

Shared value:

Self-management of incontinence







Introduction

This report highlights how well-functioning continence care benefit the society as a whole and the value that self-management of incontinence creates. This is a value that individuals, care organizations, companies and society as a whole can benefit from. This shared value can only be created by integrating the efforts from many actors in the care system, as well as companies providing products and services, and policy makers setting priorities, policies and defining regulations. This value benefiting many actors is the shared value.

A prioritized aim in any health care system should be to help people with incontinence to become continent. Incontinence is a widespread set of diseases, affecting over 400 million people around the globe¹. To put this number into context, if incontinence was a country, it would be the third largest in the world.

Managing incontinence can take up a significant part of any society's resources, whether it is the person living with incontinence managing their own situation, if it is carried out by relatives, or provided by care organizations.

This document is produced by Essity with input and modelling from the organization Leading Health Care Foundation² and written for the benefit of leaders designing, overseeing and making decisions in the health and social care system. With a holistic view of the implications of incontinence and the benefits surrounding self-management, this report aims at illustrating what shared value is and provides actionable insights and concrete opportunities that exist for future improvement and lead to societal shared value.

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Self-management

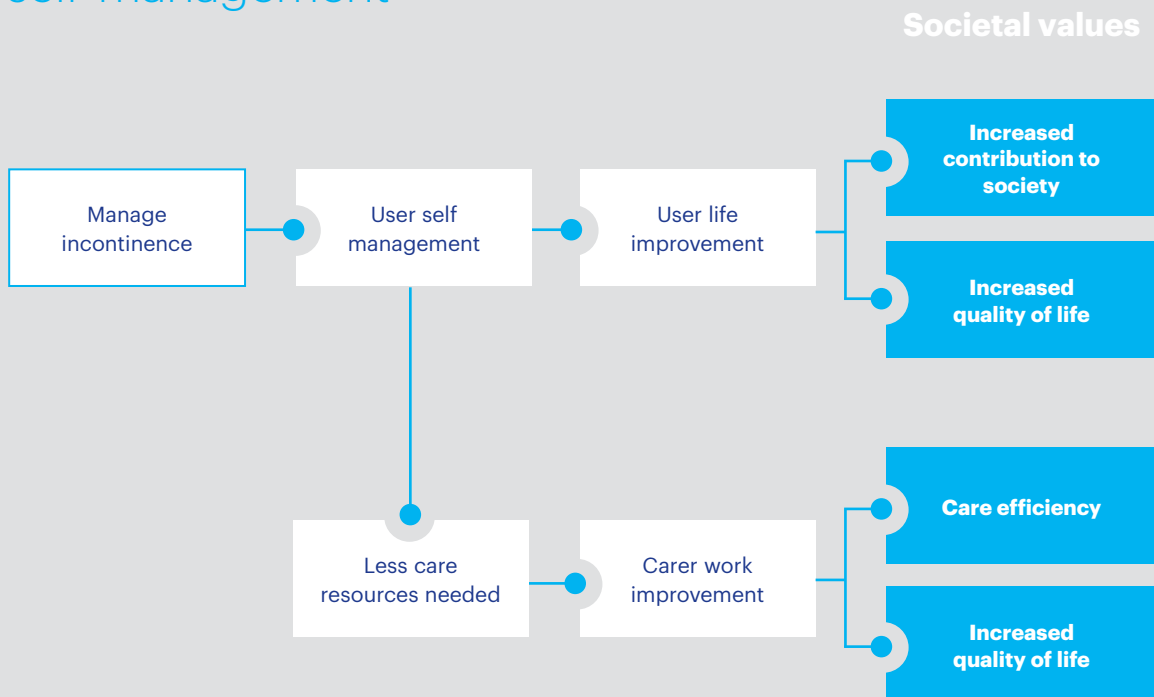
is a way to increase individual and societal values

Most individuals with incontinence do not find a cure – for them, incontinence is a chronic condition that must be managed daily. This means that the implications on everyday life are substantial for many people living with this condition, and so it is for the professional caregivers and caregiving relatives supporting them.

Individuals with incontinence who are able to manage situations on their own, e.g. by managing their toilet visits and incontinence products, can live a more independent and dignified life, improving their well-being, as well as taking part in, or contributing more to society.

In addition, less care resources are needed from professional caregivers and caregiving relatives, which improves both their well-being and the efficiency of the care. Therefore, societal values are financial as well as social, due to increased contributions to society and increased well-being for incontinent persons and their caregivers.

The financial and social values of self-management



What do we mean by shared value?

Shared value is the results of innovation, decision-making, education and experiences carried out in many parts of the health and social care system. These actions do not have a single source, as there are many contributors involved. Together these create a shared value and positive impact on society as a whole.

It is through an efficient and effective integration of products and services, competences and practices that daily continence care works well.

Likewise, it is through efficient and effective care planning and care execution systems that continence care works well on a structural level.

By having systems in place, health care staff with the required competences and products with the features optimal for each individual are made available.

Through existing policies, regulations and prioritization of resources supporting a well-functioning continence care system, individual people, as well as health and social care organizations are enabled to ensure the best outcome related to continence care.

All of the above elements impact the lives of people and care organizations involved, an impact that in addition to the individual and organizational values also creates societal values.

Example: the role of absorbing incontinence products

Core value

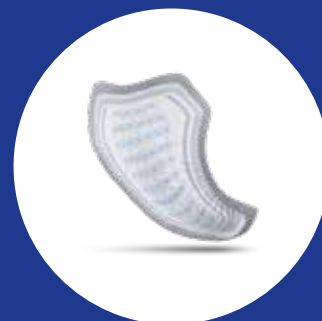
The core value of absorbing products is related to how the products enable the user to live an independent and dignified daily life – creating well-being.

Added value

The added value is related to the impact that daily continence care – using products and related routines – as well as toileting, has on caregivers and care organizations and related stakeholders.

Shared value

Shared value concerns societal value created by the impact of well-functioning daily continence care and continence care organizations. It is a spinoff of the use of the products and related practices. Its beneficiaries are not directly related to continence care, but to the context where it exists. Shared value is for example created when people are able to stay independent and continue to live at home, not needing to be institutionalized. This leads not only to individual benefits but also to benefits for society by freeing up resources or reducing costs.



Incontinence: a common condition

Around the world, incontinence leads to social challenges, as well as a high need for resources in service delivery by means of professional caregivers, caregiving relatives, and products. One of the most common types of incontinence is urinary incontinence and this affects women (30-60% >40 years old) more than men (3-11% >40 years old). Unfortunately, 50% of individuals with incontinence are not seeking help due to reasons such as the misinterpretation of symptoms, misbeliefs or even shame.³ This intensifies the need for better transparency surrounding the benefits of self-management.

In some countries around the world, the impact of incontinence on a national scale is proving to be very costly for society. For example, in Sweden, half a million people have incontinence, but it is estimated that only 20-50% of individuals with incontinence problems seek care.⁴ Incontinence is also one of the reasons why people cannot stay at home and instead have to move into nursing homes. In addition to the direct costs of formal care, secondary costs arise due to productivity losses of those with incontinence, as well as their caregivers. Evidence shows that the secondary costs of incontinence are one order of magnitude (ten times) higher than the care expenses.⁵

A global challenge. The impact of incontinence around the world

Sweden

The overall cost of incontinence care is 2.8-4.4 billion SEK a year, not including secondary costs.⁷

China

Incontinence reduces working people's productivity with 12.6 days/year on average. Relatives spend an estimated 3.7 h/week supporting people affected.⁸

USA

Costs for women over the age of 65 were more than twice the cost for those under 65 years (7.6 and 3.6 billion USD, respectively).⁹

Australia

In 2010, the total financial cost of incontinence (excluding burden of disease) was 42.9 billion AUD, or approximately 9,014 AUD per person with incontinence. As a secondary cost, productivity losses of family and friends who care for people with incontinence on an unpaid basis were around 2.7 billion AUD.⁶



50%

of individuals with incontinence are not seeking help

10x

The indirect costs of incontinence are ten times higher than the care expenses

Self-management

creating value for individuals and society

Regardless of whether individuals with incontinence require a caregiver or not, they should be supported to be able to handle their incontinence (managing toileting and changing products) as far as possible by themselves. This is down to three reasons: First, self-management leads to less dependency on others, increasing dignity and well-being for the individual. Secondly, individuals who are able to self-manage their incontinence are more likely to function better in social contexts (e.g. at work), thus increasing their contribution to society. Thirdly, self-management places fewer demands on society, both in terms of people with incontinence needing less assistance from caregiving relatives and professional caregivers, as well as delaying or even avoiding institutional care.

The implications of this need to be understood sometimes monetized to be able to prioritize this area and justify investments in products and services for supporting those living and dealing with incontinence. There is a strong indication that successful care that encourages self-management leads to improved well-being for the individual as well as for their relatives – care that has impact on many related areas and may generate significant societal value.

Self-management requires an awareness of the problem, and also an ability to access, select, and use suitable solutions. A study conducted by AGE Platform Europe in 2016 shows that patient knowledge and involvement, coupled with funding provisions based on individual patient needs, are key for enabling people living with

incontinence – and their caregivers – to live independent and dignified lives.¹⁰ The study highlights the following three success factors:

1. Information and knowledge about the different containment products available
2. Involvement in selecting the containment product type
3. Tailored funding provisions based on patient profiles and individual needs

The impact of self-management – social and economical

Effective continence care through self-management increases the shared value for all actors involved – it helps to improve not just the quality of life of those suffering from the disease and their relatives, but also positively impacts the use of available resources and the efficiency at point of care.

There are of course costs attached to providing continence care, practices, and products designed for enabling self-management, but these costs are significantly outweighed by the shared value provided to society. To understand the potential impact self-management can have in both social and economic terms read the case study on the next page.



Total potential savings per year in Sweden

1,392
MSEK PER YEAR

Creating shared value with self-management in Sweden

Background

The below overview of potential social and economic benefits related to self-management is based on the following assumptions and incontinence numbers in Sweden:¹¹

- Total number of incontinent individuals with daily incontinence: 335,000
- Independently managing their incontinence: 197,000
- Cared for by informal caregivers: 45,000
- Receiving public home care (>25 hours/week): 26,000
- Cared for in nursing homes: 66,000

Reduced need of public home care

The average cost of 1 hour of public home care is 472 SEK.¹² If 10% of the 26,000 individuals with daily incontinence who receive public home care (>25 hours/week) could manage with 1 hour less care per day – due to solutions that support self-management – municipalities would save 455 MSEK per year.

Delayed institutionalization

In nursing homes, approximately 80% of the residents have incontinence. Every year, approximately 20,000 persons move into nursing homes in Sweden.¹³ If 10% of these individuals with daily incontinence were to delay the transfer by three months, and instead use solutions that support self-management at home, municipalities would save 280 MSEK per year. If 50% of these individuals received public home care (>25 hours/week,)

additional costs (113 MSEK) would arise, but municipalities would still be able to save 167 MSEK per year.¹⁴

Reduced secondary costs

The productivity loss in Sweden, due to lower than average employment rate for incontinent individuals, is around 6,200 MSEK per year.¹⁵ The costs for informal care in Sweden are estimated to be 25,000 MSEK.¹⁶ Assuming that 10% of these costs are related to incontinence, then the costs of informal continence care are 2,500 MSEK. The total secondary costs added up total to 8,700 MSEK.

If 10% of the secondary costs related to productivity losses and informal continence care could be reduced through better self-management, this would result in savings of 870 MSEK per year. Summarizing the reduced cost for need of public home care (455 MSEK), delayed institutionalization (167 MSEK), secondary costs (870 MSEK) comes to 1,492 MSEK in reduced costs.

Total potential savings

The total cost of incontinence products is approximately 1,000 MSEK per year.¹⁷ If the investment in using better products and services that encourage and support self-management is 10% (100 MSEK), then taking into account all the savings detailed above, we would achieve a saving of 1,492 MSEK with an investment of 100 MSEK. Or expressed differently, this would result in total potential savings of 1,392 MSEK per year.

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Essity creates shared value and quality of life by breaking taboos, developing solutions for continence care and doing this through partnerships.



Essity's contributions towards self-management

At Essity, we are working every day to develop and integrate solutions to liberate people from a world affected by incontinence. We have a lot of experience and knowledge, because we have been in the market for more than 50 years.

The essence of self-management takes the patients' and care givers' perspective as the starting point. Essity has been a part of driving an improved continence care, where self-management is a key aspect:

- Through cooperations in all areas of the health and social care system, together with health care professionals, managers, purchasers, policy makers and politicians to raise standards of care
- By expanding the solutions offered in the form of information, services (training, routines and support tools) and continuously improved safe and high-quality products for continence care. Products and services developed with a strong sustainability agenda that lowers the environmental impact and increases the social contribution and economic value
- Through measuring and communicating the impact of the efforts; financially, socially and environmentally

With this approach, we can create shared value.

Essity has a role to develop products and services and make them available – supporting the development of the overall continence care system and its stakeholders at the same time.

For a successful self-management approach, individuals affected by incontinence require awareness of the problem on a general level, through education and information. They also require access to appropriate products, services and care systems that can support them. Below is an overview of the initiatives in which Essity in partnership with others have contributed to improving continence care and self-management.

Creating awareness

Essity, together with key stakeholders within the international community of care experts, has developed a shared agenda for sustainable continence care. Essity has also collaborated with patient and caregiver organizations, academia and health care professionals to develop a shared and consistent vision and approach. An approach that positions the individual living and dealing with incontinence in the center and that suggests that all players within societies – from caregivers to policymakers – play a role in enabling them to live an independent and dignified life. The results of Essity's work in this area include multiple research papers supporting policymakers' challenging tasks to address the area of incontinence, as well as a global continence conference with a related educational and debate platform – the Global Forum on Incontinence (GFI). The shared agenda developed among key stakeholders has helped prioritize this area and given important answers to the why, what and how when addressing the issue of incontinence.



Normalizing the subject

Many different voices are needed to work on normalizing the subject of incontinence. Essity has consistently contributed through cooperation with non-governmental organizations, e.g. Sinoba and Nikola in Sweden, and in partnerships with specialists within, for example, urotherapy with a focus on needs and challenges.

Whether it is sharing personal stories via various channels, instructional videos on YouTube or providing information in conferences and publications, Essity has constantly aimed to normalize the subject of incontinence in their communication. The purpose has always been to make it easier for the individuals living and dealing with incontinence to talk about it with those who can help and receive information and advice.

Educating users

For individuals living and dealing with incontinence, having knowledge about self-managing incontinence is essential to improving their everyday independence, as well as quality of life. This also applies to caregivers – regardless of whether they are professionals or family members. Since successful self-management of incontinence requires an understanding of how and when to provide toileting support, as well as combination of the correct product type, size and absorption, Essity has provided training for health care professionals, ensuring the level of competence needed.

Responding to individual needs

The types, sizes and absorption levels of available incontinence products is wide and ensures theoretically the needs for each individual. However, the issue is to make the right solution available for the person in need. Individual needs are met with different solutions, which can be different types of products but sometimes toileting. Essity contributes to this through dialogue with public providers and payers to secure systems that encourage availability and free choice of products, while ensuring a cost-effective approach. The level of the individual, as well as organizational and societal value, is directly related to whether everyone can obtain incontinence products that meet their specific and everyday needs. This is a main focus for Essity – to develop these products, but the shared

value is only realized when the products are used, so they must be made available.

Providing technically advanced and superior products

Essity has more than 50 years of experience in developing incontinence products. The research and development center in Gothenburg is among the largest in the world. Since absorbing products are close to the body, worn by people with different needs and must be fitted – sometimes with the help of others – many aspects must be considered when developing products. Listening to patients, healthcare professional and other voices in continence care is a foundation of Essity's innovation and product development process. Essity has contributed to the development of an international standard (ISO 15621) that gives guidelines for evaluating absorbent incontinence products, and continuously considers the complex combination of user/patient, usage and product factors described when developing products. Incontinence products are medical devices and all aspects of the development strictly consider that the products are fit for their purpose and safe for the user – from ensuring safe and high-quality material to ensuring that user experiences are as expected.

Improving the care system with effective solutions

Person-centered continence care is a necessity to support self-management. Essity takes a holistic approach to continence care and provides a wide range of support, enabling caregivers to provide continence care that benefits the individual.

With TENA Solutions – an integrated offering with innovative products, best-practice care routines, tools, training and expert support – Essity provides a service that offers continence assessment and individual continence care plans for nursing home residents. The goal is to find the optimal product and continence routines based on each user's needs, which leads to optimal independency and dignity for toileting and management of incontinence products, while reducing costs and lowering the impact on the environment.

Global evaluations of TENA Solutions show that substantial improvements have been made in nursing homes: ¹⁸

47%

reduction in skin irritation

44%

time saved on incontinence related tasks²⁰

38%

less leakage outside the product

81%

of staff agree residents' wellbeing is improved

29%

lower incontinence related costs¹⁹

37%

less laundry

79%

of staff agree they have better care routines

31%

less waste



Example of Essity's work towards creating shared value:

TENA Identifi: Improved solutions for individualized care

- A sensor-based system for facilitating fact-based incontinence assessments
- Provides health care professionals with valuable information related to voiding patterns – used to individualize the product selection and care routines
- Supports facilitating self-management of toileting
- Has measurable positive impact e.g. in Sweden, the absorption level needed has been reduced by 23% and leakage outside the product with 61% ²¹



Looking ahead to shared value for individuals and society

Continence care should be seen as an investment, as good continence care frees up health care resources and creates shared value. But improving the possibility for self-management is not only a monetary issue. At the heart of it all is the quality of life for the individual and their caregiver, and the importance of making a continued and valuable everyday life in the ordinary home possible. Ultimately, a dignified life is something we all deserve.

A greater societal acknowledgement and awareness of self-management can enable leaders in health and social care, as well as those designing the system, to drive outcomes in continence care. Given the magnitude of the population affected by incontinence and the diversity of the group this can create a more positive outlook for patients, caregivers and health and social care systems and for society as a whole.

Provision of a broad and high-quality assortment will be key for sustaining and improving values in all parts of the continence care system – without availability for the individuals, the base for the value creation will be gone.

Incontinence products should be purchased considering the needs of individuals and all the various forms of value

involved in continence care. The procurement process should include cost, but also the value creation and effects on the total cost of care, along with the additional shared values created for society.

Caregivers and nurses must have the competence and support required to assess the needs of individuals and propose, test, evaluate and decide what products to use and related routines for products and toileting. The value of their knowledge and skills should be utilized to ensure a person-centered delivery of care where independence and dignity is the goal.

When the preconditions to do this are made available, along with a broad and high-quality assortment – in all phases of continence management – the effects will be invaluable to those living and dealing with incontinence as well as for society.

To succeed in sustaining and improving a complex area such as continence care, all parties involved need to work together and find sustainable solutions that will work in daily care, to ensure the values expressed in this document will become real. Societal values are shared values because we create them together and we will all benefit from it.



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This report examines how self-management in continence care creates a shared value of which individuals, care organizations, companies and societies will benefit.

The report draws attention to the fact that incontinence is a disease that affects more than 400 million people globally, leading to social challenges, as well as a high need for resources in service delivery by means of professional caregivers, caregiving relatives and products.

Self-management presents itself as an effective way of enabling the individuals with incontinence, as well as their caregivers, to live more independent and dignified lives, and thereby also creates value to society, the shared value. The case study from Sweden highlights the shared value of self-management, demonstrating how products that encourage self-management can reduce the need for public home care and delay the transfer to nursing homes. The report also provides an overview of the initiatives in which Essity, together with others has contributed to improving continence care and self-management.

This report recommends viewing continence care as an investment showing the values created through better possibilities to self-manage. Effective continence care leads to better and more dignified lives for the individuals affected by the disease, enabling them to be more confident and participate in society, as well as having an overall better utilization of available resources in health and social care thus creating shared value.