Impact of stoma surgery on young people

1. In the initial weeks and months after stoma surgery, young people experienced distress, worry, hopelessness, anger towards their bodies. In some cases, they reported having suicidal thoughts.

2. Over time, many young people felt freed from IBD symptoms and restrictions. Through this gradual process, they formed a new sense of identity, signalling a ‘new normal’.

3. 3 forms of change were needed: (a) practical level: fitting stoma management around daily routine and lifestyle, (b) emotional level: ways of coping and attitude, and (c) identity level: integrating the stoma into their identity.

4. In the longer-term, many young people who saw their stoma as freeing them also said they felt ‘depressed’ and ‘anxious’ at the same time.

5. Anxiety and depression came from challenges of living with a stoma. This included fear of leaks, unhappiness with body image, fear of others’ reactions, reduced self-confidence and concerns about romantic relationships.

6. Young people often played down this emotional impact. Some felt this was an acceptable trade-off for reduction or freedom from IBD symptoms.

7. Health professionals need to be aware that young people may feel distressed even if the stoma improves their life. Also important for professionals to offer ongoing support, such as regular assessments of people’s emotional needs.