Dealing with the emotional roller coaster

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MIND MY HEALTH &
TREAT ME TREASURE ME
The roller coast of illness AND life....

- Being sick and needing a stoma can happen to anyone
- People of all age
- At any point in their lives (being a new parent, just having retired, recently divorced etc)
- With any pre-existing emotional, health, psycho-social, personality or mental health problems
- Need to remember that a person’s coping with a stoma has a context

- Getting a stoma doesn’t happen in a vacuum
Serious illness comes with lots of hurdles

- Searching for meaning in what you have faced, why me? Why now?
- Many things feel different
  - Mind, body and spirit is facing a huge change/trauma
  - Perspectives on life and what matters can be affected
  - Value placed on themselves as person, relationships, work, health, future....all disrupted

- Finding “normal” can be a huge, unexpected struggle
When the operation first happens

▸ **Expectations:** relieved, healthy, able to get control, grateful for the offer of health....

▸ **Instead feel:** anxious, resentful, traumatised, fatigued, lonely, embarrassed and insecure
16-26% experience significant emotional issues post-surgery for at least 1 year

- Feeling depressed and anxious
- Fatigue from the surgery (and the illness)
- Discomfort with gas, pain
- Sexual problems
- Dissatisfaction with appearance
- Worry about noises and smells
- Struggling with how to dress
- Uncertainty about managing a stoma and travelling
- Frustration with constant need to think/plan/adapt

Von-Klaasen, de Vocht et al (2016)
How some people feel....

- Frustrated and angry
- Could it have been prevented?
- Punished
- Like a “failure”
- They have let others down
- Isolated
- repulsive-the look, smell
- Loss of control
- Disfigured
- Life being ‘hijacked’
- Exposed with no dignity
- Frustrated at dependence
- Worried about work
- Relationships and sexuality
The stoma is only one set of issues

- For a cancer
  - May be going on to have chemotherapy or other adjuvant treatments
  - Chronic uncertainty and anxiety about the outcome

- For other illnesses
  - Rebuilding health

- For wellbeing in the long term
  - Getting used to the basics pain, eating, sex...
  - Threat/promise of reversal
Other people can fuel the distress….

- Anxiety & horror stories
  - “Why didn’t they scan you more?”
  - “How did it come to this?”
  - “I’d hate it if it happened to me”
  - “I knew a guy who had one of those it…….”
  - “They leak, doesn’t it smell?”
  - “It doesn’t matter”
Clichés and platitudes

- You’re lucky – you could have died
- It’s over now, just be normal
- Be grateful
- You’ve got a second chance: Change the way you eat, drink, exercise,
- You shouldn’t stress so much – that caused it…
- Why can’t you just get used to it?
I’m 39 years old and on 20th Aug I was told I had bowel cancer. I’ve just returned home from hospital after lower anterior operation and have a bag, which I pray can be reserved In a year. I’m really struggling with my stoma, even looking at it makes me feel ill. I’m wondering how I’m ever going to cope. I absolutely despise it all and changing my bag is just horrifying. My husband has had to change it for me since we’ve got home and I just feel humiliated by the whole thing. Will it ever get easier? Will I be able to cope on my own and accept it? Just wondering if anyone else felt like this!
While I certainly sympathise, realising that you're one of many who feel this way, I'm unable to empathise.

I've got a different cancer, multiple myeloma, but I got sepsis and had to have my sigmoid colon removed. Ended up with a colostomy and a mucous fistula, two bags. I've had it redone twice due to it closing over and am about to undergo a major op to have a stricture removed and my stoma redone yet again and maybe changed to an ileostomy.

Due to a lifetime of bowel problems a stoma was always a possibility. You'll probably hate me for saying this but I've never had a problem mentally/emotionally and I'm unable to fathom why people do. I could actually change my bags in a roomful of people and it wouldn't bother me in the slightest. In fact, I've offered to do just that if my stoma nurse thought that somebody might benefit from it.

What I can say is that disgust is learned behaviour and that learned behaviour can be changed. Would you, for example find changing a baby's nappy offensive, or just something that needed doing for the wellbeing of the baby?
Some people come into our lives and leave footprints on our hearts...

Others come along and we want to leave footprints on their face.
Children and adolescents

- Stoma happens after illness
  - Unpredictability of bowel movements
  - Being teased or bullied b/c of loss of bowel control

- Add to that
  - Not wanting to be different
  - Not easy to talk about – very personal and private
  - Fear of not being able to do the things that make life fun
  - Body image is so fragile anyway
  - Thinking about kissing, sex, noises, smells can be overwhelming
  - At a time they want to become individuals they are dependent
  - Want to find own privacy but the timing is off
Sex, stomas and adolescence

- Insecurity is excruciating
- So much (unhelpful) info out there about what sex is about and the ‘script of perfection’
- Stomas are not part of that script!
- Fears about how to cover them, not have them leak, make a noise, smell, flop about, fill unexpectedly
- So much self-identity is wrapped up in appearance at that age
Hey, I just met you.
And this is crazy.
But here's my stoma.
So call me maybe?
Impact of a stoma on sexual functioning

- Fundamentally, sex is about:
  - Wanting to give and feel pleasure,
  - being there for another person and
  - having something to give

- This is incredibly difficult if you feel changed, a shell or unworthy of affection, love or lust

- WHY? The brain is our largest sex organ
  - People who have had sex often have a framework of it needing to be the same to be “good enough”
  - Those that haven’t find it hard to imagine, and terrifying with an unwanted, unpredictable ‘guest’
So many issues in a rubics cube

- About half of all people with a stoma don’t resume having sex after the surgery (for many reasons…)
- Of those that do, about 70% report that they are satisfied
- It seems that helping people to resume an intimate life should be a goal

- So what do we do about it?

- (1) **Elicit and understand** the concerns
- (2) **Don’t avoid** talking about them
It doesn’t get discussed...why?

“it’s not my job”
“it takes special training”
“it takes a lot of time”
“they will mention it if it is a problem”
“it’s only for healthy people”
“what will they think of me? it is embarrassing”
“I may not be able to help”
“I might get out of my depth”

“if they bring it up again I’ll do something”
“what if the patient is lesbian/bisexual/gay?”
“I may not be able to help”
“I may appear too intrusive”
Myths about sex that we hold

- We are all able to talk openly about sex
- We are all interested & ready for sex
- “The fantasy model of sex”: women are always ready & waiting for a huge erect phallus to come their way!
- All touching is sexual & leads to sex
- Sex equals intercourse & ends in orgasm
- Good sex is spontaneous & requires no planning
- Good sex is only for the young & healthy
- Our partner can always turn us on
- Real men/women don’t have sexual problems
Myth Busting and Sex with a stoma

- My partner will know what I want
- The smell will disgust them
- I can’t have an orgasm
- If it doesn’t feel the same, it’s no good
- Sex will damage the stoma or the bag
- Only young people care about sex
- I can’t get pregnant when I have a stoma
- No-body will love me because I have a stoma
- I can’t have an erection again
- I have to hide everything or it’s a total turn off
- Intercourse is the only way to be intimate with a person
Yep, checked the receipt.
Just as I thought.

I didn't buy
any of your bullshit lies.
There’s a layering effect - with other life struggles

- **Stage of development** (adolescence, menopause)
- **General physical and emotional health**
  - Depression and anxiety (and psychotropic medications) can directly affect desire and responses
  - Some antidepressants can prevent or delay orgasm
  - Energy levels
  - Flexibility and pain.....
  - How a person feels about themselves and how they look
- **Life** (time, kids) and relationships
- **Whether sexual issues existed before this** (sexual and relationship problems are REALLY common)
There’s a layering effect - with other illnesses such as cancer

- Often stoma occurs in the context of cancer
- Treatment side effects
  - Nerve innovation and sensation change
  - Fatigue
  - Nausea
  - Hair loss and thinning (not only on the head)
  - Loss of confidence
- Emotional side effects
  - Depression, loss of confidence, helplessness, anger
  - Anxiety, fear of more harm, not wanting to be vulnerable
  - Beliefs about causes of cancer (stress, punishment, infection....)
Stoma and surgery
Health and illness
Life and person
Putting it back together
Intervention depends on the jigsaw puzzle of their life....

- Their illness and treatment plan
- Where they are in their life
- What they have seen and heard
- Underlaying personality and confidence
- Other stresses and concerns (e.g. anxiety/depression/PTSD/substance use)
- Supports; friends, family, siblings...
Get Information & make a plan

- **Encourage what they CAN do** to manage
- **Problem solve**
  - Using a mirror, cutting tape, gradually doing it themselves
  - Irrigation and timing, getting the right device
  - Making a home and out “kit” that works for them
  - Putting boundaries on a parent if too intrusive
  - Talking to a partner about what they think and feel, rather than assuming they are revolted
  - Realising that anxiety affects output
Learn the do’s and don’ts of sex after ostomy surgery.

Yes, it is possible to continue to have a healthy sex life – or even improve upon it – after ostomy surgery. Here are a few intimacy do’s and don’ts to consider after your operation.

**DO start slowly.** You’ll need to take it easy and gently to start. Keep in mind that tenderness and romance make sex pleasurable as well. Remember that loving, kissing, and touching are an important part of sexuality.

**DON’T change anything (unless you want to).** How do people with stomas have sex? The same way as people without stomas. Conventional sexual positions are almost always possible. Of course, sex is about your comfort level and individual preferences.

**DO empty your pouch.** Take a few minutes before you get intimate to empty your pouch. It will give you a little more confidence and ease your mind.

**DON’T let the pouch get in the way.** If your pouch doesn’t have a comfort panel, consider using a fabric pouch cover made from cotton during sex. This will prevent the pouch from rubbing on you and your partner’s skin. It will also hide contents if you use a transparent pouch. Another option is to wear an ostomy wrap with an inner pocket. The wrap will conceal your pouch and hold it close to your torso. There are also various clothing accessories such as belly bands, cummerbunds, and crotchless underwear that help conceal the pouch during intimacy.

**DO wear what makes you comfortable.** Some women choose to wear a silky or cotton vest-like top that covers the pouch and torso. There are also smaller pouches that can be worn discreetly for certain stomas.

**DON’T use the stoma for intercourse under any circumstances.** You or your partner should never use the stoma for a sexual activity (penetration).
Encourage communication

- Don’t assume they’re OK
  - Pick up cues with their jokes, non-verbals
  - This is normal for you, NOT for them
  - Complication are a risk for worse coping
- Ask they how they feel
  - Don’t treat this as just one conversation
  - For some, adjustment doesn’t get better – they just get better at hiding feelings
  - Compliance and silence may be no indication
I’ve had my stoma for just over a month now. I’m not sure if my brain has processed my new body yet....
Encourage control when talking to others too

- **Horror stories**
  - “Just want to stop you there, I only listen to stories with happy endings!”

**Conversation is too confronting**

- Don’t feel they have to talk about the stuff they don’t want to
- It may feel deeply personal to them
- They may feel better if they just ‘own it’
The stoma does not define them: Live for wellbeing

- They’re a DIAMOND – cut some bits and polish others
  - Exercise
  - Get help with pain/sleep
  - Nutrition
  - Alcohol & smoking
  - Managing stress better
  - “Everything in moderation…including moderation…!”
I’M TRYING TO BE AWESOME TODAY, BUT I’M EXHAUSTED FROM BEING SO FREAKIN AWESOME YESTERDAY
Now for your thoughts and feelings
Illness changes how people view life

- They may not be “on the same page” anymore as others
- Grief is normal; they do feel different, that’s a loss
- For a time, the stoma sucks all the air out of the room!
  - People worry this is permanent
Balance up the see-saw of stress

- Future relationships
- Will I have a reversal?
- Money
- Chemo
- Pain
- Dinner
- Walk
- Friends
- Listen to ipod
Sometimes I feel like throwing in the towel but you know what that means... more laundry

aunty acid
Live a life consistent with your values – it leads to contentment
This is not the first time they needed resilience to uncertainty

- What **strengths** and resources do you have?
- What are you **thankful** for?
- What has **worked** before?
- Who will **support** and connect with you?
- What brings you **joy** and peace?
- Where will you **direct** your energy?
In any new challenge - Mind your thinking

- We all have irrational, catastrophic and unhelpful thoughts
  - “I will never have another relationship”
  - “I did this all to myself”
  - “I will never be the same again, I am damaged”
  - “Sex is gone, I can’t stand the thought of it”
  - “I have nothing in common with anyone now”
  - “I was always the strong one, now look at me”
"It is not the mountain we conquer but ourselves."
Sir Edmund Hillary
Challenge unhelpful thoughts

Try

▶ Being less **black and white** about things
▶ Speaking to themselves **calmly**
▶ Being their own **friend**
▶ Believing they are **NOT the 1%**
▶ **Stop assuming** what others think
▶ **Ditching generalisations** / conclusions / pessimistic judgements
▶ **Not jailing yourself** behind your own fears, beliefs
If thoughts repeat – stop struggling

- “Don’t wrestle with the pig in mud”
  - Your both get dirty AND the pig likes it!

- Turn your “struggle switch” off for a bit

be happy
Thoughts are just thoughts

- Distress/self doubt/fear/sadness/anger are part of life – we can’t enjoy every emotion

- Does staring at their pouch/flabby tummy/pictures on the internet make them...?
  - older/younger/thinner/cleverer /healthier/richer...

Help them feel happier and engaged in life...?

Make the pouch disappear, brain develop, stop illness, win lotto and melt fat? NO
I decided to return all the expectations people had given me.
Mindfulness: Settling mind and body

- Great for when challenging is not helping or the “mind struggle” won’t let up
- Allows a quiet mind
  - About paying attention in a deliberate way
  - Can use breathing meditation practice OR
- Immerse in detail of life experience
  - Shower/eating/cuddling a loved one/enjoying a view/watching a smile
“Can I call you back, Ed? I’m in the moment here.”
Talk to carers about what’s unhelpful....

► Offer cliches or give false reassurance
  ► “Just be positive”
  ► “I know how you feel”
  ► “I know you will be ok”
  ► “Stop worrying about it”

► Push Particular beliefs
  ► “It was stress” “It’s the hormones in chickens”

► Give advice a person didn’t ask for

► Ask probing and personal questions

► Tell them other stories of illness and doom

► Draw comparisons with others and how they cope
I saw your grief and loss. There was nothing I could do but feel a tiny bit of it with you.
Oh pull yourself together!
Professional help
Especially if they have...

- Distress that persists or doesn’t fluctuate
- A past emotional problem that is getting worse with this
- Overwhelming fear, panic attacks, phobias
- Kept avoiding aspects of life/work/relationships
- Depressive thoughts/hopelessness/little joy
- Physical symptoms (sleep/appetite/SOB that aren’t related to health)
- Others tell them that they seem unhappy, lost, frightened, moody (!)
- They think they aren’t coping OR
- Want to take the opportunity to work out how to live the life they really want to

GP MENTAL HEALTH CARE PLAN FOR REBATES
MY STOMA

M Make expectations sensible and flexible
Y You are not alone, and it’s OK to feel upset
S See-saw of stress – balance it
T Take control where you can
O Others are here for tips and support
M Manage unhelpful thoughts
A Adjustment takes time and effort