



## Public Statement: Advancing Personalized and Preventive Ostomy Care – A Holistic Approach for Stoma Management

### 1. Preamble

The following statement is drafted by the Royal Danish Embassy in Japan and Coloplast K.K.

Subsequently, the paper has been revised and finalized to reflect oral and written input to the statement following a roundtable discussion at the Danish Embassy with patient representatives and medical professionals from both Denmark and Japan by the following participants:

- Mr. Shizuo Kinoshita, Former President of the Japanese Ostomy Association, Inc.
- Dr. Etsuhide Yamamoto, DDS, Ph.D., Vice President of Japan Ostomy Association, Inc.
- Mr. Shiro Otake, Former Board member of Japan Ostomy Association, Inc.
- Ms. Kaori Sasaki, Board Member of General Incorporated Association Peer Ring / Representative, Peer Ring Blue
- Ms. Marie Uth Pilebo, WOC nurse, Zealand University Hospital Køge, Denmark. Former Chair of the Danish National Association of Stoma Care Nurses
- Dr. Kotaro Maeda, MD, PhD, Deputy Chief Director, Medical Corporation Himawariseishinnka Oumeimai Hospital. Honorary member of the Japanese Society of Stoma and Continence Rehabilitation.
- Ms. Yasumi Matsubara, OCNS, CWOCN, RN, PhD, Professor, Kitasato University School of Health Sciences. Board member of the Japanese Society of Stoma and Continence Rehabilitation, Board Member of Japanese Society of Wound, Ostomy, and Continence Management

The purpose of the public statement is to promote knowledge on the importance of a holistic end-to-end stoma care approach for the betterment of ostomates.



## 2. Advancing Personalized and Preventive Ostomy Care – A Holistic Approach for Stoma Management

Surgeries that result in the creation of a stoma are lifesaving, but also life-changing interventions that may negatively impact patients' physical and psychosocial wellbeing (1,2). Living with a stoma necessitates the use of pouching systems for the collection of stomal effluent. Although innovation in these systems has been ongoing since their inception, many people living with a stoma continue to face challenges.

Seventy-six percent of people with a stoma experience leakage and 92% of people with a stoma worry about leakages (1,3). Additionally, 88% have peristomal skin complications, and 26% experience leakage onto their clothes every month. These issues can lead to substantial reductions in quality of life (QoL), affecting emotional wellbeing, and willingness to participate in societal activities (1). The mental burden of leakage events that go all the way onto the clothes can be long-lasting, with effects reported at least up to a year after a single incident (4).

In both Denmark and Japan, there is a growing recognition of the need to enhance ostomy care and ensure that patients receive sufficient support and guidance. An approach that aligns with the principles set out in the Charter of Ostomates' Rights – an international, patient-led declaration – calling for comprehensive pre- and postoperative support, access for people with a stoma to sufficient care, and protection from discrimination (5). Through collaboration between healthcare professionals, industry, government and people with a stoma themselves these rights can be upheld and foster a society where people with a stoma can live with dignity and inclusion. By prioritizing personalized and preventive ostomy care, we can significantly improve the quality of life for people living with a stoma, enhance their sense of autonomy and independence, and empower them to self-manage their condition – further realizing the vision of the Charter.

### 2.1 Importance of Personalized and Preventive Ostomy Care

Undergoing stoma surgery is a permanent, life-altering condition that necessitates healthcare support to people living with a stoma. The level of support can vary significantly from person to person, as stomas – like people – differ in anatomical shape and effluent depending on the type of stoma. Stoma care is a lifelong journey, as stomas also change over time, often requiring adjustments in type of stoma appliances and level of support. Ensuring the right fit and level of support for the individual also serves as a preventive approach to minimizing stoma-related complications.

Holistic ostomy care thus encompasses personalized treatment plans and preventive strategies that begin at the point of pre-surgical patient education and continue throughout hospital



discharge into daily life. When these elements are in place, this approach can potentially prevent complications such as leakage, skin irritation and infections, and contribute to ensuring that all people with a stoma can live with dignity, independence, and optimal well-being whilst reducing long-term costs on health systems.

A holistic end-to-end standard of care for people with a stoma must account for the full patient journey, from preoperative preparation to long-term care (6 -9).

- Before surgery, structured patient education and psychological support help patients understand the transition to life with a stoma.
- Proper pre-surgical stoma site marking, guided by standardized protocols, prevent future complications and improve the patient's quality of life
- Structured pre-surgical education can help reduce geographical differences in life with a stoma after being discharged.
- Early establishment of proper stoma care routines empowers patients to get involved in their own care and decision making to enable personal quality of life goals
- Effective post-discharge programs with structured follow-up checks by the stoma care nurse can reduce reliance on trial-and-error methods by patients.
- As stomas evolve over time, it may be necessary to adjust existing care plans: types and shapes of stoma adhesives, need for supporting products and amount of stoma bags.

It is therefore important for clinicians to have the ability and resources needed to schedule pre-surgical education, follow up consultations post discharge with the patient to assess the stoma, and ensure sufficient access to stoma products.

## 2.2 Person with a stoma – personalized care

Access to appropriate ostomy products is a cornerstone of quality care. The right product solution provides confidence and dignity for the person with a stoma, helping to prevent common issues such as leakage, odor, and peristomal skin complications. For proper long-term care of stoma patients, a personalized approach is needed to address individual needs while minimizing leakage episodes, peristomal skin complications, and other medical complications, especially as no two people with a stoma are alike, including different anatomical differences, necessitating personalized stoma care.

- In collaboration with the stoma care nurse, a clinical assessment should determine what type of stoma care plan is needed for the person living with a stoma.



- Factors like what type of stoma is created (ileostomy, colostomy & urostomy), the person's peristomal body shape (regular, inward, or outward), the person's lifestyle and activity level, as well as potential disabilities may influence the stoma appliances needed to cater for the individual needs.
- To enable personalized care for people with a stoma, it is imperative to have broad access to sufficient stoma appliances – securing the right care plan for the individual need.
- The right fitting stoma product solution and a personalized stoma care plan can enable people with a stoma to be more independent and minimize interactions with healthcare professionals due to leakage episodes or skin complications (10,11).
- Reducing leakage and peristomal skin complications provides a sense of dignity and autonomy for the person with a stoma.

When people with stoma are equipped with the right stoma care plan, society benefits:

- The healthcare system benefits from empowered people who are more effective at performing more self-care, thereby easing healthcare burden.
- The broader community benefits when people with a stoma continue to contribute meaningfully to the workforce and society through active participation.

### 2.3 Preventive stoma care

Preventive stoma care is an all-encompassing term spanning from pre-surgical education to peristomal skin management, to ostomy appliance application and mental health management while living with a stoma. The purpose of preventive stoma care is intended for both patient acceptance and to prevent stoma related complications; peristomal skin complications, leakages and mental health complications. Literature suggests that a single episodic leakage event will have a negative psychological impact on the person with a stoma for up to a year, affecting emotional wellbeing and pronging isolation from society (4).

It is important to remember that the center of ostomy care is not a hospital, a stoma care nurse, or a policy—it is the patient. Consequently, the system should cater to meet the needs of the patients, rather than requiring patients to adapt to the system.

- Once discharged, stoma patients become the primary decision-maker in the management of their stoma and they do so in collaboration with the stoma care nurse who prescribes the ostomy appliances needed.
- To support the person with a stoma it is of paramount importance to secure adequate support and resources to manage their stoma and prevent any complications related to the stoma.



- Managing a stoma is not a choice, but a necessity. People with a stoma must change their ostomy bags regularly, monitor their stoma for skin complications, and adhere to a routine that ensures their well-being. Something as simple as emptying the bag in a timely manner before too much stomal effluent occurs can mean the difference between relative comfort and painful complications.
- If access to suitable products is limited, patients may resort to prolonged wear times or inappropriate alternatives, leading to discomfort and medical concerns. Preventive interventions, which could mitigate these risks, become difficult to implement if patients lack the necessary resources and education.
- If people with a stoma don't have broad access to ostomy appliances; adhesives, bags and supporting products – many may come to accept leakage or skin complications as inevitable when, in reality, they can be addressed with the right support.

#### 2.4 Healthcare is both an empowerment of patients and an investment for society.

In 2022, a survey was conducted among 684 individuals living with a stoma in Japan (12). The survey showed that the main difficulties included managing the practical aspects of stoma care, changing stoma products, maintaining skin health around the stoma, and experiencing embarrassing situations. The most impactful challenges were difficulties in intimate relationships and not recognizing the stoma as part of their identity – stressing the multifaceted difficulty of empowering people with a stoma and the need to ensure access to personalized care plans.

- Personalized and preventive stoma care supports the preservation of dignity, confidence, independence and overall well-being of the patient.
- Without proper support and assessment, patients often face challenges like poor body image (9), loss of confidence, sexual dissatisfaction, and even depression (7).
- When people with a stoma are restricted in access to sufficient amount of products, they may resort to compromising life choices such as swimming, doing sports and leaving the home in favor of prolonged use of the stoma appliances.
- When stoma care routines are followed consistently, complications can be prevented and patients can better regain a sense of stability and normalcy in their lives.
- Failing to prevent stoma related complications can be expensive for society, as complications such as peristomal skin issues and leakages are associated with added healthcare costs on
  - Extra consultations needed with stoma care nurses
  - Re-hospitalizations
  - Diminished ability to work
  - Lowered quality of life



- Increased need for healthcare products / treatments (10).
- Due to the various costs of stoma complications, investing in preventive stoma care is valuable for the patient, the healthcare system and society at large (1, 8).

It is important to note that the successful implementation of personalized and preventive stoma care is dependent upon sufficient government frameworks that empower healthcare professionals to provide this approach effectively. Subsequently, healthcare professionals play an important role in translating the government issued frameworks into individualized and preventive practices to support people living with a stoma.

### 3. Conclusion

This statement reinforces the need for cross-functional collaboration among multiple stakeholders to implement a holistic, end-to-end stoma care. By fostering a personalized and preventive care approach – ensuring access to medical support and sufficient stoma appliances – the person with a stoma, the healthcare system and society benefits. Tailoring stoma care plans will alleviate some of the multifaceted needs of a person with a stoma, reducing possible stoma-related complications, minimizing consultations with stoma care nurses and re-hospitalizations. All whilst fostering better conditions for people with a stoma to re-enter the workforce, further advancing the vision of the Ostomates Rights Charter and allowing people with a stoma to live a more autonomous and dignified life.



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