



THE STATE OF CAREGIVING: A SUMMARY LITERATURE REVIEW

OVERVIEW

Millions of people around the world do incredible work looking after loved ones every single day, and with ageing populations and health services struggling to adapt, a lot more of us will become family carers in some capacity in the coming years.

Becoming a carer is an incredibly rewarding role born out of love, but the journey is hard – there's no joy like it, no pain like it, no bond like it, there's no love like this.

With over 50 years' experience working with carers and their relatives, TENA understands what it takes to be a family carer. We have a responsibility to shine a light and encourage better support, so that carers can do the best job for their loved ones and feel supported.

The following report provides an overview of existing literature summarising the global state of caregiving, its large-scale impact on economies and the healthcare sector, and the impact of caring responsibilities on individuals to better understand the real-life challenges of family carers across the world.





1. GLOBAL SCALE OF CAREGIVING

Family carers are the world's largest workforce and come from every walk of life. We need the world to recognise everybody who cares for a loved one, especially those you wouldn't expect.

Looking after a loved one when they need care and support with a disability, mental health challenge, illness, chronic or terminal condition, or simply due to aging, can be the biggest privilege and there really is #NoLoveLikeIt. But taking on unpaid care responsibilities can also be a 'long-term commitment and time-consuming, taking a heavy toll on the carer's health and well-being'.¹

At TENA, our mission is to help the world recognise and support the many faces of caregiving and open the door to conversations about caregivers from all walks of life, shining a light on those who feel 'unseen'.



Across the globe, there are as many as up to 1 in 5 people* who care for a loved one.

It's important to note that there are different definitions of unpaid caregivers ranging from 'family carers', 'informal caregivers', 'close caregivers' or simply 'carers'. This means that data points across regions are difficult to compare as some individuals may be omitted depending on the precise definitions used.

EUROPE

In the UK, an unpaid caregiver is defined as someone who provides unpaid care to a family member, neighbour, friend, co-worker, or companion, including children, who need help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support (NHS England).

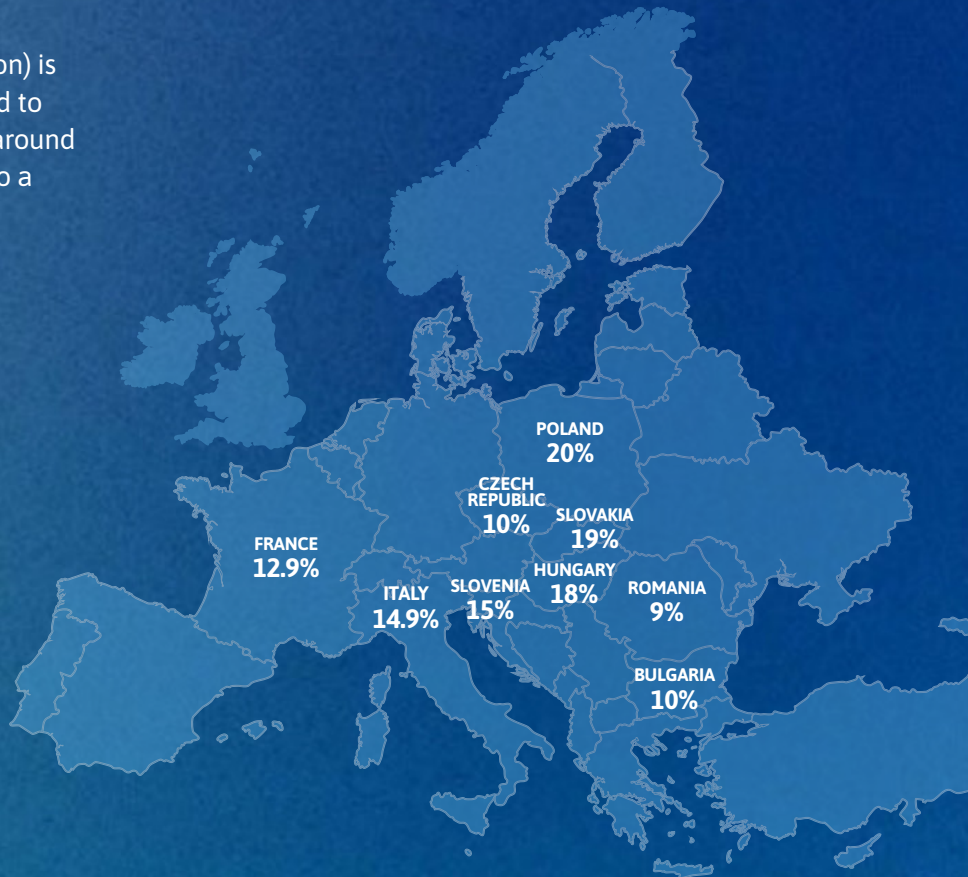
On average, around 52 million Europeans (14.4% of the population aged 18 to 74) provide informal long-term care to family members or friends on a weekly basis. When using full-time equivalents, informal carers account for close to 80% of care providers at EU level.² However, this figure is believed to be underestimating the true prevalence of unpaid informal caregiving as many family carers are hidden and not recognised.

There are approximately 13.6 million people in the UK, 26% of the population, who have informal caregiving roles,³ with around 800,000 of those being young people under the age of 25 years old.⁴

Figures are similar across other European countries.

In France, 12.9% of the population (8.3 million) is estimated to serve as unpaid carers (referred to most commonly as 'close caregivers'), with around 4.3 million providing regular care at home to a person over 60 years old.⁵

In Italy, 14.9% of the population are caregivers (7.5 million people) and 9% of adults in Romania provide informal care at least once a week (1.4 million people). This figure rises slightly to 10% (784,200 people) in Czech Republic, 10% (568,180 people) in Bulgaria, 15% (256,060 people) in Slovenia, 18% (1.4 million people) in Hungary, 19% (845,290 people) in Slovakia, and 20% (6.2 million people) in Poland.⁶



In Poland, the vast majority (93.5%) of all dependent elderly people receive care through an informal carer⁷, and according to the Centre for Supporting Informal Caregivers for Independent People⁸, 80% of unpaid carers are close relatives (children taking care of their parents or siblings), with around 70% of that care being provided by women.

In Germany, figures for unpaid caregivers are lower, making up just 6% of the population.⁹ However, it's estimated that one to two children in every German classroom have some sort of caregiving responsibilities.¹

This difference in statistics may be due to different definitions of unpaid caregivers being used in each country, meaning some people providing care may be excluded from overall numbers. In Germany, informal caregivers are defined in legislation as "people who provide non-professional home care to a person in need of long-term care due to a physical, mental or emotional illness or disability".¹⁰

While the scale of unpaid care givers varies across Europe some similarities are evident with women taking on most caregiving responsibilities across all countries.



Four out of five carers are women (81.4%), with the highest percentages in Estonia (90.7%) and Czechia (89.1%) and the lowest percentages in Sweden (77%) and Italy (79.6%).¹¹



**SWEDEN
22.7%
ARE MEN**

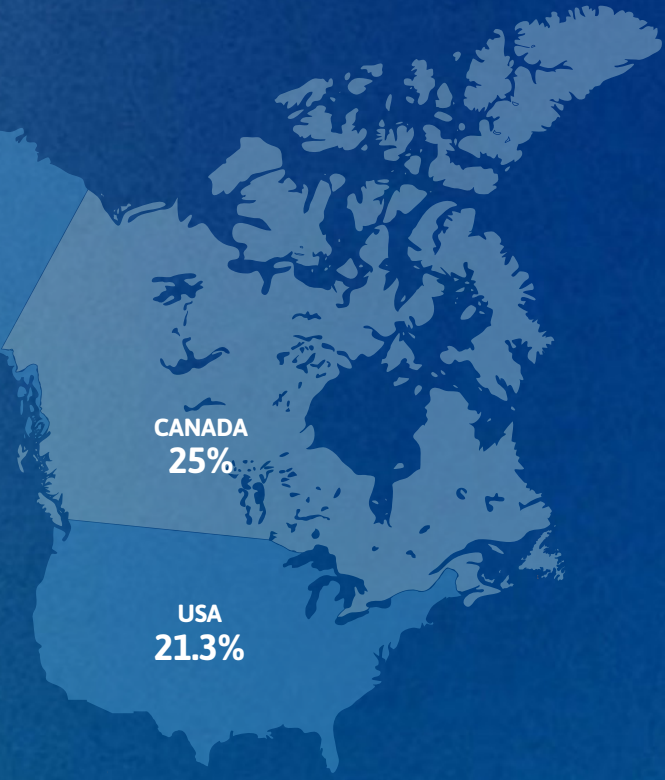
Men represent just 18.1%, with the highest percentage in Sweden (22.7%).¹⁰

USA & CANADA

In the USA the estimated number of unpaid caregivers stands at 56.4 million,¹ while some research estimates that one in five Americans (21.3%) have provided care to an adult or child with special needs in the past 12 months.¹²

Women dedicate three times as much time than men to unpaid care work,¹³ and it's estimated that 5.4 million children in the US provide unpaid care.¹⁴

In Canada, 8.1 million Canadians over the age of 15 are estimated to be serving as unpaid caregivers to family or friends,¹⁵ giving around 19 hours of care per week to family members or loved ones.¹⁶



2. IMPACT OF COVID-19 ON UNPAID CAREGIVERS

While the world was adapting to a new normal in 2020, the pandemic added another layer of challenges for unpaid caregivers as they stepped in to support loved ones, often for the first time. The pandemic had a negative impact on caregivers across the globe and many more people took on new caregiving responsibilities as health and social care systems struggled to keep up with the unprecedented need for care.

Across the globe, caregivers faced many challenges, with common themes of difficulties which were more or less evident depending on different countries. However, most caregivers felt the impact of the pandemic in the following areas.¹⁷



- Increasing care commitments
- Concerns related to COVID-19 (infecting those they care for)
- Availability of formal and informal support
- Carer health and well-being
- Carers' adaptability (many had to adapt, be more resilient and find a way through)

EUROPE

Across Europe, the average number of hours of informal care provided every week increased from 46.6 before the pandemic to 54.5 (+17%). During the pandemic, informal carers, especially women, had to intensify their caregiving activities.³

Women particularly felt the increase of their caregiving activities, providing emotional support (60.3%), remote communication (49.7%), practical help in person (43.9%), care coordination and support (43.7%), and help with transportation (37.7%). This took place in the context of reduced support from health and social services and the practical challenges posed by the COVID-19 outbreak.³



In the UK, the pandemic “exacerbated” an already worrying situation according to Joe Levenson, Executive Director for Policy and External Affairs at Carers Trust.¹⁸

Before the pandemic, around 17% of the UK population provided unpaid care, with this figure rising to 26%, the equivalent to one in four adults, since the outbreak began.³

An online survey of 5,000 current and former family carers in the UK conducted during the COVID-19 pandemic also found an overall increase in the time spent caring, with a large proportion (70%) providing more care due to the pandemic:

In Wales, it is estimated there are 196,000 new unpaid carers since the start of the pandemic, with four in five unpaid carers (81%) providing more care than before lockdown.¹⁹

In Northern Ireland, there are now more unpaid carers than before the COVID-19 pandemic began, with one in five (20%) adults now supporting a relative, close friend or neighbour because of chronic illness, including mental ill-health, dementia, disability, or older age.²⁰



USA & CANADA

In the United States, the COVID-19 pandemic heightened caregiving needs, forcing some into caregiving roles and disrupting others.²¹

Before the start of the pandemic, it was estimated that around 16% (40 million) of adults in the US were providing unpaid care to someone with care needs.¹⁶

Latest research shows that this figure has increased significantly, with an estimated 53 million adult carers and around 3.5 million carers under the age of 18-years old, today.¹

As evident globally, the COVID-19 outbreak has also exacerbated the gender impact of caregiving in the US by increasing women's economic and social insecurity, unpaid care work, and domestic violence rates, while cutting women off from crucial social and institutional support.²²

While women were already conducting the majority of the world's unpaid care work prior to the onset of the pandemic, emerging research suggests that the crisis and its subsequent lockdown response has resulted in a dramatic increase in this burden. It is likely that the negative impacts for women and families will last for years without proactive interventions.²³

A report published by the Centre for Disease Control and Prevention (CDC) states that 10,000 US adults surveyed during the pandemic, including unpaid caregivers of adults and parent-caregivers, had significantly worse mental health than adults not in these types of roles.



Parent caregivers handling both parent/guardian and adult-caregiving

roles, were 12 times more likely to experience the most extreme of adverse mental health symptoms including serious suicidal thoughts.²⁴



Two-thirds of survey respondents who identified as unpaid caregivers said they experienced mental health challenges during the pandemic, such as symptoms of anxiety or depression, or suicidal thoughts. Only one-third of people with no caregiving responsibilities reported the same symptoms.²⁵

In Canada, COVID-19 has had a negative impact on all family caregivers, whether the care receivers lived with the caregiver, in a separate community home, in supportive living, or in long-term care. Family caregivers felt the under-resourced care system delayed pandemic planning, and that silos in health and community systems made caregiving more difficult.²⁴

One study interviewing a group of caregivers in Canada highlighted that there was a mutual feeling among the group that communication with family caregivers was deficient in the pandemic.

Only 32% of the family caregivers had been asked by a healthcare provider how they were or about their caregiving responsibility, while several interview participants began to cry when asked how they were doing in the interviews, showing the real life impact a lack of support can have on them.²⁶

3. EMOTIONAL IMPACT OF UNPAID CAREGIVING

Anyone can become an unpaid carer, whether that's a child looking after a sibling with a disability, an elderly husband looking after his frail wife in later life, or a daughter taking on caring responsibilities for a parent with dementia while balancing family life simultaneously.

Everyone who takes on caring for a loved one has a different experience, and there is no one way to care or feel. People who care for a loved one do it out of love, but it's the emotional burden- and sometimes reward- coupled with the physical labour that makes being a family carer so unique. It's the uncertainty, loss, frustration, connection, disgust, shame, guilt, pride. TENA's mission is to not only showcase the breadth of caregivers, but also shine a light on the very real emotions and challenges caregivers face:



- Nearly half (47%) of unpaid carers have feelings of depression with almost 3 in 5 (57%) feeling that they needed medical care/support for a mental health condition (e.g., depression, anxiety, stress) due to their role as an unpaid carer. Of these a quarter (25%) have not sought medical help.²⁷
- More than half (55%) of unpaid carers feel that their physical health has suffered because of their carer duties.²⁶
- More than half (54%) of unpaid carers don't have time to book or attend medical appointments for themselves.²⁶

EUROPE

Carers UK's annual survey (2015) with over 5,000 carers across the UK, revealed that 84% of carers feel more stressed, 78% feel more anxious and 55% reported that they suffered from depression because of their caring role²⁸, compared to one in five of the UK general population.²⁹

In the UK, female caregivers report feeling more anxious, depressed, overworked, or ill because of their increased unpaid care work³⁰. In addition, three-quarters (72%) of carers reported they had no breaks at all since the first UK lockdown and 74% have said they are exhausted, because of caring.³¹

Specifically, women and men who provide care to parents experience important psychological well-being losses across Europe, especially when caregiving is intensive. A heavier caregiving burden associated with co-residence explains a regime gradient in depression, not least for women in Southern Europe.³²

Across France, Germany, Italy, Spain and the United Kingdom, caregivers versus non-caregivers also had significantly higher odds of depression, insomnia, headache and gastrointestinal symptoms, and worse health related quality of life.³



USA & CANADA

In the USA, symptoms of anxiety, depression, and suicidal ideation were more common among caregivers, with younger age and higher intensity associated with worse mental health symptoms.¹⁹

- A study in the USA evaluated the mental health risk to unpaid caregivers bereaved of a care recipient with the risk to persons otherwise bereaved and to nonbereaved caregivers. Both caregivers and bereaved individuals were estimated to be between 20% and 50% greater risk for mental health problems than non-caregivers in similar circumstances.³³
- Caregivers were also at risk for ill mental health while providing care and after the death of the care recipient.³²
- In Canada, a new analysis shows that more than one in three unpaid caregivers of individuals who receive home care experience distress — which can include feelings of anger or depression, or the inability to continue with caring activities.³⁴

4. SUPPORT OPTIONS

The data paints a worrying picture regarding the welfare of all caregivers and demonstrates a need for society, governments, and industries to come together to better support their incredible contributions.

But support options, such as measures to support carers' financial security and alleviate the pressure on personal finances from caring, vary across the globe.

EUROPE

Last year, EU President Ursula von der Leyen announced that the European Commission would put forward a new European Care Strategy as part of its Work Programme 2022 to support unpaid caregivers, stating "if the pandemic taught us one thing, it is that time is precious. And caring for someone you love is the most precious time of all. We will come forward with a new European Care Strategy to support men and women in finding the best care and the best life balance for them".³⁵

- In the UK, all carers are entitled to a carer's assessment from their local council. This could result in the carer, or the person they are caring for, being able to get additional help or support.³⁶
- Poland state financial aid includes a disability pension and a care allowance for the sick, as well as carer's allowance for the carer.³⁷
- In Russia, many carers do not use services provided by health and social services.³⁸



USA & CANADA

In the USA, unpaid carers can receive financial assistance, income or tax breaks that can reduce the burden of the cost of caregiving. These options are embedded in various government programs and tax incentives if certain qualifying criteria are met. Through the Kupuna Caregivers Act, Hawaii provides financial assistance to support employed carers to remain in the workforce.³⁹

In Canada, the Recognition Act sets out principles and actions for government and non-government agencies to support unpaid carers.⁴⁰



5. ECONOMIC IMPACT OF UNPAID CAREGIVING & CONTRIBUTIONS OF CAREGIVERS

It's crucial to recognise the immense contribution unpaid carers make to the functioning of societies across the world, even if they themselves and those they are caring for simply see themselves as a wife, husband, child, parent, family member, friend, or good neighbour.

Unpaid caregivers are one of the largest workforces, providing significant value to the functioning of societies and economies. However, too many unpaid caregivers are not recognised for their hard work and contributions.



Almost 3 in 10 (28%) of unpaid carers feel their role as a carer is unrecognized by their healthcare system.²⁶

People who provide unpaid care to a family member or loved one are often juggling their care duties alongside their own daily routines, including work, which can have a significant impact on their employment and finances:



30% of unpaid carers feel that their role of a carer has put pressure on their financial situation.²⁶

In the UK, young people aged 16 to 25 who provided care were less likely to be in employment, had lower earnings from paid employment compared to young people of the same age who were not providing care.⁴¹



In the USA, those who provide intensive care to a loved one are: ⁴²

- 13% less likely to be employed than non-caregivers
- 12% more likely to quit a job
- 6% more likely to take unpaid time off from work
- 5% more likely to retire early
- 4% more likely to cut back work hours
- 3% more likely to cut back on schooling

While unpaid caregivers are often negatively impacted financially by their care giving duties, anyone looking after a loved one is saving health and social care systems significant costs. Unpaid caregivers are stepping in to support family and loved ones with care needs that would otherwise have to be provided by a professional, paid carer, costing health and social care systems across the global significant amounts of money.



EUROPE



£132 billion per year

In the UK, it is estimated that carers save the economy £132 billion per year, an average of £19,336 per carer. ⁴³

There are around 100,000 new stroke cases and over a million people living with its consequences annually in the UK. Aggregate societal cost of stroke is £26 billion per year, including £8.6 billion for NHS and social care. The largest component of total cost was unpaid care (61%), which amounted to £16 billion per year.



72 billion hours

It is estimated that across 33 European countries, time devoted to unpaid care reached 72 billion hours in 2016. The economic value of that time is estimated at €576 billion, which represented about 3.63% of Europe's gross domestic product (GDP). ⁴⁴



USA & CANADA

In the US, it is estimated that caregivers provide the equivalent of approximately \$470 billion in unpaid assistance which is based on the average American caregivers' wage of \$13.81 per hour.⁴⁵

One study even suggest that the spending of care-related activities is as high as \$648 billion, making it a larger economy than pharmaceuticals.⁴⁴

In Canada, every year, unpaid caregivers are saving the economy an estimated \$24 to \$31 billion.⁴⁶

We know that 1 in 4 Canadians are providing unpaid care to a family member or friend. In 2018, there were over 7.8 million adult Canadian caregivers. Together they provided 5.7 billion hours of unpaid care. The "annual economic value of family care work is \$97.1 billion." This means that it would take 2.8 million full time equivalent workers to replace the unpaid hours provided by family.⁴⁷

6. FUTURE CHALLENGES/ SCALE OF CAREGIVERS

With an ageing population, unpaid care is increasing. It's important to understand these future projections on the state of caregiving and acknowledge the inevitable burden this will have on unpaid caregivers, to generate the right support and encourage accessibility of that support; ultimately providing better care for everyone, as most of us will provide some sort of care to a loved one at some point in our lives.



EUROPE

In the UK, unpaid care increased at a faster pace than population growth between 2001 and 2011. This combined with an ageing population with improved life expectancy for people with long term conditions or complex disabilities is resulting in more high-level care being provided for longer.⁴⁸

Carers UK estimates that we will see a 40% rise in the number of carers needed by 2037 – an extra 2.6 million carers. Every year, over 2.1 million adults become carers and almost as many people find that their caring responsibilities come to an end.⁴⁹

In France, the Directory for Research, Studies, Evaluation and Statistics (Direction de la recherche, des études, de l'évaluation et des statistiques / DREES) anticipates 25% of people in employment will assume caregiving responsibilities by 2030. A more recent study by Fondation April et BVA (2017) assessed the number of carers in France at 11million, meaning one in six people are providing daily assistance to a dependent person, because of old age, illness or disability.⁵⁰



USA & CANADA

Older Americans living in the community who need care and support with functional limitations overwhelmingly rely on unpaid care, which is often provided by working-age family members.

The current economic cost stood at \$67 billion and is expected to double to \$132–\$147 billion by 2050, fuelled primarily by a growing disabled older population and the increased share of better-educated caregivers.

Over the next 50 years the number of older Americans with disabilities is projected to double. The increase will be most prevalent among the oldest-old adults (people aged 80+), which will see numbers rise at a faster pace than any other age group, with their long-term services and support needs higher than the younger population.⁵¹

Between 2011 and 2031, it is estimated that Canada will see a two-fold increase in the number of people living with dementia. By 2031, the projected informal caregiving for those living with dementia in Canada is two billion hours per year and 100 hours per year per Canadian of working age. This increase in dementia is largely related to the expected increase in older Canadians, with projections sensitive to changes in the age of dementia onset.⁵²

7.) CONCLUSION

The global state of caregiving is a complex, yet important area to understand, not only for the welfare of those receiving support, but crucially, for those providing it.

This report not only depicts the sheer scale of the contributions of unpaid carers, but also demonstrates a need to do more to ensure they are given the recognition and support they deserve.

Millions of silent heroes work tirelessly to care for their family members, whether elderly, disabled or unwell, yet we also know millions are suffering as a result.

At TENA, we believe it's time for change. A time to help the world recognise the many faces of caregiving, so unpaid care givers can do the best job possible for their loved ones. Ultimately providing better care for everyone, because #ThereIsNoLoveLikeIt



* For the purpose of calculating an overall figure of global caregivers, we've used the following population figures:

- EU adult population – 285 million (52million caregivers = 18% caregivers)
- US adult population – 264 million (56.4 million caregivers = 21% caregivers)
- Canada adult population- 39 million (8.1 million caregivers= 21% caregivers)

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Notes to editors

For the purpose of calculating an overall figure of global caregivers, we've used the following population figures to arrive at 'as many as 1 in 5:

EU adult population – 285 million (52million caregivers = 18% caregivers)

US adult population – 264 million (56.4 million caregivers = 21% caregivers)

Canada adult population- 39 million (8.1 million caregivers= 21% caregivers)

Full EU country profiles for official caregiving numbers are available at EuroCarers <https://eurocarers.org/country-profiles/>

UK specific carer figures are available on Carers UK: <https://www.carersuk.org/>

About Essity

Essity is a leading global hygiene and health company that develops, produces and sells Personal Care (Baby Care, Feminine Care, Incontinence Products and Medical Solutions), Consumer Tissue and Professional Hygiene products and solutions. Our vision is; dedicated to improving well-being through leading hygiene and health solutions. Sales are conducted in approximately 150 countries under many strong brands, including the leading global brands TENA and Tork, and other brands, such as Leukoplast, Libero, Libresse, Lotus, Nosotras, Saba, Tempo, Vinda and Zewa. Essity has about 48,000 employees and net sales in 2016 amounted to approximately SEK 101bn (EUR 10.7bn). The business operations are based on a sustainable business model with focus on value creation for people and nature. The company has its headquarters in Stockholm, Sweden, and is listed on Nasdaq Stockholm. Essity used to be part of the SCA Group. More information at www.essity.com.

About TENA

TENA is a brand of Essity, a leading global hygiene and health company. With over 60 years of experience TENA is the No 1 adult incontinence brand globally*. We offer a full range of absorbent products, skincare and digital health technology solutions that are tailored to the needs of individuals, their families and healthcare professionals.

With TENA, Essity is at the forefront of developing products and services that help improve dignity and the quality of people's lives. Our products reduce our carbon footprint, step by step, we're not just protecting people, but the planet too.

*Euromonitor International Limited; Retail Adult Incontinence, all channels, RSP value sales, Tissue & Hygiene, 2020 edition.