



# THE NGO COMMITTEE ON AGEING

## BUILDING A SOCIETY FOR ALL AGES



### Welcome to the October 2024 Issue of the UN NGO Committee on Ageing/NY Newsletter

#### What's in this issue?

Our newsletter this issue is focused on Caregiving, which is the theme of this year's U.N. International Day of Older Persons (UNIDOP), to be observed at the United Nations in New York on Monday, October 7<sup>th</sup>, from 10 a.m.—1 p.m. The NGO Committee on Ageing in New York organizes this annual event with sponsorship and support from the Programme on Ageing at UN DESA (Department of Economic and Social Affairs)

The date for In-Person-registration at the U.N. International Day of Older Persons has passed, but if you have not already registered, we hope you will watch and listen to our program on U.N. WebTV <http://webtv.un.org> from 10 a.m.-1 p.m. on October 7<sup>th</sup>. It will also be available on YouTube, and shortly after the program, the recording will be available on our website: <https://ngocoa-ny.org>.

Whether you join us in person or watch us on the web, you will enjoy the pieces in this issue that provide both information on the state of Caregiving in the world and inspiration to work for greater support of caregivers.

In this issue, our chair, William Smith, leads us in a celebration of caregivers. Maud Bruce-About's, *Deeper Dive* gives us a lot of information about the financial benefits to society and costs to providers of so-called informal or unpaid care, along with the shortage of formal caregivers and insufficient public investment in care for older persons.

Adriane Berg, in *Words That Are Trending*, follows the inroads and challenges of caregiving programs and policies in several countries, including the USA, Vietnam, and Sweden.

We welcome a new contributor to this issue, Imran Ali, M.D., a practicing geriatrician at Mt. Sinai Hospital in New York, who urges us to help spread the word about the need for more caregiver support across the world to address the "caregiver crisis."

**Martha Bial, PhD, editor, Communications Chair of NGO CoA-NY, UN Representative, International Association of Gerontology and Geriatrics (IAGG)**

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## **From The Chair of the NGO CoA**

This issue will focus on the noble and important work of Caregivers. It is truly a special calling.

At some point in our lives, we may be summoned to perform this important service to a loved one, a friend, or a neighbor. It is important work. We know that much of Long-Term Care is provided through formal structures like nursing homes, hospices, home, and community-based services, and often with the support of acute care facilities and professionals.

Yet, our healthcare system works best when integrated with the informal support systems, like family members, friends, and neighbors. Many countries rely on this informal service to meet the growing needs of individuals, especially as they age through the years. Yet even in developed countries with mature healthcare systems, day-to-day personal care for those with chronic disabilities is frequently unavailable or unaffordable as a paid service.

As a caregiver for many years, I know the importance of this exceedingly difficult work. I know that it is an awesome responsibility, that training is often lacking in some regard so that many caregivers have to "learn on the fly." Rest assured, the presence of these individuals on a consistent basis can make all the difference.

This newsletter will cover many aspects of the critical role of the Care Giver. Make sure that each of you who knows an individual in this role takes the time to acknowledge them and thank them for this tireless service.

***William T. Smith, Ph.D., Chair, NGO Committee on Ageing/NY, lead UN representative Global Ageing Network***

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## **International Day of Older Persons: The Caregiver Focus**

***Imran Ali MD, MS, MPH, NGOCOA-NY Communications Committee, Assistant Clinical Professor, Icahn School of Medicine at Mount Sinai, Medical Contributor ABC News 8 Good Morning Connecticut***



This International Day of Older Persons, we focus on the larger picture; we focus on dignity and community. Caregivers not only support the dignity of

older persons in need of care, but they contribute positively to the social fabric of their communities. Governments and cultures shape the ways that care is given, but all societies are strengthened by the rich connections among and between caregivers and care recipients.

Sarah in Brisbane, Australia, may approach caring for her older aunt differently than Abdullah in Doha, who cares for his aging father. However, the common thread that binds communities worldwide is the shared experience of dealing with Caregiving's emotional, physical, and sometimes unrecognized logistical challenges.

At this year's commemoration of the 34th International Day of Older Persons at the United Nations, the focus lies on what improvements at the systemic level exist to address the essential lack of resources to help older adults age with dignity. While reducing health inequity is one of the United Nations Sustainable Developmental Goals, little attention has been paid to what some call the "Caregiver Crisis." This crisis not only centers on the family unit but also broader resources, such as the lack of direct care workers in long-term care facilities around the world.

Dr. Jennifer Olson, who chairs the Rosalynn Carter Foundation, which focuses on Caregiving, spoke with me about how the Caregiver Crisis was identified back in 2010. Although there has been some considerable progress, there is still much to do to ensure that resources are in place for families. In all our professional and personal interactions, we can help to promote greater societal awareness of the need for support structures at a human level.

It's not just about acknowledging the problem but about taking responsibility and being part of the solution. Chronic disease and functional decline cannot be eliminated entirely. Still, the adverse effects, especially on the older person's dignity, can be mitigated. As Josh Carter is expected to speak at this year's event at the U.N., he is going to highlight the fact that the need is not just country specific.

While some Westernized countries talk about the need for caregiver support, in many countries, it becomes a challenge that stays within the family that society and government do not see a need to address. Another component of Caregiving most likely highlighted at this year's International Day of Older Persons is the emotional toll it takes on the aging spouse or an adult child. Actor Bradley Cooper helped produce a documentary that will be screened at the event highlighting the emotional role reversal. The guilt of not being able to meet the needs of work and children and, most of all, self-care doesn't have to be ignored and not discussed.

The United Nations is committed to strengthening communities and, for the most part, supporting caregivers, and having the infrastructure in place is essential to ensure that the rights of older adults and their caregivers are upheld. From an economic standpoint, we can now see that relying on family caregivers may not be feasible in all circumstances. Robust home-based care or long-term care must be available so that older adults can thrive with dignity,

The simple day-to-day tasks that society takes for granted are affected by aging and inevitable physiological and psychological decline. It is time for not only families and healthcare providers but also policymakers and entrepreneurs to come together to address the challenges that lie ahead. Policymakers play a crucial role in shaping the healthcare system and social policies that affect older persons and their caregivers. Entrepreneurs can bring

fresh perspectives and innovative solutions to the table. This International Day of Older Persons promises to inspire and encourage innovation in the support infrastructures that are essential to maintaining the dignity of the world's ever-increasing demographic. By working together, we can create a more supportive and inclusive society for older persons and their caregivers.



## **Deeper Dive: Caregiving in the Context of the Rights of Older Persons**

***By Maud Bruce-About, UN Representative, International Federation of the Association of Older People (FIAPA), Chair NGO CoA Subcommittee on Older Women***

This article focuses on care for older persons in the context of the upcoming **2024 UNIDOP** (U.N. International Day of the Older Person ) **themed: "Ageing with Dignity: The Importance of Strengthening Care and Support Systems for Older Persons Worldwide."**

Before honing in on the specificities of care of older persons, we will outline Caregiving and care receiving, in general, to contextualize and frame Caregiving within the rubric of the [Strategic Development Goals](#) and the very recent **U.N. System Policy paper** on the Care Sector.

**The starting point of the [U.N. System Policy paper](#) is that everyone will need to give care, be a care recipient at some point in their lifetime, or both.**

Therefore, *"care systems are fundamental for all persons, in all their diversity, to participate equally in society and enjoy the fulfillment of their rights."* As a result, care should be human rights-based; the accountability of each state; universal; transformative; non-discriminatory, and pro-gender equality so that policy addresses the structural barriers of inequality to leave no one behind.

### **The current situation:**

**What you might already know:** The paid, professional care sector employs 381 million persons worldwide, corresponding to 11,5 % of total employment.

**What may surprise you:** Unpaid care work is estimated to oscillate between 2 percent and 41 percent of Gross Domestic Product (GDP) by country, the median being 10 percent), and some estimate its value to be US\$10.8 trillion annually.

**What you might have seen around you** is that caregivers are primarily women and girls who are both employed in paid care professions and have unpaid care responsibilities within their families.

- Women contribute an average of 4 hours and 25 minutes of unpaid household/care work per day, compared to 1 hour and 23 minutes for men.

- Two-thirds of the workers in the paid care sector are women - healthcare, childcare, disability care, aged care, education, and paid domestic work - the majority being migrant workers.

**It remains unrecognized that caregiving** work limits the ability to seize other opportunities or constrains women to accepting low-paid and less secure jobs, leading to deprivation and insufficient life course savings, pensions, and public entitlements, in turn, leading to old age poverty and incapacity to pay for health care and other care needs.

**It is often also overlooked (particularly by policymakers)** that economic, social, and humanitarian crises force women and girls into domestic work. During the COVID-19 pandemic, 90 percent of the 647 million persons who ceased paid work to care for their families were women.

**Compounding** the difficulty women face, paid care work suffers from a lack of rights, protections, and benefits, low compensation, low unionization, and high exposure to physical and mental stress, violence, and harassment. Ninety percent of domestic workers have no social security.

In fact, many gender-based stereotypes, such as "caregiving is unskilled" or a "natural" or "traditional" role for women, result in low status, compensation, and representation of those in care professions.

**To redress this situation - improve conditions, integrate carers in the formal economy - and promote care as a growth sector to attain the SDGs, the Policy paper and the SDG Agenda advocate for:**

- Greater investments,
- A change in how economic models value and compensate for care work,
- That care system respects the human rights and needs of both caregivers and care recipients.

**As for older persons, the [U.N. Decade of Healthy Ageing](#) envisions a world in which all people live long and healthy lives and recognizes the right to the highest attainable standard of health of older people.**

Still, [across developed and developing countries](#), long-term care suffers from a lack of policymaker attention, low budgets, and inattention to the regulation of service providers and other issues mentioned earlier. To worsen the situation, care demand for older persons is increasing fast as care models that rely primarily on families increasingly become inadequate. Intergenerational co-residence is declining in both developed and developing countries due to urbanisation and development in general as world population continues to age.

### **Longevity and Caregiving Needs**

As reported in earlier newsletters, globally the number of persons aged 65 years or more will reach 1.6 billion and account for 16 percent of the world population in 2050, meaning that one in six people you meet will be aged sixty-five or older, compared to one in 11 today.

Although societies age at different paces, all societies' populations are ageing and experiencing growing longevity. Currently, longevity is the furthest advanced in Europe, Northern America, Australia, New Zealand, and most of Eastern and South-Eastern Asia, with the proportion of older persons exceeding 10 to 20 % of the total population.



Most other parts of Sub-Saharan Africa and Oceania are still in an early stage of this transition, while most countries in Central and Southern Asia, Western Asia and Northern Africa, Latin America, and the Caribbean are at an intermediate stage.

Hence, according to the [World Social Report](#), the geography of the world's oldest countries will shift from Europe towards Eastern and South-Eastern Asia between now and 2050, when the latter is expected to include five of the ten oldest populations. Among regions, Northern Africa, Western Asia, and Sub-Saharan Africa are expected to experience the fastest growth in the number of older people over the next three decades.

In developed nations, [Life Expectancy at birth is 73 today, although varying between affluent and under-resourced](#) areas within and between countries - and is set to rise to 77 in 2050 when one in six people will be 65+.

### **Current research indicates that longevity has equally positive and concerning aspects.**

The noted increase in life expectancy and good functional health is positive, as it means that future elders will be healthier, better educated, and more productive, given sufficient investment in health, education, and anti-ageist measures.

The equally noted increase in the number of years lived in bad health or [with disabilities reported in the same research is a concern](#) - especially as the report concomitantly points to the risk of future increased income disparity with possible "widening disparities in health and life expectancy among future cohorts of older persons," as it points to increased care needs."

As the [World Social](#) report points out, with a longer life comes non-communicable disease and disability, diabetes, visual or hearing issues, depression, dementia, etc., often one in conjunction with the other. Hence, there is a need for increased support for those with chronic care issues. For instance, it is estimated that the share of the population in need of care in Japan will increase from 8,3% in 2020 to 14,4% in 2065.

### **What is needed now:**

With high-quality care and support from primary to acute to end-of-life care that respects different health conditions and needs, older persons can live independently with dignity and choice, personal safety, and the opportunity to participate in their communities.

Interestingly, the World Social report refers to "*Ageing in Place*" - the ability to live in one's home regardless of age, income, and capacity and "*Ageing in the Right Place*," the ability to live in the place the most suited to a person's needs and preferences - hence, not necessarily at home. According to the report, availability, accessibility, cultural beliefs and financials, disease profile, and living arrangements - in reality - influence the form of care, either at home or in institutions.

According to the OECD, "*Many people receiving LTC wish to remain at home for as long as possible.*" In alignment with this wish, countries increasingly promote community and home care. Hence, between 2011 and 2021, OECD countries reduced the number of LTC beds in facilities by an average of 4,7 beds per one thousand people aged sixty-five or above, with the number of beds per thousand now averaging forty-six.

## The COVID-19 wakeup call:

The COVID-19 pandemic severely affected LTC residents. Across 25 OECD countries, 40% of pandemic deaths were among residents, and containment measures – visitation bans – affected the well-being of many residents.

Most important however - whether care is given at home or in institutions, with the latter being either public or private— carers are needed for the system to work, and that is where we fall short.

Already in 2015, there was [a shortage of 13,6 million formal care workers across all regions](#). Obviously, immigrants and informal carers fill part of the gap. According to OECD statistics, [one in eight persons above 50 across 25 OECD countries provide informal care](#).

Furthermore, because of overall societal ageing, one would expect that public spending as a share of GDP would increase. Still, among OECD countries, spending on formal care was capped at just above 1% from 2016 to 2020. This obviously leads to caregiver shortages and high out-of-pocket expenditures that not all can afford.

**These issues will undoubtedly be elaborated and discussed at the 2024 New York UNIDOP. Don't miss the opportunity to learn more!!**

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## Words that Are Trending: Caregiving in an International Framework

***By Adriane Berg, Representative to the United Nations from the International Federation on Ageing, Board Member of The U.N. Global NGO Executive Committee (GNEC), and Host of On The Ground, the podcast of GNEC.ngo***



In recent decades, the global landscape of aging has undergone a profound transformation. Longevity is increasing worldwide, even in underserved and developing nations where healthcare advancements are slowly catching up with the demographic shift. This shift is particularly notable among those aged eighty-five and older, a demographic that is growing in size and importance in societies across the globe.

In countries like Japan, the United States, and several European nations, the population aged eighty-five and older has been steadily rising, with projections indicating continued growth in the coming decades. While increased longevity reflects advancements in healthcare and lifestyle changes that contribute to longer life spans, with increased longevity comes a parallel increase in age-related chronic illnesses that require Caregiving.

Conditions such as Parkinson's disease, Alzheimer's dementia, and the inability to perform activities of daily living are becoming more prevalent among the elderly population. Traditionally, Caregiving for these conditions has largely been shouldered by families. However, the burden is becoming overwhelming

as longer life spans mean longer periods of chronic illness that demand care and support.

## **The Need for National and Global Support**

The evolving landscape of Caregiving necessitates a shift towards national and global support systems. While familial Caregiving remains crucial, it cannot be the sole solution in the face of increasing demand. Governments and healthcare systems worldwide must step in to provide adequate resources, infrastructure, and policies that support both caregivers and those in need of care. This includes ensuring access to affordable healthcare, respite care options for caregivers, and support services that address the complex needs of individuals with chronic illnesses.

## **Longevity Equality: A Holistic Approach to Aging**

While addressing caregiving needs is crucial, it is equally important to consider the broader concept of "longevity equality." This involves ensuring that everyone, regardless of age or socioeconomic status, has access to the lifestyle factors that promote healthy aging and prevent the onset of debilitating illnesses. Key factors include access to nutritious food, opportunities for regular physical activity, social companionship, a sense of purpose in life, and timely medical interventions.

In many societies, a sizable portion of the aging population enjoys relatively good health and independence well into old age. These individuals have benefited from advancements in healthcare, lifestyle choices, and social support systems that enable them to lead fulfilling lives without the need for extensive Caregiving.

## **Looking Ahead: Balancing Caregiving Needs and Longevity Equality**

One of the cornerstones of longevity equality is promoting healthy aging through proactive measures. This includes:

**Nutrition and Physical Activity:** Encouraging access to nutritious food and opportunities for regular physical activity can significantly impact overall health and reduce the risk of chronic illnesses that often require Caregiving.

**Social Engagement:** Facilitating social connections and community involvement can combat loneliness and isolation, which are detrimental to mental and physical health as individuals age.

**Purposeful Living:** Supporting opportunities for older adults to engage in meaningful activities, such as volunteering or mentoring, fosters a sense of purpose and contributes to overall well-being.

**Access to Healthcare:** Ensuring equitable access to healthcare services, including preventive care and timely medical interventions, is crucial for managing chronic conditions and promoting healthy aging.

## **Addressing Disparities**

While some older adults enjoy robust health and independence, others face significant barriers that contribute to disparities in longevity and quality of life. These disparities may be influenced by factors such as socioeconomic status, geographic location, and access to healthcare. Addressing these disparities requires targeted interventions and policies that prioritize equity in health outcomes across diverse populations.



## **Building Resilient Communities**

Creating resilient communities that support aging populations involves collaboration across sectors, including healthcare, social services, urban planning, and public policy. These efforts can include:

**Age-Friendly Cities:** Designing urban environments that are accessible and supportive of older adults, with features such as accessible transportation, safe outdoor spaces, and housing options that cater to diverse needs.

**Caregiver Support:** Implementing policies that support caregivers, including respite care options, caregiver training programs, and financial assistance to alleviate the burden of caregiving responsibilities.

**Technology and Innovation:** Harnessing technological advancements, such as telemedicine and assistive devices, to enhance healthcare delivery and improve the quality of life for older adults.

## **Global Collaboration**

Achieving longevity equality requires a global commitment to sharing knowledge, resources, and best practices across borders. International collaborations can foster innovation in aging research, healthcare delivery models, and policy development aimed at supporting aging populations worldwide.

## **The Role of Family Caregivers**

Family caregivers play an essential role in managing the day-to-day needs of individuals with chronic illnesses. This care often includes administering medication, assisting with daily activities such as bathing and eating, coordinating medical appointments, and providing emotional support. The burden on family caregivers can be immense, leading to physical, emotional, and financial stress. In many societies, this caregiving role is traditionally taken up by women, though this is gradually changing.

## **United States: A Growing Crisis**

In the United States, family caregiving for chronic illnesses is becoming increasingly common as the population ages. Approximately fifty-three million Americans are unpaid caregivers, with many of them providing care for aging parents or spouses. The U.S. healthcare system, while advanced in many respects, places significant pressure on families to manage chronic care at home. Medicare and Medicaid provide some support, but coverage is often limited, and navigating the healthcare bureaucracy can be overwhelming.

Many U.S. caregivers face financial hardships, as they may have to reduce their work hours or leave their jobs entirely to care for a loved one. This situation is exacerbated by the rising costs of healthcare and long-term care facilities, making it difficult for families to afford professional help. The emotional toll is also substantial, with caregivers experiencing higher rates of depression and anxiety compared to the general population.

## **Japan: Balancing Tradition and Modernity**

Japan, with one of the oldest populations in the world, faces significant challenges in chronic care. Traditionally, caregiving in Japan has been the responsibility of the family, particularly women. However, the rapidly aging population has led to a shift in this dynamic. The Japanese government has

recognized the unsustainability of relying solely on family caregivers and has implemented the Long-Term Care Insurance (LTCI) system to provide support.

Under LTCI, citizens aged forty and older pay into a system that, upon reaching a certain age or level of disability, provides access to various caregiving services. This system has alleviated some of the burdens on family caregivers by offering professional home care services, nursing facilities, and respite care. However, cultural expectations still weigh heavily on family members, particularly women, to provide care, creating a delicate balance between traditional and modern support systems.

### **Italy: The Family as a Pillar of Care**

In Italy, the family is considered the cornerstone of Caregiving for individuals with chronic illnesses. Italian culture places a strong emphasis on family ties, and it is common for multiple generations to live together or near each other, facilitating caregiving roles. This close-knit family structure means that professional caregiving services are less commonly used, and the state provides limited formal support.

However, the strain on family caregivers in Italy is growing, particularly as the population ages and the prevalence of chronic diseases increases. The economic crisis has also impacted the ability of families to provide care, with many caregivers struggling to balance work and caregiving responsibilities. The Italian government has begun to acknowledge these challenges, introducing some financial support measures, but the reliance on family care remains predominant.

### **Sweden: A Comprehensive Support System**

In contrast to the more family-centric approaches seen in countries like Italy and Japan, Sweden offers a comprehensive national support system for caregivers. The Swedish welfare state provides extensive services for individuals with chronic illnesses, including home care, daycare centers, and residential facilities. These services are heavily subsidized by the government, reducing the burden on family caregivers.

Swedish law also recognizes the rights of caregivers, offering financial compensation and support services to those who choose to care for a family member at home. This approach allows caregivers to maintain a balance between their caregiving responsibilities and personal lives, reducing the emotional and financial stress commonly associated with Caregiving. Sweden's model demonstrates the potential for a more balanced approach to Caregiving, where family members are supported by a robust social safety net.

### **Vietnam's Innovative Approach to Caregiving: Older Adults Helping Each Other**

As Vietnam experiences a rapid demographic shift with an increasing older population, the country faces significant challenges in providing adequate care for its aging citizens. According to the World Bank, the proportion of people aged sixty and over in Vietnam is expected to rise from 12.5% in 2019 to around 25% by 2050. This shift brings with it an increase in chronic health conditions and a growing need for long-term care.

In response, Vietnam has implemented an innovative program that enlists older adults to help care for one another, fostering a community-based approach to Caregiving that is both sustainable and culturally resonant.

## **The Mutual Care Model: A Community-Based Solution**

Vietnam has developed a program that leverages the strength and solidarity of its older population. Known as the "Intergenerational Self-Help Club" (ISHC) model, this initiative promotes mutual caregiving among the elderly. The idea is simple yet effective: older adults within a community come together to support each other, providing care, companionship, and assistance with daily activities.

The ISHC model operates on the principle of mutual aid, where members of the club—typically older individuals themselves—volunteer their time and skills to help fellow seniors who may be more vulnerable or in need of assistance. This could involve helping with grocery shopping, cooking, cleaning, or simply providing companionship and emotional support. The program also encourages health promotion activities, such as regular exercise, disease prevention education, and home visits by trained health volunteers.

### **Government and NGO Support**

The success of the ISHC model is bolstered by support from both the government and non-governmental organizations (NGOs). The Vietnam Association of the Elderly (VAE) plays a key role in promoting and organizing these clubs, with support from various NGOs that provide training, resources, and financial assistance. The government, recognizing the potential of this grassroots approach, has also integrated the ISHC model into its broader strategy for elderly care.

In addition to the direct care provided by club members, the ISHCs often serve as a platform for older adults to advocate for their rights and access to services. They work closely with local authorities to ensure that elderly citizens receive the benefits they are entitled to, such as healthcare, social security, and housing support.

### **Benefits of the ISHC Model**

The ISHC model offers numerous benefits, both for the individuals involved and for the wider community. For the elderly who participate, it provides a sense of purpose and belonging, as well as the opportunity to remain active and engaged in their community. It also helps to alleviate the social isolation that many older adults experience, particularly in rural areas where access to services and social networks may be limited.

For the wider community, the ISHC model reduces the burden on formal healthcare systems and families. By empowering older adults to take care of one another, the program fosters resilience within communities and reduces the need for costly institutional care. Moreover, it aligns with Vietnam's cultural values of mutual support and collective responsibility, making it a socially accepted and sustainable approach to care.

However, urbanization and the changing dynamics of family life in cities pose unique challenges, and the ISHC model will need to be adapted to address these differences.

### **Conclusion**

Family caregiving for chronic illnesses presents a complex challenge that varies significantly across nations. While cultural expectations and social norms continue to shape caregiving practices, there is a growing recognition of the need for national support systems to alleviate the burden on family caregivers.

As populations age and the prevalence of chronic diseases increases, it is crucial for governments to implement policies that support both caregivers and those in need of care. Balancing the demands of Caregiving with the need for family well-being requires a multifaceted approach, incorporating cultural sensitivity, economic support, and access to healthcare services.

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**Thank you for reading this issue of our newsletter. We welcome any feedback! Feel free to drop us a line [here](#).**

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To discover more about how you can be part of the dialogue and the solutions, visit [ngocoa-ny.org/participate](http://ngocoa-ny.org/participate)

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