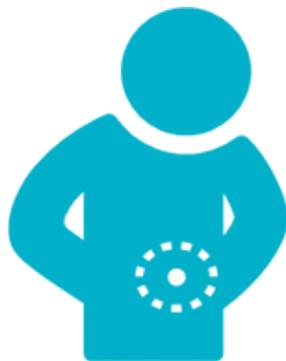




Ostomy Association Of India



our mission is life, our speciality is YOU, a culture of care and compassion.



Way forward..... *in discussion with Richard McNair*

Ostomates world over, most with add-on Cancer, life does become unequal, even in countries where equality is celebrated.

Disability -

Despite ticking all boxes, including medical, this categorization has bypassed ostomates in most countries.

In India, the word ostomy is missing from govt. Gazettes over the years, its almost as if it does not exist ! Incontinence is spelt out medically without use of the word ostomy which denies any benefit to the ostomates.

OAI has run a campaign for this correction with recommendations from all the major hospitals, Surgeon bodies, oncologists & a few politicians. The issue was also discussed in parliament. However Covid has put everything else on the back burner. We live to fight another day.

We wondered if it has to do with the fact that it is still not openly talked about in many countries especially if there is a stigma associated with it. Apparently, a few years ago in NZ an attempt was made to get a spot on a prime time TV show to talk about it but there was not even a response to the request! Indeed media coverage is the best way to get things out in the open and get some long awaited action. Also, the older people are the less likely to talk than the younger lot, not to rule out any cultural angle.

Any positive breakthrough in any country can be used as a precedent to action out other countries.



Way forward.....

Tax Breaks –

The situation is not much different here. There are more countries not extending tax breaks to ostomates than those who do.

In India the anomaly of lack of mention of Ostomy in the govt.gazette has resulted in ostomates getting no tax breaks for ostomy surgery. They have to rely on standard breaks available generally rather than specially. Those with no history of cancer get no breaks at all. Tax breaks availed are more by exception than norm.

This too needs to be strongly followed up and any breakthrough to be shared for attempts elsewhere.

“Awareness is the greatest agent of change” - Eckhart Tolle

This is a major issue in countries of South East Asia and CIS. There is a need to put in efforts in an organised way to create awareness.

In many countries with no govt/voluntary central agency coordinating, ostomates suffer. Recently example is Pakistan where patients are individually approaching OAI who are forced to offer alternatives, wish it could be differently done.

This is a major problem all over. Stigma or taboo whatever it is needs to be tackled and overcome. Getting high profile people who have Ostomies and who are prepared to speak out could be one way out. But finding these people will be the hard part.

Sir Cliff Richards we believe is an ostomate and if people of his level in the world could be brought on board then it could make things happen. Obviously a Govt minister with an ostomy would also be a great help.



Way forward.....

ET nurse shortage -

This is a major issue with specialized nursing not easily available.

In India the ratio is pretty skewed, there are less than 130 trained ET nurses for approx. 90k patients added each year. The 65% mortality rate notwithstanding, the ratio is abysmal !

There is an urgent need to have many more trained nurses. May not be too different elsewhere ?

A “one size fit all” nurse in the UK was tried a few years ago, unfortunately it did not work and are now starting to revert to specialist nurses. In association with Dr Buch, Richard has been discussing a way that we could get more trained nurses by putting the training online, this would take time and money to set up but could be worth the effort.

The major stumbling block worldwide is the nurses organizations themselves, individual nurses are great and are happy to work with the ostomy associations however their governing bodies do not support this effort as they deem it competition. It needs to be ironed out.

Here too, any breakthrough in any country can be used as a stepping stone for others to follow through.

#Don't tax my Stoma – the OAI experience so far..

With the ostomy appliance needing to be changed every 7-8 days, in summers this change may need to be done every 2-3 days due to leakage.

Over 90% of the appliances are imported and with 22% customs duty (post set off) and 12% GST, the appliances sell for Rs.700-900/- a piece (A\$ 14-18) !! We have proposed a waiver of both levies and the state Govt.has recommended GST waiver, but the recommendation remains stuck at Central Govt., Delhi for the last 3 years.

Any similar or positive experience elsewhere may please be shared.



Thank you