page



PalliativeCare
AUSTRALIA

THE
SHARED
PROJECT

Dying
Matters

*Let's talk
about it*

Messages

- Thank you for organising and trying to teach us what you think is important in pall care!
- We found out about this page during a social media session at the International Congress on Palliative Care. I look forward to following and sharing your stories and resources. (**Canadian Virtual Hospice**)
- Thought you might find this post interesting. Thank you for the great palliative care information you share. (**Crossroads Hospice**)

Thanks to Abbie Hyde and her family who sent this fantastic picture from Yarrawonga Hospital with this message:

"Thought you might like this, my nana during her palliative care stay. Spending time with her daughters, son and husband on New Year's Eve, precious moment." Cheers to you all!!



Do you see what I see ?

Do you see an elderly man being tube fed
or do you see a father eating a home cooked roast Mum
prepared?

Do you see a man who can barely speak because his
tongue is badly swollen
or do you see a highly intelligent man who can concisely
answer a difficult question?

Do you see a disfigured face with cancerous tumours
protruding around his neck
or do you see a handsome clean shaven man?

Do you see a frail old man incapable of doing anything for
himself
or do you see a totally self sufficient man who never
asked for help?

Do you see a man struggling to breathe
or do you see a man chopping firewood in the backyard?

Do you see a man semi-conscious in a hospice bed
or do you see a devoted only child to my widowed
grandmother since Dad was fourteen, a self made man, a
loving husband, father, grandfather and great
grandfather, who loyally worked for the same organization
for forty years, providing extremely well for his
family, helping his two sons establish themselves and
ensuring a comfortable life for his wife and in turn
sons, grandchildren and potentially generations he will
never know?

You can't see the things I see
I really wish you could.

Thankyou for your care and compassion

We would like to thank Barry Doddrell for his kind permission to share his moving words about his father. As healthcare professionals we often fail to see the real person and what they mean to their family.

These words moved us all at our Palliative Care Unit (McCulloch House) and we appreciate the Doddrell family's openness at this time in their lives.

We had an "anointing of the sick" ceremony for my mum who is here at McCulloch house with close family. 20 people fit in her room where we played music, read gospel, and shared memories and blessings for mum. Her room looks fabulous! Adorned with photos, flowers, scarves and her favourite earrings.

She keeps saying how lovely it is here. Peace is with her.

Thankyou to everyone here who has made our (big) family feel like we can enjoy every last minute with our mum.

It's been so lovely making the most of the last days of mum's life here in palliative care. I am happy to share these photos, in the hope that it may inspire some of you.

Pauline Langmead



Latest metrics 01.09.15

- 4,085 Likes
 - 1,383 Posts – 725 Photos, 658 Links
 - 5,260,093 people reached
 - 350,208 clicks
 - 220,620 engaged
-
- On average, each post reaches 3803 people and is clicked on by 253 of them. Of these, 160 people are engaged with the post.

EJPC & EAPC Blog



European Association for Palliative Care (EAPC Onlus)

12 August at 17:29 · 

On the EAPC Blog today, another great post from Australia: Dr Leeroy William talks about using Facebook as a teaching tool based on his longer article in the European Journal of Palliative Care...



With great power comes great responsibility: Using Facebook to explain palliative care

Dr Leeroy William is a Consultant in Palliative Medicine at Monash Health and Eastern...

EAPCNET.WORDPRESS.COM

Twitter





TWEETS **716** FOLLOWING **1,041** FOLLOWERS **635** FAVORITES **449**

PallMedEd

@PallMedEd FOLLOWS YOU

Aim: Educate the next generation of clinicians, and the wider population, about the benefits of learning from your patients' lives through Palliative Medicine.

 Melbourne

 facebook.com/PallMedEd

Tweets Tweets & replies Photos & videos

 PallMedEd retweeted



Katherine Sleeman @kesleeman · Aug 28

#AssistedDying will be a personal choice the same way poorer people have a choice in supermarkets - a choice with few options.

[@giles_fraser](#)

  4  2 

 PallMedEd retweeted

Key Points of Facebook

- Has helped to reach and engage people
- Develops longitudinal relationship
- It facilitates the dissemination of the ***right*** palliative care message
- The open access permits extended learning, reflection and connectivity.
- Promotes inter-professional learning
- Provides an opportunity for patients and families to educate healthcare professionals
- Educational resource
- Societal relevance to teaching medicine