



SUPPORTING PEOPLE WITH INCONTINENCE IN THE RED CROSS RED CRESCENT CONTEXT

WASH and incontinence fact sheet

Incontinence is an often hidden and neglected issue. There is growing interest within the Red Cross Red Crescent (RCRC) in supporting people with incontinence, both in emergency contexts and long-term programming. This fact sheet outlines in plain, non-medical language what incontinence is, key impacts and practical needs of people who experience incontinence.

Although primarily for water, sanitation and hygiene (WASH) staff, this fact sheet can be useful for others and includes information on who is involved and key responsibilities of different sectors, as well as actions to take to support people with incontinence.

What is incontinence, and who can experience it?

Incontinence is where a person is not able to hold onto (or control) their urine (pee) or faeces (poo), or both¹.

The type and severity of incontinence can vary significantly from person to person – ranging from managing occasional leakage and smells, to a constant flow of urine or faeces. Incontinence can be conscious (when the person knows it is happening) or unconscious (when they don't know it is happening). In some cases, incontinence can lead to frequent urinary infections, bladder complications and bed sores – that can become life-threatening if not properly managed². For more information see the [Incontinence: We Need to Talk About resource](#) (IDS, 2020).

Incontinence is a complex issue, which is largely hidden and can have significant impacts on quality of life, personal dignity and physical and mental health. Prevalence may seem low, as many people will keep it a secret, however recent studies estimate that 29% of women who have given birth and between 1–39% of men have some type of urine incontinence, and around 30% of people with disabilities experienced both urinary and faecal incontinence⁴.

A wide range of people may live with incontinence, including^{3,4}:

- older people,
- adults and children with physical disabilities and/or learning difficulties,
- women and adolescent girls who are pregnant or who have given birth (including those with complications including long or obstructed labour, prolapse or fistula),
- children and adults who have experienced highly stressful situations, such as conflict or disasters, and develop incontinence or night-time bed-wetting,
- people who have suffered from a sexual assault,
- people with certain medical conditions (e.g. enlarged prostate, diabetes, uterus prolapse), illnesses (such as stroke) or who have had an operation (e.g. removal of the prostate).

For some people incontinence is temporary, for others it may start and continue, and others have lifelong incontinence.

1 Summary guidance: Supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs), 2019, Informal email group of professionals interested in incontinence in low- and middle- income countries (LMICs) <https://wash.leeds.ac.uk/wp-content/uploads/sites/45/2019/08/Four-pager_August_2019_Version_1.pdf>.

2 Netherlands Red Cross 'think paper' on incontinence (draft, 2022).

3 Claire Rosato-Scott, Dani J. Barrington, Amita Natiksha Bhakta, and others, Incontinence: We Need to Talk About Leaks, 26 October 2020 <<https://doi.org/10.19088/SLH.2020.005>>.

4 Sphere Association (2018). The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response, 4th ed. Geneva, Switzerland: Sphere Association <<https://handbook.spherestandards.org/en/sphere/>>.



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What are the impacts for people who experience incontinence?

Incontinence is a highly sensitive and stigmatised issue which can have a significant impact on someone's life, as well as their family members or carers. Many people may live with it hidden for many years (either by personal choice or by families/communities), and may be reluctant to talk about it or seek help⁵

Stigma, embarrassment, loss of self-esteem (e.g. due to issues related to cleanliness and smell, or feelings of loss of control). Incontinence is associated with depression and anxiety. People with incontinence can sometimes withdraw from society, further compounding exclusion and depression (and in some cases leading to suicidal thoughts).

People with incontinence may be **unable or excluded from accessing basic services** such as water, distributions or health services (e.g. due to embarrassment or stigma about their smell). At the same time they have increased needs for soap, water, privacy etc. (see below). Some may also restrict consumption of water and/or food as a means to avoid leakage.

Having incontinence can **exacerbate vulnerability** because of exclusion from personal relations, and social and community life. People with incontinence (particularly when it is severe) can be socially ostracised, unable to earn a living or take care of a household.

Practical and financial impacts such as not being able to earn an income, and increased time and money spent on washing, drying and purchasing hygiene items. Children or other family members who act as caregivers may have to reduce attendance at school or work.

⁵ Summary guidance: Supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs), 2019, Informal email group of professionals interested in incontinence in low- and middle- income countries (LMICs) <https://wash.leeds.ac.uk/wp-content/uploads/sites/45/2019/08/Four-pager_August_2019_Version_1.pdf>

What are the practical (WASH related) needs of someone with incontinence?

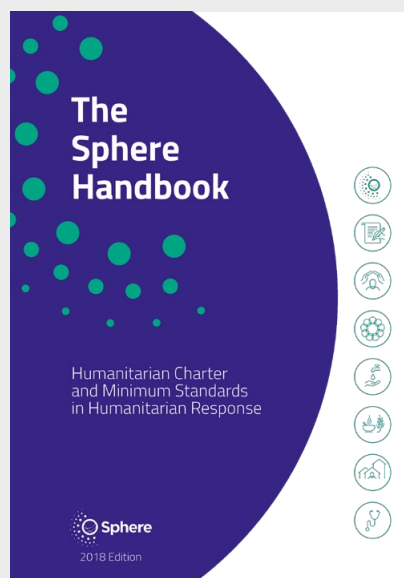
- Significantly increased **need for water supply, soap and private WASH facilities** for washing and drying clothes, bedsheets etc. and disposing of materials.
- It is estimated that people with incontinence and their carers each need **five times as much soap and water** as others⁶.
- **Incontinence items and materials**, for example disposable or reusable incontinence pads or diapers, waterproof mattress covers, extra clothes and underwear, extra soap and water containers, bed pans, potties, urinal bottles and toilet commode chairs.
- **Items needed will depend on the severity and type of incontinence, context and preferences. Keep in mind that pads are not always the answer** – ask people (and where appropriate, their caregivers) what they need and involve them in selecting items and decision making for siting, planning and ongoing management of WASH facilities. [Page 104 in Sphere](#) has additional guidance on suggested minimum incontinence supplies.
- Short **distances and easily accessible latrines, bathing and laundry areas**, as well as **minimal queues** to access communal facilities (e.g. some people may be able to prevent leaking on their clothes, seat or bedding, if they can access the toilet quickly and safely, including those with disabilities or mobility issues).
- **Having someone to talk to or ask for support, who treats them with dignity**: start with de-mystifying and de-stigmatising incontinence and learning from people who live with the condition.

What does Sphere say about incontinence?

Sphere includes incontinence (together with menstrual hygiene management) in the WASH chapter. Hygiene promotion standard 1.3 states that “...males and females with incontinence should have access to hygiene products and WASH facilities that support their dignity and well-being”. Key actions include:

1. understanding the practices and social norms concerning incontinence management,
2. consulting people with incontinence (in a confidential, appropriate way) on the design, siting and management of WASH facilities,
3. providing access to appropriate incontinence materials, soap (for bathing, laundry and handwashing) and other hygiene items (including through either in-kind distribution or cash and voucher assistance⁷), and
4. ensuring supplies are distributed discretely to ensure dignity and reduce stigma, and demonstrate proper usage for any unfamiliar items.

There is also some mention of incontinence in both the [Minimum Standards for Child Protection](#) (Standard 26: WASH and child protection) and the Sphere Health chapter (related to stocking incontinence pads and catheters etc. at health facilities).



⁶ The Sphere Project, i.

⁷ Cash and voucher assistance (CVA) may be an option for incontinence or personal hygiene items. CVA can give people more freedom to choose the materials and items they prefer and feel most comfortable using, can increase beneficiary satisfaction, be more convenient and reduce risks associated with distributions, as well as support local vendors and markets.

What are the main challenges and what can we do to support people with incontinence⁸

People with incontinence are 'hidden', and may be embarrassed, afraid or shy to talk about it

Work collaboratively together (WASH, PSS, PGI and Health teams) to collect appropriate information (to understand the extent of needs) and to identify people who may have incontinence, in a dignified and private way.

Prior to identifying people with incontinence, identify the most appropriate ways to communicate with people with incontinence, to ensure they are engaged in a dignified way that does no harm or causes further embarrassment.

Train staff and volunteers and build their understanding and confidence to talk about incontinence.

Link people with incontinence to local specialist health, disability and/or older person organisations or services.

Build trust with people by talking about other issues first (e.g. menstrual hygiene, personal hygiene and access to WASH facilities).

Use child-friendly approaches to support children with incontinence (using specialist support).

Lack of materials to manage incontinence

Ask people with incontinence (and where appropriate, their caregivers) about their preferences and needs. Items specific for children and youths (e.g. diapers/underwear/incontinence pads) may be challenging to access.

Keep a stock of appropriate supplies in health, PSS or DAPS (dignity, access, participation and safety) centres for on-demand distribution to people who have incontinence. Different types, sizes and absorbency levels may be needed for different types and severities of incontinence.

Always think about the life cycle of incontinence materials – including use, washing, drying and disposal.

Conduct a market analysis and assess whether cash or voucher modalities could enhance dignity and privacy.

Page 104 in Sphere has additional guidance on suggested minimum incontinence supplies.

⁸ Adapted from: Summary guidance - Supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs), 2019, Informal email group of professionals interested in incontinence in low- and middle- income countries (LMICs) <https://wash.leeds.ac.uk/wp-content/uploads/sites/45/2019/08/Four-pager_August_2019_Version_1.pdf>.

Lack of access to sufficient water for washing, and/or private facilities for laundering, drying and bathing

Make sure people with incontinence (or their carers) are part of consultations for siting, design and management of WASH facilities (for washing, drying and disposal), and for selection of incontinence items and materials.

Ensure that people have access to other items such as urine containers or potties (including for children who don't like or don't use latrines), waterproof mattress covers, extra soap, water, clothes and underwear, creams or oils to prevent bedsores etc.

Incontinence is not considered a need or priority, especially in emergency contexts, or it is argued to be 'someone else's responsibility'

Work to understand and document the scale of incontinence needs in the context you are working, who is affected etc.

Advocate for action and inclusion of incontinence into plans with other staff, management and external stakeholders.

Find out if there are any local initiatives or organisations working on incontinence that could provide support and advice.

Talk about incontinence with colleagues to raise awareness, and include incontinence into existing trainings for volunteers.





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Incontinence in the Red Cross Red Crescent: Who is involved?

Incontinence is often considered a medical issue or solely for health – however this is not correct. Incontinence is complex, and needs cannot adequately be addressed by one sector alone.

Effective coordination and working together not only within the RCRC, but with other local and specialist organisations, local authorities, and between sectors and clusters (e.g. Health and WASH) is key. In the RCRC context, the key sectors involved are⁹:

All sectors can

- Use the “[How to Talk About Incontinence: A Checklist](#)” to increase your understanding of incontinence, and the options available to support people living with it¹⁰
- Find out how to involve people and communicate with them about incontinence (including what the local term for it is), what are the barriers and establish different ways to get feedback from people suffering incontinence and/or their caretakers, supported by the CEA approach
- Include incontinence into existing training packages: make sure that all staff and volunteers are aware of incontinence (including ways of talking about it, or the local term for incontinence if one exists), trained and feel confident to listen to community members and share their feedback with others
- Include questions around incontinence in vulnerability and KAP assessments
- Coordinate with other teams and sectors on how to most effectively support people with incontinence, even in acute emergencies - focus on referral mechanisms to identify people with incontinence, information and items/WASH facility support

⁹ Rosato-Scott and others.

¹⁰ Claire Rosato-Scott, Dani J. Barrington, Amita Bhakta, and others, ‘How to Talk About Incontinence: A Checklist’, 2020 <<https://doi.org/10.19088/SLH.2020.006>>.

Takes the lead on



Water, sanitation and hygiene (WASH)

- Facilitate access to accessible, safe, private and culturally and age-appropriate WASH facilities – including for the changing/washing/drying/disposal of incontinence pads, clothes and bedsheets, and washing of the body
- Provision of appropriate hygiene items for incontinence (either in-kind or through CVA) with adequate quantity to allow for washing, drying or changing day and night
- Promote good hygiene behaviours related to the management of urine and faeces (e.g. handwashing with soap and disposal into a latrine) and management of soiled pads (both re-usable and disposable)
- Give people with incontinence and their caregivers a voice in decision making for WASH facilities and support; and monitor the support
- Training and support WASH/hygiene promotion volunteers to build their capacity and confidence in talking about and addressing incontinence



Health

- Provide advice and training for people living with incontinence, their caregivers, traditional birth attendants, health care staff and WASH practitioners - on how to manage incontinence and how to detect and treat injury to the skin, pressure sores and infections
- Include incontinence into routine health screening questionnaires, as a way to identify people with incontinence who may seek health for another issue
- Provide diagnosis, treatment and advice for incontinence that meets people's needs, for example, access to therapy or rehabilitation (including ante- and post-natal), access to medical equipment and training in their safe use (e.g., catheters and urine bags) and items (e.g. pads or commodes), or access to medicines (e.g. to reduce constipation or diarrhoea)
- Stock incontinence materials at health facilities.



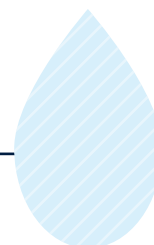
Mental health (MH) and psycho-social support (PSS)

- Provide appropriate support to people and families affected by incontinence, to improve well-being, esteem and inclusion
- Provide appropriate mental health support and treatment, for those who suffer incontinence as a consequence of trauma, or who suffer due to their inability to manage their incontinence with dignity
- Support WASH and other sectors to identify people with incontinence
- Support people with incontinence and their caregivers to link up with other sectors for support (e.g. provide referrals for incontinence items, or health services), and follow up to check that effective support has been received



Protection, gender and inclusion (PGI)

- Be aware of protection risks (including sexual and gender based violence, or SGBV) to those with incontinence (including children) in specific contexts and connect them to service providers and support organisations
- Support WASH and other sectors with identifying people who may have incontinence, and sensitive approaches to discussing incontinence
- Support with developing child-friendly education and training materials around incontinence and information for parents, guardians and teachers



Volunteers and incontinence: What is their role and what do we need to think about?

Community-based volunteers are the foundation and the heart of any RCRC action, and can be involved with engaging and communicating with women, girls, men and boys on incontinence, including their needs, preferences, practices and challenges. In addition, volunteers will be involved in identifying people with incontinence including people with disabilities, older people, and minority or vulnerable groups and including them in decision making as part of programming (e.g. design and siting of WASH facilities) so that it meets their specific needs.

Community-based volunteers often have a close connection and direct contact with communities through their activities, such as group discussions (e.g. planning improvements to sanitation or collecting feedback on WASH facilities), community events (e.g. drama and songs to communicate health messages) or house-to-house visits (e.g. providing support and referral to those in need).

These are opportunities for listening and for community members to provide feedback; for example if a person with incontinence (or caregiver of a child with incontinence) has sufficient access to water to meet their needs or not, or if they have challenges with accessing sanitation and washing facilities. Volunteers can collect simple data to monitor progress and inform future activities and projects.

It is important that information coming from different volunteers (e.g. hygiene promoters, psychosocial support volunteers, and volunteers working in community health) and their actions are coordinated and aligned. Volunteers can play an important role in the monitoring of and minimising stigma around incontinence in their communities – by beginning to normalise it as a topic for discussion and support.

Volunteers may also assist with distributions (in-kind or using cash and voucher assistance) of incontinence items and materials, including training and sharing information, and can be an important first step in the referral pathway by directing people with incontinence to health and support services (e.g. emergency or local clinic, including sexual and reproductive health, or in case of a disclosure of violence).

Volunteers should be aware of incontinence (including the local term for it, which may not always be clear in all languages), trained and feel confident to listen to community members and share their feedback (e.g. if a person tells the volunteer they need adult diapers, or have a challenge accessing distributions due to their incontinence/ personal hygiene).

WASH practitioners have a key responsibility to support people living with incontinence, as without appropriate WASH, people living with incontinence are likely to not be able to live with dignity and can lead to much more serious consequences.

Where can I find more information?

- [Incontinence: We Need to Talk About Leaks](#) and [How to Talk About Incontinence: A Checklist](#) (The Sanitation Learning Hub; 2020)
- [Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts \(LMICs\)](#) (LMIC Incontinence email group, University of Leeds; 2019)
- [Incontinence and WASH webpage¹¹](#), including key resources, case studies, and information about current projects in humanitarian and development settings
- [Incontinence webinar \(recording\)](#), Global Hygiene Promotion Technical Working Group speaker series (2022)

For further information, contact: Alexandra Machado, WASH in Public Health Senior Officer (alexandra.machado@ifrc.org) or the IFRC Global WASH team (wash.geneva@ifrc.org).

11 Webpage hosted on behalf of the informal LMIC incontinence email group by the University of Leeds