
Monograph:
Rosato-Scott, C orcid.org/0000-0002-7838-7773, Giles-Hansen, C orcid.org/0000-0001-8744-5915, House, S et al. (6 more authors) (2019) Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs). Report. LMIC-Incontinence-email-group.

https://doi.org/10.5518/100/13

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Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)

Contents

Version 1 – August 2019

Authors

This document has been prepared on a voluntary basis without funding. The authors have included guidance to the best of their abilities, based on their combined knowledge and experience, including from learning through the discussions as part of an informal international incontinence email group. All are still continuing to learn.

The authors would be happy to hear from you if you have suggestions on how this document can be improved. If you have any comments please use the following email: lmic-incontinence+owners@googlegroups.com.

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Suggested citation

Rosato-Scott, C. Giles-Hansen, C. House, S. Wilbur, J. Macaulay, M. Barrington, D, J. Culmer, P, Bhakta, A. N and Burke, L (2019) *Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs).* LMIC-Incontinence-email-group. DOI: https://doi.org/10.5518/100/13

Acknowledgements

The authors would like to acknowledge the following individuals and organisations for their contributions and materials, which have been drawn upon for the development of this document:

- The people and their caregivers from various countries who live with incontinence, who have kindly shared their experiences and suggestions, which has allowed this learning to-date
- All members of the informal international email group on incontinence
- Dr Fahmida Akter and team from Hope Foundation Hospital, Cox's Bazar, Bangladesh
- HelpAge; and other humanitarian actors in Cox's Bazar, Bangladesh – from the WASH, Health and Gender / Protection sectors, who participated in a workshop in incontinence in Feb 2019
- International Continence Society
- The authors of the Waterlines paper *"Incompetent at Incontinence"* (2015)
- World Vision and CBM Australia
- Zara Ansari and Sian White, London School of Hygiene and Tropical Medicine

Background

This guidance document for supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs), has been developed by an informal group of professionals interested in

incontinence in humanitarian and development contexts. Members have recognised that people who experience incontinence face many challenges that can significantly affect their quality of life, and that of their family members. They have also identified that there is a glaring lack of acknowledgement and support for people who have incontinence across multiple sectors, in both development and humanitarian contexts.

Aims of this guidance document

a) Provide a basic introduction to incontinence and the practical realities that people living with incontinence face

b) Provide practical suggestions as to the support that people with incontinence may appreciate

c) Highlight key challenges and risks that people experiencing incontinence may face

d) Provide links to further information and practical guidance

Who is this document for?

This guidance document will be useful for development or humanitarian professionals working in LMICs, across a wide variety of sectors and roles. Support for people with incontinence cuts across a number of sectors, including: Health, Midwifery, WASH, Disability and Older Persons, Protection / GBV / Children / Gender, and Logistics. In order to provide appropriate and effective support to people with incontinence, it is very important for specialists working across sectors to coordinate and work together.

Limitations and disclaimer

This guidance document focusses on the basic practical support that can be provided for people with urinary and/or faecal incontinence in low- or middle-income countries, from the perspective of the hygiene challenges faced. The authors however acknowledge, that they currently know less about faecal incontinence than urinary incontinence. In addition, although it includes some pointers to more specialist support and options that may be available, such as the use of catheters, it is not a guide to their use.

This document provides information on best practices, as understood by a number of specialists who are themselves still learning in this area. It is a starting point from which to continue to learn. We encourage anyone working in this area, to document what they are doing and what they are learning and to share it with others across sectors; so as to improve knowledge and practice across sectors and contexts.

Associated documents

This document is one of a set of four, that focus on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs):

a) Guidance (this document)
b) Summary guidance four-pager
c) Case studies
d) References

1. What is incontinence?

Incontinence is where a person is not able to hold on to their urine or faeces ('the involuntary loss of urine or faeces'). It is a complex health and social issue and effective containment of leakage is essential for quality of life. Leakage of urine and faeces can happen at any time, day or night.

Types of faecal (or bowel) incontinence[1]:

- Urge (when there is an awareness that bowels need to be opened to pass faeces, but there is such an urgency, that a toilet cannot be reached in time)
- Passive (when there is no awareness that faeces are being passed)

Types of urinary incontinence[2]:

- Stress urinary incontinence (SUI; the involuntary leakage of urine on coughing, sneezing or on physical effort such as exercise)
- Urge urinary incontinence (associated with a sudden, unexpected and intense urge to pass urine)
- Overflow (due to an inability to empty the bladder)
- Functional (due to not being able to get to the toilet in time because of, for example, mobility issues, or unsuitable access to toilet facilities). This is also known as 'Social incontinence'.
- Mixed (a combination of the above)
- In children, urinary incontinence at night is also known as 'bedwetting', or 'enuresis'.

The level and severity of incontinence experienced varies between people, and for each person can also vary day to day and over time. A person with urinary and/or faecal incontinence can experience[3]:

- Occasional leakage, regular leakage or constant leakage
- Odours
- Incontinence associated dermatitis (IAD; similar to nappy rash), skin infections and pressure sores due to exposure to prolonged exposure to urine and/or faeces and poor hygiene
- Urinary tract infections and bladder complications that can become life threatening if not properly managed

[1] Guys and St Thomas' Hospital (2017) *Faecal incontinence. Advice from the pelvic floor unit.* Available at: https://www.guysandstthomas.nhs.uk/resources/patient-information/gi/faecal-incontinence.pdf

[2] Continence Foundation (2011) *Types of Incontinence* [*Online*] Continence Foundation, United Kingdom. Available at: http://www.continence-foundation.org.uk/types-of-incontinence.html

[3] Hafskjold, B. Pop-Stefanija, B. Giles-Hansen, C. Weerts, E. Flynn, E. Wilbur, J. Brogan, K. Ackom, K. Farrington, M. Peuschel, M. Klaesener-Metzner, N. Pla Cordero, R. Cavill, S. and House, S (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' [*online*], *Waterlines*, 35(3). Available at: https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018

2. Who might be living with incontinence?

2.1 Groups of people who may experience incontinence

Some people experience incontinence due to being **born with a malfunctioning bladder and/or bowel and hence it is an issue that affects them throughout their lives -** but **also anyone at any age can also develop some form of incontinence**.

Those at an increased risk of incontinence include[4]:

- Older people
- Women and adolescent girls who are pregnant or have given birth
- Women and adolescent girls who have suffered an obstetric fistula (an abnormal opening between the vagina and bladder and/or colon through which urine or faeces leak out) due to a prolonged and/or obstructed childbirth (often due to giving birth young), or from sexual assault
- Women who are going through the menopause process, or the transition to menopause, known as perimenopause, as well as post-menopausal women who have completed the menopause[5]
- People with certain types of illness (such as cancer, diabetes, arthritis, asthma), or after an operation (such as the men after the removal of the prostate)
- People with neurological conditions (such as a spinal cord injury, or brain injury)
- People with physical, intellectual and / or psychosocial disabilities (including dementia)
- People who have experienced highly stressful situations, such as conflict or disasters

Many (but not all) people who have an increased risk of incontinence are part of groups of people who are often considered as vulnerable or disadvantaged by development and humanitarian actors. They can also become marginalised due to their incontinence.

[4] From the following reference unless otherwise noted: Hafskjold, B. et al (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' [*online*], *Waterlines*, 35(3). Available at: https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018

[5] Bhakta, A. (2019) *Opening the doors to the water, sanitation and hygiene needs of women from the onset of the perimenopause in urban Ghana*. PhD Thesis, Loughborough University, Loughborough Available at: https://repository.lboro.ac.uk/articles/Opening_the_doors_to_the_hidden_water_sanitation_and_hygiene_needs_of_women_from_the_onset_of_the_perimenopause_in_urban_Ghana/8230220/1

2.2 Estimates of prevalence of incontinence

Estimating how many people have incontinence is not easy and particularly in LMICs where there are few studies which have established prevalence. However, to the best of our ability, these figures can be used as a starting point[6]:

- Most studies tend to report that between **25% and 45% of women** in the study population have a type of urinary incontinence
- Studies have found that between **1% and 39% of men** (increasing with age) have urinary incontinence
- Studies tend to report that less than **15% of adults** in the study population have faecal incontinence
- The prevalence of daytime urinary incontinence in **children,** decreases with age (from 2.0-9.0% in seven-year olds, to 1.1-3.0% in 15 to 17-year olds), as does bedwetting (from 7.0-10.0% at seven years of age, to 0.5-1.7% by age 16-17 years)
- Studies report that women in early perimenopause, are 1.3 times more likely to develop urinary incontinence[7]
- Data for low- and middle- income countries is lacking, but figures could be higher due to, for example, a higher number of young mothers and a lack of maternity services. Examples include:
    - In rural Ethiopia[8] it is estimated that 0.2% of women of 15 years and above suffer from a fistula. In Bangladesh it is estimated that 0.17% of married women suffer from a fistula[9]
    - In Cox's Bazar, Bangladesh, 17% of older people interviewed, stated they have an incontinence problem, from which 77% stated they were struggling and did not know where to get support[10]

Figures could also be higher in conflict situations - anecdotally humanitarian workers in Syria have reported an increase in bedwetting amongst children due to psychosocial distress.

[6] Data has bene taken from the following reference unless otherwise noted: Abrams, P., Cardozo, L., Wagg, A., Wein, A. (Eds) (2017) *Incontinence 6th Edition,* International Continence Society, Bristol UK

[7] Waetjen, E., Ye, J., Feng, W., Johnson, W., Greendale, G., Sampselle, C., Sternfield, B., Harlow, S., and Gold, E. (2009) Association between Menopausal Transition Stages and Developing Urinary Incontinence. *Obstetrics and Gynaecology* 114(5) Sampselle, C.M., Harlow, S., Skurnick, J., Brubaker, L., and Bondarenko, I. (2002) Urinary Incontinence Predictors and Life Impact in Ethnically Diverse Perimenopausal Women. *Journal of Obstetrics and Gynaecology* 100 (6)

[8] Muleta, M., Fantahun, M., Tafesse, B., Hamlin, E. C. and Kennedy, R.C. (2007) Obstetric fistula in rural Ethiopia. *East Afr Med J* 84:525-533

[9] Akter, F (2019) *Incontinence in female genital tract,* Hope Foundation Hospital, Ramu, Cox's Bazar, Bangladesh. Available at: https://drive.google.com/file/d/1wvRPn6jprw60r7-sEVkdG4J9R6W8FYB2/view?usp=sharing

[10] HelpAge (2018) *Needs and Gap Analysis Older Refugee Population Cox's Bazar, Bangladesh.* Available at: https://drive.google.com/file/d/1ONvnk89W7BsqiM-h6VQbFI2S7tUB2QzM/view?usp=sharing

3. What is the practical reality for people living with incontinence?

Incontinence is **associated with stigma and remains a taboo subject**. Many people with incontinence are therefore reluctant to seek help and may live with their incontinence hidden for many years. It can have the following impacts in **both development and humanitarian contexts**[11]:

Emotional and social impacts[12]

- People with incontinence can feel ashamed and embarrassed, and experience a loss of self-esteem (due to feeling a loss of control and/or issues related to cleanliness), particularly if bullied and/or teased
- The condition is also associated with depression and anxiety
- Having incontinence can lead to exclusion from personal relations, social life and community life, for example, by limiting opportunities to participate in decision-making processes. This can exacerbate vulnerability and lead to loneliness
- Caregivers may also be prevented from having a social life away from their caring role

Practical and monetary impacts[13]

- Having incontinence can reduce, or exclude sufferers and caregivers from attending school, or earning an income
- Access to incontinence products that are affordable, effective and culturally appropriate, may be limited, or even non-existent
- Managing incontinence requires significant extra water, soap and time to bathe and to wash clothes, pads and bedding; such resources may be costly
- Caregivers may suffer from back and associated problems, if they need to move the person living with incontinence to go to the toilet or to bathe; especially if lifting devices aren't available (and few are available in LMICs)
- It may be difficult to access a toilet at short notice; dispose of soiled pads safely and discretely; and to wash, dry and store underwear and bedding safely and discretely

In addition, in **humanitarian contexts,** incontinence also has the potential to[14]:

- Restrict physical access to services, such as water or health, and to distributions of food or non-food items due to, for example, embarrassment about odour
- Restrict consumption of water and/or food as a means to avoid leakage
- Cause significant problems for people on the move due to, for example, an inability to access resources, such as soap and water

[11] A range of these issues were highlighted by members of the informal email group, where they have learnt them from people living with incontinence in different contexts; including research by Ansari, Z (2017) and Scott, C (2017)

[12] Gjerde, J.L., Rortveit, G., Muleta, M. and Blystad, A. (2013) 'Silently waiting to heal. Experiences among women living with urinary incontinence in northwest Ethiopia', *International Urogynecology Journal* 24: 953–8

[13] Hu, T., Wagner, Y.H., Hawthorne, G., Moore, K., Subak, L.L. and Versi, E. (2005) 'Economics of incontinence', in P. Abrams, L. Cardozo, S. Khoury, and A. Wein (eds) *Incontinence, 3rd edn*, pp. 73–96, ICUD-EAU, Paris.

[14] Hafskjold, B. et al (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' [*online*], *Waterlines*, 35(3). Available at: https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018

- Make life particularly difficult, because WASH facilities are often at a distance from the home / shelter, and communal or shared. If communal or shared, other users may prohibit incontinent users from using the facility, believing that the facilities will be soiled by the incontinent users

4. Barriers faced and strategies to overcome them[15]

4.1 Barriers and strategies - general for all

Important note: *Some medical treatments and surgery are available for some kinds of incontinence. In general, this section does not include medical treatment, as: a) this is likely outside the remit of those for whom this document is intended; b) and in some contexts medical treatment and surgery will not be available.* ***However, surgery is specifically noted for fistula, as there is increasing effort in LMICs to build capacity in fistula surgery and to raise awareness on its availability and life-changing impacts.***

Note that all people with incontinence have **significantly increased needs for water supply and for accessible, private WASH facilities**.

Strategies should begin with a **de-mystification and de-stigmatisation** of the condition.

Education about diet (including the reduction of aggravating agents such as caffeine), fluid intake (both volume and timing), a regular toilet routine, pelvic floor exercises and toilet posture (especially for children), may also be appropriate first steps.

Barrier – general for all	Strategy
People are shunned, teased, bullied or even punished (particularly children)	• Understand why (e.g. the underlying reason) the affected person is being shunned/teased/bullied; assess what support is needed and if it can be possible to address the cause of the bullying/teasing • With permission of the affected person when possible, undertake awareness raising with relevant people, for example, community leaders, families and the wider community
Physically inaccessible sanitation and hygiene facilities	• Ensure people with disabilities and older people are involved in emergency WASH preparedness planning and in emergency WASH programming from the earliest opportunity

[15] Adapted from: World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]. Available at:* https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf

	• Make sure that all WASH facilities are culture, gender and age-appropriate, safe, accessible and well-maintained sanitation and hygiene facilities • This might include the addition of handrails, larger doors, seats, wider paths, water inside the unit etc • People with incontinence may benefit from dedicated facilities or additional non-food-items to help them manage their incontinence
Lack of access to soap, water and disinfectants	• Increase regular supply (humanitarian) • Consider options for livelihoods for income generation (development)
Reduction in opportunities for livelihoods and income generation for the person with incontinence or their caregiver	• Link with livelihoods programmes / opportunities, including for activities that can be undertaken at a suitable location

Barrier – against level / type of incontinence	**Strategy**
Person cannot control when they release urine or faeces, including due to spinal cord injury and fistula	• Disposable or re-usable incontinence pads (*see **Sections 10 and 11**)* • Catheters and urine bags (under the supervision of a health professional) • An operation to repair the fistula and access to rehabilitation and therapy post-surgery
A person can control the release of urine or faeces sometimes, but not all the time	• Keep a toilet diary to establish toilet patterns • Create a regular routine for toileting • Where available, referral to appropriate rehabilitation and therapy services that provide incontinence support. For example, physiotherapists that can provide appropriate guidance on pelvic floor exercises.
Person gets a sudden urge to urinate or defecate, but is not able to get to the toilet quickly enough to prevent an accident occurring	• Handheld urinal containers or bed pans *(see **Section 10**)* • Commode chair in the house / near to bed

	• Where available, referral to appropriate rehabilitation and therapy services that provide incontinence support. For example, physiotherapists that can provide appropriate guidance on pelvic floor exercises.
Person needs to urinate or defecate, but does not want to go to the toilet and hence wets or defecates in their bed or similar (for example, women and children at night in refugee camps) *Note that this is not incontinence, as medically defined. It however has an element of 'functional' or 'social' incontinence, as the person is not able to keep in their urine or faeces, because the facilities provided are not suitable*	• Ensure that latrines are gender segregated (by screen or distance) and safe for use at all times (consider for example lighting and locks), and appropriately designed for use by men, women and children, and people with disabilities (see **Barrier: *Physically inaccessible sanitation facilities*** above) • Distribute torches and sandals (humanitarian) • Handheld urinal containers or bed pans *(see **Section 10**)*

Tip: Disposable versus reusable incontinence pads

The safe disposal of disposable incontinence pads can be a significant challenge in contexts where there is no formal waste disposal system.

Re-usable materials can help overcome this problem, but additional challenges are then faced to be able to wash and dry the materials discretely and effectively.

Tip: Disposal of urine or faeces

If supporting people with incontinence with handheld urine containers, bed pans or commode chairs; care must also be taken to identify and agree safe mechanisms for disposal of the urine or faeces.

A risk is that people may simply empty the contents into open drains or open areas outside, if they do not understand the need to dispose of the waste in a toilet.

Also make sure that children do not use the handheld urine container for drinking water.

Tip: Moisture or barrier cream to help the skin

Some people may benefit from such creams. Make sure that such creams do not irritate the skin and are safe for children. It may be preferable to not have perfume or colouring. Monitor the skin for any signs of irritation and **STOP** the cream use immediately if there are BROKEN SKIN OR WOUNDS. They should only be used under the supervision of a health professional. (World Vision / CBM, 2018)

4.2 Barriers - people with impairments that restrict mobility and/or understanding[16]

Barrier	Strategy
Person is not able to get to the toilet, but is usually able to control when they release urine or faeces (Functional, or Social incontinence)	• Caregiver establishes a toilet routine and works with the person to understand it • Handheld urinal container or bed pan • Commode chair with a bucket underneath (*see **Section 10***) • If appropriate, consider referral to services which could provide appropriate mobility devices and/or therapy or rehabilitation
Person requires assistance to get into a bathing chair or commode chair	• Lifting sheet (*see **Section 4.4***)
Person requires support to get into a wheelchair, or to stand up and to walk to a toilet or bathing space	• Lifting and walking belts (*see **Section 4.4***)
Person is unable to stand or sit on a chair when bathing	• Tilted bathing chairs • Bathing benches
Person cannot regularly access household bathing area	• Bed baths
A person does not use the toilet because they do not understand or have not learned the purpose of a toilet and how to use it	• Use modified approaches to teach how to use a toilet (see **Section 4.3**)

[16] World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]. Available at:* https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf

4.3 Toilet training guidance for people who learn differently[17]

To support people who learn differently how to control urination and defecation and use a toilet:

- Be supportive and prevent situations where the person feels forced or fearful of using the toilet
- The person must feel safe and secure in the toilet space, before they will be able to learn successfully. Never get angry, shout or shame the person. Keep the learning process fun and relaxed
- Repeat the same information in simple steps, again and again
- Use simple language and communicate simply. It can be helpful to demonstrate each stage of the task using pictures, a doll, songs, storytelling and sometimes (if appropriate and safe for the person) a demonstration
- Encourage the person to wear loose fitting clothes, with elastic waist bands, rather than zips/buttons which can be harder to undo
- Celebrate small achievements to provide motivation, such as for reaching single simple steps
- Establish a regular toilet routine and select times that are consistent with the household routine

For more information see: World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sources and cost-effective strategies for hygiene at home for people with high support needs.*

4.4 Lifting devices

A number of useful lifting devises can be made locally where a person needs to be lifted to be able to use the toilet. For step-by-step guidance, refer to the publication by World Vision and CBM (2018)[18].

The lifting belt is a thick and strong belt worn around the waist to provide support in standing, sitting and walking.

(credit: World Vision / CBM)

A lifting sheet laid flat. The handles are strongly sewn towards the feet and the head ends of the lifting sheet. The handles are a looped belt of strong calico stitched into the two layers of the larger calico sheet.

(credit: World Vision / CBM)

[17] Adapted from: World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]. Available at:* https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf;
with advice from Chris Thomas, UK, a teacher of children with special needs

[18] World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]. Available at:* https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf

5. Support recommended in humanitarian contexts[19]

Guidance for supporting people with incontinence included in the 2018 Sphere Handbook.

Important note: Ideally people who are incontinent and immobile need their symptoms assessed, and appropriate treatment and interventions to minimise the adverse impacts of incontinence. If treatment is not available (likely in a humanitarian context), not wanted or fails, and whilst waiting for treatment and then for it to take effect, people with incontinence need: 1) effective containment products and/or toileting aids to support management of the condition; and 2) to consult health or disability specialists to learn how to prevent and manage infections and bed sores, which can be fatal.

Supplies and facilities

- Access to much larger amounts of water and soap is critical. People with incontinence and their caregivers, each need five times as much soap and water as others.
- Discuss options with affected people to understand their preferences for:
    - disposable or reusable incontinence materials;
    - disposal mechanisms in homes, schools, health centres and communal facilities;
    - laundry and drying facilities; and
    - toilet and bathing facilities.

Consider age-specific norms and preferences, as the type and quantity of supplies may change over time. Provide demonstrations for unfamiliar materials. Always consider the life-cycle of incontinence materials – use, laundering, drying, disposal and replenishment of consumable (see below).

- Different types of pads are required for faecal and urine incontinence, and for different levels of severity of incontinence. Sizing is important for safe use; diaper style pads can cut off circulation of they are too small. Supply both urine and faecal incontinence pads in a range of sizes and types.
- Consider proximity to toilets for people with incontinence. Some people may be able to prevent incontinence episodes, if they can access the toilet quickly and safely. A toilet commode chair, bed pan and/or handheld urinal bottle may need to be supplied.

Replenishment of supplies

Consider how and when to replenish materials. This includes a regular review of the supply chain and market availability. As with other hygiene items, cash-based assistance, or in-kind distributions, may be used in different ways over time. Explore options for small enterprises to provide materials or for people to make their own protection materials.

[19] Adapted from: Sphere Association 2018. *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response* [Online] 4th ed. Geneva, Switzerland: Sphere Association. [Accessed 14 November 2018]. Available from: www.practicalactionpublishing.org/sphere

A suggested minimum for supplies

Supplies needed will depend on the severity and type of incontinence and needs may change over time. **It is essential to discuss with people, and where appropriate their caregivers, what they need.**

- A dedicated container with lid, for soaking cloths and storing pads/cloths
- Rope and pegs for drying reusable pads / cloths
- Soap (500g for bathing, plus 500g for laundry per month), in addition to general soap distribution
- Disposable incontinence pads (150 pads per month); or reusable incontinence underwear (twelve per year), as preferred. Pads should be provided of an appropriate size and suitability for faecal or urine incontinence (urine pads will be ineffective for faecal incontinence)
- Underwear (twelve per year)
- Two washable leak-proof mattress protectors
- Absorbent soft cotton material or towelling ($8m^2$ per year)
- Bleach or similar disinfectant cleaning product (3 litres of non-diluted product per year)
- Bed pan and handheld urinal containers (male and female) and / or a toilet commode chair (as appropriate)
- Two additional 20 litre water containers

Schools, safe spaces, and learning centres

Support for WASH in schools and safe spaces should consider the WASH infrastructure, which should:

- Have a supply of incontinence supplies, including underwear for children who need them at school.
- Have a discrete disposal mechanism for used incontinence materials (either a container with a lid, with collection and disposal system, or a chute from the toilet to an incinerator).
- Have well maintained and gender-segregated WASH facilities that have hooks and shelves on which to put clothes and incontinence supplies while changing materials.
- In conflict situations, provide additional training for teachers on supporting children and adolescents who are facing incontinence in the classroom, due to trauma from conflict.

Shelter and camp management

Work with the shelter sector to ensure shelters offer adequate privacy for incontinence management in the household or communal shelter, and that sufficient space is allocated for communal WASH facilities. This may, for instance, include using privacy screens, or separate areas for changing or bathing

People on the move

Offer incontinence management supplies as people pass through supply points.

6. Overview of supportive environment

Creating a supportive environment for people to manage their incontinence: hygienically, safely, in privacy and with dignity

Including in humanitarian contexts

PHYSICAL NEEDS

Available incontinence materials and non-food items

Affordable, and culture, gender and age-appropriate; ongoing or continuous access (not-one off). Items such as cloth / pads, soap, water containers, small bucket and lid, mattress protectors, rope, pegs (or catheters and other associated equipment with specialist support)

Private place(s) to change and bathe, and safe, hygienic and discrete methods to manage incontinence materials

Culture, gender and age-appropriate, safe, accessible and well-maintained water supply, sanitation and hygiene facilities

For changing materials and bathing

For washing and drying of materials and disposal

KNOWLEDGE AND ENVIRONMENT

Creating a supportive and safe environment

Breaking down stigmas and myths to enable people to acknowledge their incontinence and to ask for help

Information and dialogue on incontinence for women, men, girls and boys – including from health and disability specialists

On the daily management of the condition and the prevention of bed sores and urinary tract infections

COMPETENT PROFESSIONALS AND COORDINATION

Key professionals recognise incontinence and are knowledgeable and confident

To advocate for support for people with incontinence, and to respond to incontinence needs

Cross-sectoral communication and action

WASH, health and midwifery; disability and older persons; protection / GBV / children / gender; education; logistics / shelter / camp or community services

7. Challenges to providing support and health risks

Challenges / risks	Suggestions to respond to challenges / address the risks
1. People with incontinence and their caregivers may be shy or embarrassed to talk about it	**Take care to:** • Ensure that you have a basic level of understanding of incontinence and its management, in case they have questions. Take helpful resources with you, for example, sample reusable pads or underwear and/or documents about how to make pads (tailored to the recipient and easily understood) • Have men speaking with men and women with women when possible • Make sure that discussions are held in a private location where other people cannot hear and the person with incontinence feels comfortable • Build trust, for example by talking about other issues first • Ask permission before asking questions on incontinence, and explain why you would like to discuss the issue. Make it clear that a lot of people experience it, but few talk about it, and that this is a safe place to speak • Have a list of referral services that can be left with the person, ensuring that telephone numbers and addresses are included *(See **Section 6** below - for more guidance on identifying and engaging with people with incontinence)*
2. People with incontinence may face increased stigma, bullying and/or teasing if other people know about it (for example if they have a strong odour, or are not able to keep clean)	**Try to:** • Breakdown stigma in the wider community, in a general and sensitive way, as part of other programme activities, while not identifying specific people living with incontinence • Ensure availability of sufficient water, soap, buckets, etc. for bathing, and that bathing, laundering and disposal facilities are private and accessible to people with incontinence and they feel safe to use them

3. Pads and incontinence underwear that are the wrong size may cause chaffing or cut off circulation, leading to other problems	**Make sure that:** • Products supplied are suitable, both in terms of size and absorbency
4. People who have incontinence, and in particular those who are immobile, can be vulnerable to pressure sores and urinary tract infections – both of which can be very serious (pressure sores can lead to death)	**Always:** • Consult with health professionals about strategies - there are important health considerations around managing incontinence • Make sure that people who are immobile with incontinence receive professional advice, for example, by linking them with health and/or disability specialist organisations/institutions • Look out for early signs of injury to the skin, pressure sores and infections[20] (see below)

Pressure sores

- *It is important to monitor the skin for any redness, swelling or skin breakages that could be an early sign of a pressure sore. Advise individuals and households to seek medical attention immediately if any of these things occur.*
- *In addition, it is important to change the position of the individual regularly.*

Urinary tract infections

- *A person who experiences barriers to communication, may not be able to say when they are feeling pain or discomfort. Advise households to look for other signs of discomfort, such as unusual crying or tremors, that could be a sign of a health condition, such as a urinary tract infection.*

[20] Adapted from: World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]. Available at:* https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf

8. Identifying and engaging with people with incontinence

8.1 Challenges to engaging with people with incontinence

There are a number of challenges that may be faced when trying to identify people with incontinence:

- People, including health professionals, may not understand the term “incontinence”
- People with incontinence may face increased stigma, bullying and/or teasing if other people know about their condition, and/or they are identified in an inappropriate way
- It is a sensitive and highly stigmatising issue that people may not even feel comfortable talking about with their family and friends
- People with incontinence may also not perceive that they have a medical condition that needs to be discussed. Particular care needs to be taken in this instance not to alarm or frighten

8.2 Identifying people with incontinence

To identify people with incontinence - consider who might have a good network in the community and who will also be discrete. For example:

- Medical practitioners, including community health workers, at community health centres and at hospitals, and also including traditional health practitioners
- Community based organisations (particularly outreach workers), and especially those that support people who may be particularly disadvantaged
- NGOs (national and international) supporting people who may also have incontinence in their programmes (particularly outreach workers). For example, disabled person’s organisations, older person’s organisations, women’s organisations, children’s organisations
- School teachers
- Community leaders

8.3 Talking to people and their caregivers about incontinence

To talk about incontinence - the following phrases may be useful, using culturally appropriate words where applicable[21]:

- *Are you able to control your urine / is it difficult for you to control your urine / do you have the capacity to control your urine / can you hold onto your urine / do you face problems dealing with your urine?*
- *Do you have difficulty or problems holding in your faeces / can you hold onto your faeces?*
- *Does your urine or faeces sometimes come out involuntarily / does your urine or faeces sometimes come out when you don't want it to / do you ever leak urine or faeces / does your urine or faeces ever just come out?*
- *Has it ever happened to you that your urine or faeces came out before you managed to reach the bathroom / can you always get to the toilet on time / have you ever wet yourself / have you ever soiled yourself?*
- *Does your absolution for prayer get broken without you wanting it to / do you have any problems or difficulty with staying clean for prayer?*
- *Is there someone in your family who is suffering from a bad or foul smell (or odour) / is there anyone in your family that smells of urine or faeces?*

[21] Adapted from: Ansari, Z. (2017) *Understanding the coping mechanisms employed by people with disabilities and their families to manage incontinence in Pakistan.* MSc Thesis. London School of Hygiene and Tropical Medicine. Available at: https://drive.google.com/file/d/13sj4trd2XqhKNbzRXrDu3WszuYthg7b5/view?usp=sharing

9. Obtaining cross-sectoral commitment and support[22]

9.1 Responsibilities by sector

Sector	Responsibilities regarding people with incontinence

Water, sanitation and hygiene (WASH)	• Save lives by preventing the transmission of communicable diseases, including due to faeces spread through incontinence
	• Facilitate or provide easy access to accessible, safe, private and culturally appropriate water, sanitation and hygiene facilities - including for the changing of incontinence materials, washing of the body and disposal or washing and drying of incontinence materials
	• Promote good hygiene behaviours, including related to the management of urine and faeces – including when a person with incontinence is using a commode chair, a bed pan or a handheld urinal container
	• In humanitarian contexts:
	  ○ Advise on and provide appropriate hygiene items (including additional NFIs, such as soap, water containers, waterproof bed covers, commode chairs, handheld urinal containers, etc)
	  ○ Facilitate opportunities for people with incontinence and their caregivers to be able to ask for additional WASH support on an on-going basis, including replenishments
	• Develop guidance and provide capacity building for the WASH and other sector actors on the WASH elements of managing incontinence; including community mobilisers (e.g. hygiene promoters). If they are aware of incontinence and the challenges it can pose, they can refer community members for further specialist support (where needed). This is so they will have the confidence and knowledge to collect and ask for people's experiences and feedback on their needs in relation to managing their incontinence
	• Raise awareness on the WASH needs of women going through the menopause process and post-menopause (related to incontinence, as well as more general support for women going through this time of life, which may be very challenging with multiple symptoms; which include a need for great access to WASH to manage hot flushes and very heavy periods)
	• Coordinate with the health, disability / older person and other sectors, on how to most effectively identify and support people with incontinence, including referral channels

[22] Includes recommendations made during a cross-sectoral discussion on responsibilities undertaken as part of the humanitarian response in Cox's Bazar, Bangladesh (2018)

Health, including Midwifery	• Work to break down stigma on incontinence and encourage people to acknowledge their incontinence and ask for help where needed • Advise on and provide training for people living with incontinence, their care givers and traditional birth attendants - on how to manage incontinence and how to detect and treat injury to the skin, pressure sores and infections • Advise on and provide treatment for incontinence that meets their need, for example, access to therapy or rehabilitation, or access to catheters • Provide skilled assistance to deliver babies in appropriate healthcare facilities • Provide ante- and postnatal guidance on reducing the risks of incontinence • Raise awareness on the incontinence needs of women going through the menopause process and post-menopause (as well as more general support for women going through this time of life which may be very challenging with multiple symptoms) • Provide medical care to people experiencing incontinence that have experienced injuries, for example surgical interventions for obstetric fistula or other conditions, and / or provide advice on physical exercises and medication • Where available and appropriate provide access to therapy or rehabilitation support. For example, physiotherapists who could provide appropriate exercises. • Coordinate with the WASH and other sectors on how to most effectively support people with incontinence
Disability and older person's specialists	• Assess the needs of people with disabilities and incontinence • Advise on how best to manage and/or treat incontinence experienced by older people and people with disabilities • Facilitate or provide access to equipment, including assistive products and accessible facilities to manage and/or treat incontinence experienced by people with disabilities • Where necessary, link people with disabilities who experience incontinence to appropriate professional support, for example, health practitioners • Coordinate and work with the WASH sector to ensure all water supply, sanitation and hygiene related facilities are safe, appropriate and accessible for people with disabilities and older people
Protection / GBV / Children / Gender	• Create awareness around the issue, including to be aware of the risks for GBV and isolation of people who have incontinence • Establish systems and strengthen referral systems to ensure timely access to medical services for survivors of sexual violence

	• Utilise safe spaces for women and adolescent girls and for older persons to share information about incontinence and how they can get support, and on sexual reproduction and health (SRH) • Build capacity of health workers and frontline staff on incontinence and SRH • Engage husbands, wives and other family members in supporting family members with incontinence • Work with the WASH sector to ensure all facilities – including water, sanitation, health, child friendly spaces – are safe and appropriate for people facing particular challenges to manage their WASH, such as women and children or people with disabilities and older people
Education	• Ensure that water, sanitation and hygiene facilities in educational establishments provide accessible, private and safe access for children, youth and adults who have incontinence, who use or work at the facilities • Be aware of students' needs and make provision for spare incontinence materials to be able to support them, if they have an accident and need to change • Ensure students feel comfortable to talk about their needs and how teachers and support staff can best support them
Those with responsibility for NFIs including Logistics, Shelter, and Camp or Community Services	In humanitarian contexts: • Coordinate with the WASH, health, disability / older persons and gender / GBV children / protection actors, to determine the ongoing NFI needs for supporting people with incontinence • Make sure that any cash-based support provides additional funds for the management of incontinence for families with members who experience it • Assess availability and identify sources of, purchase and supply (in-kind or cash-based) non-food items that are needed for the management of incontinence, including soap, incontinence pads, mattress protectors, bed pans and commode chairs • Ensure an initial distribution (in kind or cash-based) of needed items, and regular replenishment (or top-up) of consumable items and materials

9.2 Advocacy arguments to encourage cross-sector commitment and support

Possible "against" arguments	Suggested responses "for"
It is another sector's responsibility, not ours	**Response for the WASH sector:** • The biggest needs of someone with incontinence, relate to water, sanitation and hygiene. • To support communities to prevent the spread of disease, as well as live with dignity, everyone must be able to manage their hygiene tasks effectively. • To be open-defecation free, people with incontinence need support, not to have to defecate in the open. • The WASH sector is meant to ensure the WASH needs of *everyone* are met – this includes people who may be more vulnerable and including people with incontinence, who are likely to have additional WASH needs. **Response for the disability and older person's sector:** • People who have incontinence, and in particular those who are immobile, can be vulnerable to pressure sores and urinary tract infections – both of which can be very serious (pressure sores can lead to death). • Being able to manage your urine and faeces hygienically and with dignity, is a human right and significantly improves the quality of life of people living with incontinence
It is only small numbers of people, and we focus on the majority / **It is a niche area, or a fringe subject /** **There are more important issues to focus on**	• A wide range – and number – of people are affected by incontinence (**see Section 2** on who might be living with incontinence). • In humanitarian contexts, the management of WASH is often challenging for everyone. For people with incontinence and their caregivers, it is much more difficult and stressful and can limit their ability to participate in society or access services. • The SDGs are very clear that we are now working to "Leave No One Behind". We must prioritise people who are most vulnerable, and women and children first, including those that have incontinence. • Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity[23].

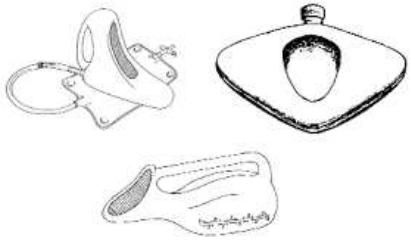
People with incontinence may therefore need support to have good health.

- People with incontinence are likely to have additional needs in all stages of an emergency – including the acute and early stages and so this should be considered, even if the support provided is basic. In the maintenance and recovery phases of a humanitarian emergency, there should be more time and resources available to undertake more detailed discussions on needs and improve the level of support given to people with incontinence.
- Support to people with incontinence can be embedded or integrated into existing activities, rather than being a stand-alone program.

[23] WHO (2006) *Constitution of the World Health Organisation*. WHO, Geneva, Switzerland.

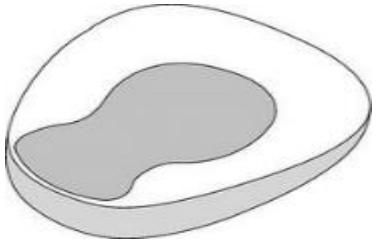
10. WASH related incontinence products: Reusable[24]

Please refer to the **Continence Product Advisor website** (https://www.continenceproductadvisor.org) for impartial advice on all continence products. Please note however, that this website has been established, based on what is available in higher income contexts, so some of the guidance may not be directly applicable in all circumstances. The items listed below are deemed to be most applicable for LMIC contexts, with examples provided for illustrative purposes only. Availability, suitability and individual preferences will vary.

Item	Image	Product examples
1. Reusable waterproof **underpad** for protection of bed mattresses		  (the right one is reusable)
2. **Handheld urinals** for males and females (used when access to a toilet is not possible or convenient). Containers are usually made from plastic. Different entrance shape needed for men and women		

[24] Line images from: Fader M, Cottenden A, Getliffe K, Gage H, Clarke-O'Neill S, Jamieson K, et al. (2018) Absorbent products for urinary/faecal incontinence: a comparative evaluation of key product designs. *Health Technology Assessment* 2008;12(29). https://eprints.soton.ac.uk/189241/1/Absorbent_products_for_urinaryfaecal_incontinence.pdf; and the International Continence Society. Other images taken by S. House unless otherwise noted.

3. **Bedpan** (portable device for passing urine and/or faeces while lying down or sitting) – usually made from plastic



(S.House/WSSCC)

Above: A simple home-made bed pan with wedge reproduced from Werner, D. (2018). Disabled Village Children: A guide for community health workers, rehabilitation workers and families. Berkeley, USA: Hesperian Health Guides.

(credit: Werner, D (2018) in: World Vision / CBM)

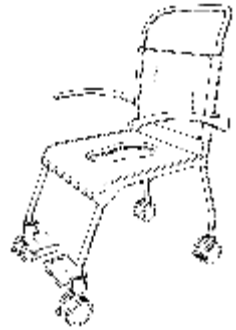
4. **Commodes** (portable toilets), used by people with reduced mobility.

Either has:

a) A container of some kind that slots into place under the seat plus lid, or

b) A chute that goes down to a bucket or pit latrine hole, or

c) Has a hole in a chair to place over a latrine hole



(Plastic chair with chute purchased by RIC/Help Age – Camp 18)

(NGO Forum / UNICEF supported – seat purchased in Chittagong – Camp 6)

(Foldable chair for placing over a bucket or latrine hole – purchased by RIC/HelpAge – Camp 18)

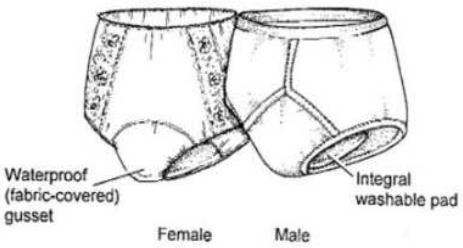
(Raza, S / OXFAM, Pakistan)

Feedback from users

This commode chair which was purchased to respond to the requests of people who were displaced due to the Pakistan / Kashmir Earthquake in 2006, who were facing mobility challenges. They preferred to use this in their shelters than use communal facilities.

Feedback on its use was that it was appreciated, but that the pot beneath the seat was a little shallow and led to some 'splash-back' when it was being used.

5. Reusable/washable incontinence pull up **underwear for light incontinence**, with thick portion for soaking urine - in different positions for males and females

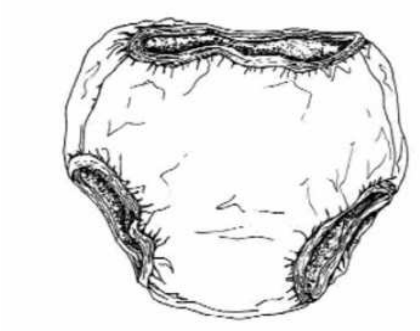


(Has fixed pad – female)

(Has pocket for inserting additional pads to soak liquids – female)

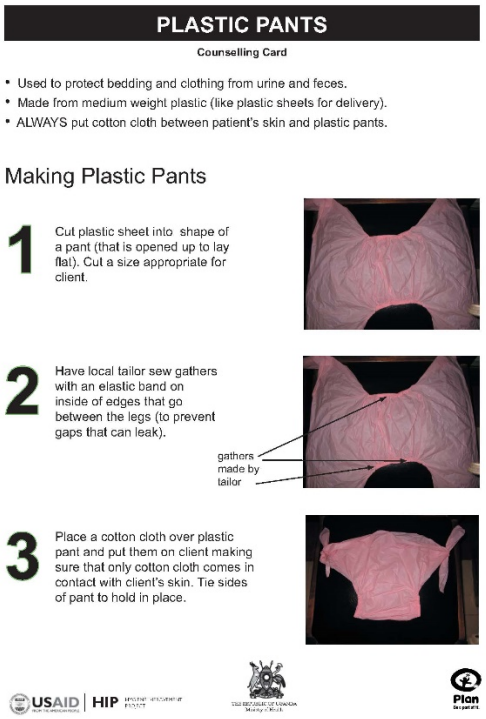
(Has fixed pad at front – male)

6. Reusable pull-up **underwear for moderate to heavy incontinence**



Plastic outer pull up pants

(Plastic outer pants pull up)



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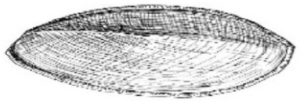
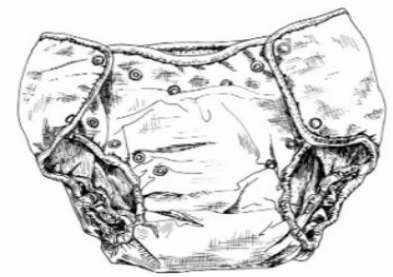
7. **Reusable pouches** for men (top: front view, bottom: side view)



[25] Credit: USAID/WASH Plus Project (2014) *Integrating safe water, sanitation and hygiene into HIV programmes, A training and resource pack for Uganda, November 2014 [online].* Available at: www.washplus.org/sites/default/files/uganda-wash_hiv.pdf

8. **Other reusable underwear** which wrap around and are fixed using poppers or Velcro



This has additional inserts for heavy flow

Making re-usable underwear

Step-by-step guidance on how to make reusable underwear, is included in the publication by World Vision and CBM (2018)[26]

However, whilst the general guidance is very helpful, care should be taken to not use towelling for the innermost layer (as recommended in this publication). This is because it is likely to be rough against the skin and also will retain the liquids against the skin. Materials will need to be selected through trial and testing by the potential users; but from learning from the production of menstrual products, it is best to have a soft material against the skin; and a material that does not hold the fluids against the skin, and then to keep the towelling behind this to retain the fluids. Such soft materials may be cotton flannel or a soft synthetic fabric, that let's fluids through, but does not retain the liquid as much as towelling.

Above: Reusable continence pads made by DeafLink Tailors in Jaffna, Sri Lanka.

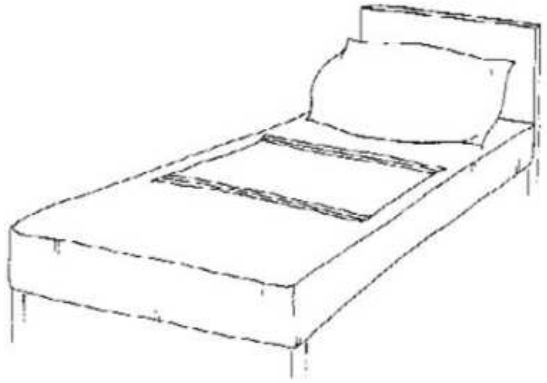
(credit: World Vision / CBM)

[26] World Vision and CBM Australia (2018) *Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs [online]. Available at:* https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf

11. WASH related Incontinence products: Disposable[27]

Please refer to the Continence Product Advisor website (https://www.continenceproductadvisor.org) for impartial advice on all continence products. Please note however, that this website has been established on what is available in higher income contexts, so some of the guidance may not be directly applicable in all circumstances. The items listed below are deemed to be most applicable for LMIC contexts, with examples provided for illustrative purposes only. Availability, suitability and individual preferences will vary.

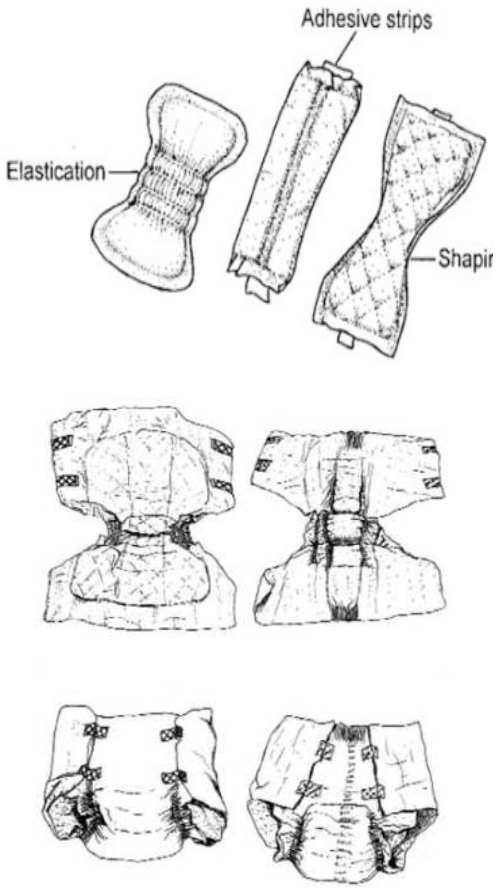
Important note: The disposal of solid waste can be a significant challenge in humanitarian contexts as well as in many LMICs; as sustainable waste collection and management systems may not exist. This must therefore be considered before deciding on the provision of disposable products; as well as how replenishment will happen on a sustainable basis.

Item	Image	Product examples
1. **Disposable underpad** for protection of bed mattresses.		 (The left ones are disposable)

[27] Line images from: Fader M, Cottenden A, Getliffe K, Gage H, Clarke-O'Neill S, Jamieson K, et al. (2018) Absorbent products for urinary/faecal incontinence: a comparative evaluation of key product designs. *Health Technology Assessment* 2008;12(29). https://eprints.soton.ac.uk/189241/1/Absorbent_products_for_urinaryfaecal_incontinence.pdf; and the International Continence Society. Other images taken by S. House unless otherwise noted.

2. **Disposable inserts/pads for light incontinence** (similar to pads for menstrual hygiene).

3. **Disposable pads for moderate to heavy incontinence,** shown open (top) and with tabs secured (bottom). Pads on right have gathering

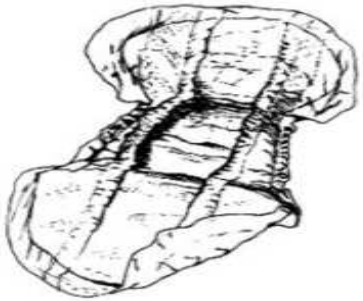


Bottom row (left to right): men's disposable pouch; women's pull up disposable underwear; disposable pad for light flow; disposable pad for medium flow

Top row (left to right): men's disposable pouch; men's reusable underwear; women's reusable underwear.

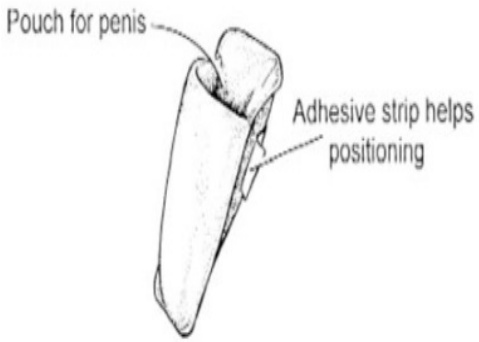
4. **Disposable inserts/ pads for moderate to heavy incontinence**

Have elasticated sides to hold in liquids.



5. **Disposable pouch for men**

Note: *This pouch is available, but is not generally recommended, as it tends to slip and not stay in place.*



6. **Catheters and associated items**

Only to be provided by specialists with expertise in this area (health, disability, occupational therapists)

(credit: University of Southampton)

(credit: University of Southampton)

For more details see:

https://www.continenceproductadvisor.org