

Newsletter

An unfamiliar body in an unfamiliar land - from 'stomaland' to a new homeland

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This article is based on a presentation given by Jessica Swinbourne, PhD (Australia) and Rune Nørager, PhD (Denmark) at the Coloplast Ostomy Days 2018.

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Profound bodily changes – such as stoma surgery – may leave the patient feeling alienated from their world and sense of self. In this article, we explore how stoma surgery impacts a patient's self-perception. And we introduce a number of strategies that you can use to help patients regain control of their bodies post-surgery, and move from 'stomaland' to a new 'homeland'.

How stoma surgery impacts self-perception

For years, we believed that thinking was only a matter of what goes on in the brain. Then researchers started to investigate the relationship between our brain and body and created experiments to explore this link. In one of these experiments, participants were asked to estimate the steepness of a hillside.¹⁻² Their estimates were pretty accurate. Except when they were tired. Or wearing a heavy rucksack. Then the hillside seemed much steeper than it actually was.

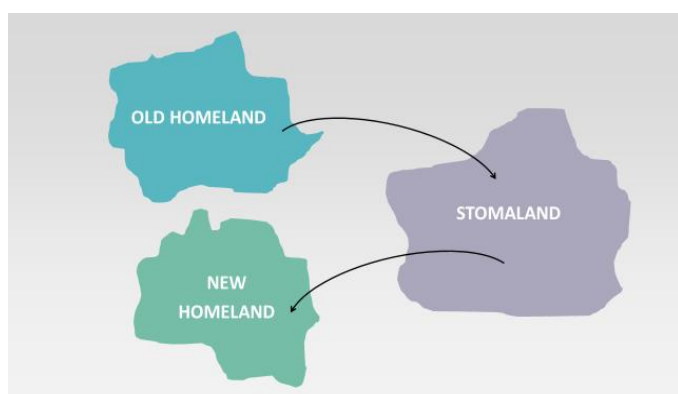
This simple experiment shows that our perception of a sloping hillside is affected by our physical state. So instead of viewing the body as a vehicle that carries the brain around, we need to perceive the body and the brain as closely interlinked. Our body affects our perception of the world,¹⁻² of other people³, and of ourselves.⁴⁻⁵ If we apply this thinking to the world of stoma patients, it stands to reason that stoma surgery changes the way patients relate to themselves,⁴⁻⁵ their social environment, and how they connect with others.⁶ They become more self-conscious, and lose their social confidence and autonomy.⁶ The changes to the person's body post-surgery not only make it difficult for them to relate to the outside world; they may also find it difficult to connect with their inner self.



From “old homeland” to “stomaland”

Let us refer to the place a patient lives pre-surgery as “old homeland”. In old homeland, the patient is familiar with and trusts her body. It allows her to engage in relationships and pursue her interests and core values. But suddenly, after surgery, she finds herself in a new, unfamiliar place.⁶ The patient has arrived in “stomaland”. Here, the body feels completely unfamiliar, even a little scary. Instead of helping her, it now interrupts – or even obstructs – the activities she used to enjoy.

Since the body has been altered, returning to old homeland is no longer possible. In order to feel at home again, the patient will need to move to a place that can accommodate her changed body and allow her to enjoy life again. She has to travel to a “new homeland” – and she will need help to do so.



Barriers on the road to new homeland

The way we perceive our difficulties has a profound effect on how we cope with them.⁷

In stomaland, patients tend to avoid situations they find uncomfortable or distressing – such as meeting people, looking at their body, or other activities they previously enjoyed. They avoid them because they believe they can't cope. The problem with this is that it prevents them from learning how to adjust to their changed body and re-engaging with the world.

To guide patients out of stomaland, we need an approach that can help them to understand their difficulties, make sense of them, and move forward.

The first step is to recognise that our environment (or 'situation'), thoughts, emotions and behaviours are all interconnected. Whenever we notice something in our environment (the situation), we connect a thought to it; then we experience an emotion, and our thoughts and emotions lead us to behave in certain way that helps us to cope.⁸

If we help patients to understand this process, they can learn to develop new ways of coping that will ultimately lead them into a new homeland.

Guiding the way

Research recommends using cognitive and behavioural strategies to help people accept their stoma, dispel negative thoughts, and engage in social activities.⁹ Here are

some of the strategies you can use to help your patient make the journey in her new homeland:

- **Create a safe space.** As a healthcare professional, you can help create a space where patients can express their experiences, thoughts and feelings openly. By providing this, you are facilitating successful coping for them.⁹
- **Build a sense of hope.** Hearing about others who have been able to leave stomaland and settle into a new meaningful life – in a new homeland – can provide a sense of hope and confidence that they can do it too.
- **Help them identify what's important.** Ask your patients what they would like to see themselves doing in their new homeland.
- **Make a travel plan.** When they are ready to start the journey towards a new homeland, you can help them work out a plan for getting there.
- **Be situation-specific.** Start by identifying the things they would like to do, but are avoiding because of their condition. You can use a technique called “graded exposure” (see fact box*) to help your patients develop control over these situations so they can start re-engaging with them.
- **Address potential roadblocks.** This strategy helps you – and your patients – to address the thinking patterns that obstruct the road to new homeland. Encourage different perspectives by asking questions such as: ‘How else could you look at this situation?’, ‘How could you cope if that actually happened?’, ‘If this happened to someone else, how would you view them?’, ‘What would need to happen for you to trust your body again?’
- **Help them tackle their emotions.** Teach your patients “emotion surfing”. This means riding out the wave of emotion until it subsides, rather than fighting it or blocking it out. Another strategy is to use distraction, particularly if the emotion feels too strong to ride out. They can choose anything that may help them get through the moment (e.g. listening to music, calling a friend, going for a walk, watching a movie/TV show etc.).
- **Help them find travel companions.** Help your patients find peers who are also finding their way to their new homeland.

Working with “graded exposure”. An example: going out with friends

Rank all of the possible situations that involve going out with friends – starting with the easiest, e.g. having a friend for coffee at home, and ending with what they believe to be the most difficult, e.g. meeting up with a few friends at a restaurant. Work your way up the scale, identifying exactly what each scenario entails and discussing how to tackle all eventualities. As your patient takes on each situation (starting with the easiest), they will gradually feel more in control and confident they can do it.

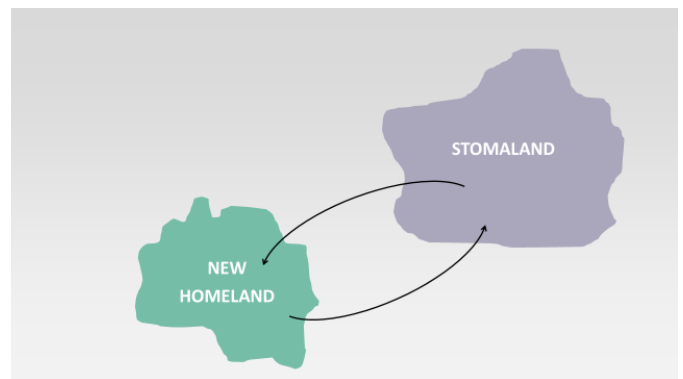


It's not a one-way trip

Arriving in new homeland doesn't mean there won't be occasional trips back to stomaland. Setbacks will happen – e.g. following leakage, experiencing a physical complication, stoma revision⁴ etc. It's important that your patient recognises that setbacks are normal and only to be expected. There may also be a certain amount of comfort in knowing that once you know the path to your new homeland, it may be easier to find it again when setbacks happen.

Helping your patient back to new homeland will mean going back through some of the steps taken on the initial journey. But this time, with the benefit of experience. Your patients will recall the positive coping strategies they used

in their initial trip to new homeland, so their return journeys will be easier and faster.⁴



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