



Care must empower us throughout our lives
Our views on change in care and support for older people



AGE Platform Europe
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Why this paper?

The impacts of the COVID-19 pandemic on older people in need of care have triggered more attention to the care sector and greater political interest. Yet, a financial focus on the costs of care and a tendency to think only of the short term are prevalent in policy responses.

What if we looked at care with new lenses? What if we looked at all the opportunities better care can offer? What if care was actually a great opportunity to seize?

Discussions need to embrace the lived realities of those in need of care, as well as their expectations and wishes. Thus, we need to discuss the future of care without avoiding the key questions:

What is our collective vision for care in older age?

What is the level of ambition we are willing to set collectively for the development of care policies and services?

The upcoming launch of a European Care Strategy in 2022 makes them more relevant than ever.

The aim of this policy brief is to put forward AGE Platform Europe's vision for change in care.

AGE members have their say: Our Re-thinking Care process

Throughout 2021, we organised a series of four workshops with our members to discuss the change we want to see in care in Europe. The process involved 60 individuals from AGE member organisations in 18 European countries. Participants had a diversity of backgrounds and profiles: many are self-advocates who draw their views from their own personal experiences of ageing and care or past professional experiences, whereas others are working professionally in advocacy or in services for older people. They participated in at least one of the workshops, more often in several or all of them. Each workshop included group discussions addressing the key aspects of a process of change:

- Workshop 1 addressed the status quo in care: what AGE members like and dislike about care systems.
- Workshop 2 identified our shared vision for care: what care should help people achieve.
- Workshop 3 focused on the changes that are needed to achieve our vision of care: what steps will be needed in policies, services and at societal level to materialize change.
- Workshop 4 discussed the role of the advocacy work of organisations of older people: how we can play our part to make sure change happens.

This paper is the result of the views shared in these workshops. It also reflects the views shared by AGE members in our Task Force on Dignified Ageing, a working group that contributes to specifically shaping our work on care for older people.

As the voice of older people in Europe, **we call for care systems that empower each of us and support us to remain full members of society, no matter our age.**

This brief begins with an overview of the status quo in care today. It then presents AGE's vision of care, and the changes that are needed to materialise it. We end with a reflection on the role the European Care Strategy can play to trigger ambitious care reforms.



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Care today: some **positive** aspects, many gaps

Europe's care systems have positive aspects we recognise, including committed care workers and dedicated informal carers, who play a key role in delivering support – often in difficult circumstances. Yet, older people with care and support needs still experience serious shortfalls that need to be addressed, including:

Do you want to develop great care? Tackle ageism

Ageism is, according to the World Health Organization, “the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age”. Ageism is far from anecdotal: 42 % of Europeans perceive discrimination due to old age (being over 55 years old) as “very” or “fairly” widespread in their country^{Error! Bookmark not defined.}.

Ageism is pervasive in all aspects of older people's lives, and that includes care and support. It fuels a society where people have unequal worth depending on their age; thus, it explains why European political systems and societies have overlooked the situations of inequality experienced by older people in need of care and support and allowed these to exist for a long time. The lack of respect for older people's equal right to autonomy, physical and mental integrity, rehabilitation, independent living and choice has been widely documented during^{Error! Bookmark not defined.} the COVID-19 pandemic, but it was previously already pervasive.

Ending ageism and affirming the full equality of everyone regardless of age or care needs is the precondition to fully and effectively address the structural shortcomings in care systems. Addressing the prejudices, stereotypes and discriminatory practices towards older people, in policymaking, in services and in societal attitudes, is key to imagining and implementing care systems

- **Ageism**^{1,2,3} in care policies and services, which is a cross-cutting challenge and is intrinsically linked to **poor quality** driven by paternalistic practices, lack of involvement of older people in making decisions about their own care and the scarcity of rehabilitation and prevention as part of care systems and services.
- **Lack of or insufficient access.** According to 2014 data, only 1 in 3 older people with severe difficulties in activities of everyday life had access to care services at home in the EU; in 2019, 47.2% of people over 65 who needed help with their personal care and household activities reported a lack of services. Financial reasons are reportedly the main obstacle. The costs of care would put the majority of older people in the EU at risk of poverty if social protection did not intervene – and many experience poverty even after receiving financial support⁴.
- **Organisational issues**, including lack of coordination between health and social care, staff shortages, insufficient funding and administrative barriers in accessing support^{5,6}.

¹ Our work on human rights and ageism is available in our [website](#).

² Definition of [ageism](#) by the World Health Organization.

³ “Shifting perceptions: towards a rights-based approach to ageing”, [report](#) of the Fundamental Rights Agency (FRA), 2018

⁴ “2021 Long-term care report”, [report](#) by the European Union

⁵ Amnesty International's [work](#) on the impacts of COVID-19 on care for older people in Spain, 2020

⁶ “We have the same rights”, [research](#) by ENNHRI (European Network of National Human Rights Institutions), 2017

For change to happen, a sustained long-term vision is essential

The greater political and societal focus on care because of the COVID-19 pandemic is an opportunity for wide debates around building better care systems and more equal societies. **Public debates on the reforms needed should be guided by a long-term vision, capable of inspiring action beyond short-term considerations.**

Yet, in the aftermath of the first wave of the COVID-19 pandemic, this is precisely what we have witnessed across Europe: a tendency to adopt sketchy policy responses driven by short-term emergencies. Some debates have emerged around the need to medicalise care homes or have focused only on ensuring preparedness for future pandemics⁷. Yet, long-term care systems in Europe do not need patches: they require systemic responses capable of addressing decades of inadequate care services and practices. They must be driven by a clear vision for the future.

Overall, the views of older people with care and support needs have most often been overlooked in debates. Yet, a rights-based approach to care and support involves, first and foremost, listening to older people and representative organisations and enabling a true societal debate to define the direction reforms should take.

Our members think of the future

In Spain, in 2020, the presidents of our members of the Spanish Confederation of Older People's Organisations (CEOMA) and the Democratic Union of Pensioners (UDP) endorsed an open manifesto calling for a new care model for older people. In [Ante la crisis de COVID-19: una oportunidad para un mundo mejor](#) (In the face of the COVID-19 crisis: an opportunity for a better world), signatories call for care to focus on home and to "eradicate the institutional model". The manifesto devotes one part specifically to the impacts of ageism and calls for action to fight it.

The Pensioners' Association of Austria (PVÖ) actively takes part in public debates around care reform. In their paper [Flege > Zukunft > Österreich!](#) (Care > Future > Austria!), PVÖ calls for the inclusion of care as a right enshrined in the Austrian constitution. They call on affordable and quality care for all, with a strong focus on prevention throughout individuals lives. They propose a vision that is holistic, and call for more support for home care and innovative housing solutions.

⁷ Our [analysis](#) of the impacts of COVID-19 on older people's rights is available in our website, as is our [views](#) on recovery from the pandemic.



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Care tomorrow: a solution that empowers

Care does not concern only older people. **Every individual needs care from the moment of birth** – and everyone should therefore enjoy the same rights in the care context at all stages. Differences in personal preferences and the kind and intensity of support people need do exist – and so within all age groups. Adopting a **life-course perspective** to care is therefore key to shape new care systems that enable everyone to enjoy the same rights⁸.

What care should enable us do

It is high time to raise the level of our demands around care and support in older age so that equality becomes a reality for everyone.

We believe that care should support everyone to **participate, be included in society and continue doing the variety of things we like**, on an equal footing with others and at all stages of life. This involves having a voice and being free to make choices (self-determination). Care should respond to people’s diverse needs and support people to live well, not just safer or in better health.



Care as a metaphorical tool according to participants to our Re-thinking Care process

If care services are capable of supporting people to do what they aspire to, they will ensure people are free, autonomous and independent – in one word, **empowered**. They will help people be part of our communities and able to continue contributing to them, as equal members of society whose voices count and are heard. Having access to care services is not the goal per se; empowering people to remain free, autonomous and independent is.

⁸ Our [contribution](#) to the consultation on the Green Paper on Ageing in 2021 and our [call](#) for a new EU Age Equality Strategy build the case for a life-course approach in policies.

In sum,

Care empowers.

Care supports and enables inclusion and participation.

As we receive care we feel better.

**Care supports us to remain included in the community,
contribute to society and participate.**

Getting there: the change we need to see

Moving from the current status quo to a Europe where care empowers will require **substantial change and continued efforts**. This change will involve new or reformed policies, services and societal attitudes, at local, regional, national and European levels.

The **matrix** on next page summarises our analysis: current status quo, identified key actions at all those levels and outcomes needed to achieve our vision of care. It is a dynamic **map** that can be used by stakeholders to:

- **Understand** the key components of a care system that empowers.
- **Steer progress** of care systems towards the realisation of our vision.
- **Plan** their own actions to make positive steps happen and steer their own progress.

This matrix is a living tool available for all stakeholders, which all can adapt and complete for their own use⁹.

⁹ If you wish to receive an editable format of this matrix to be able to adapt it to your own work and context, please contact AGE Platform Europe.



Status quo	Pathway		Vision
	Policies / services / societal changes	The outcomes we need	
Older people in need of care often lack access to services. Services may exist far from the community, only in institutional settings and/or be unaffordable.	<p>Public and regular monitoring of access to services, across the territory</p> <p>Adequate public funding and investments for care services</p> <p>Improvement of working conditions in care – including training – to increase the attractiveness of the sector and the quality of services</p> <p>Development and improvement of social protection for care, including continuous monitoring of the costs of care for different needs and income levels after social protection</p> <p>Specific policies and funding that enable the transition to home and community-based care</p> <p>Quality monitoring systems that put the focus on qualitative dimensions and on the quality of life of people</p>	<p>Care is accessible. It is available in the community and affordable for everyone, both in urban and in rural areas.</p>	<p>Care empowers.</p> <p>Care supports and enables inclusion and participation.</p> <p>When we receive care we feel better.</p> <p>We can remain included in the community, contribute to society and participate.</p>
Social stigma around care needs and disability is prevalent. Ageism and ableism are widespread and have strong impacts on older people in need of care. Care for older people is not prioritized in policy or in society.	<p>Education programmes to combat ageism and ableism in compulsory education and lifelong learning; also, in training for health and social care professionals</p> <p>Public campaigns to end ageism and ableism</p>	<p>Care needs and disability are socially accepted and prioritized. There is a shift in mindsets to full social acceptance of care needs as inherent to all stages of the life cycle.</p>	
Care services put safety and organisational needs above the wellbeing of people in need of care. They fail to respect people's needs and decisions.	<p>Care professionals have a continuous, meaningful and timely dialogue with people in need of care so that services are organised around the care decisions expressed by them.</p> <p>Care services adapt to the changing needs of individuals.</p> <p>Care regulations – laws, policies, protocols in services – promote autonomy; they make safety compatible with autonomy and independent living.</p>	<p>Care services are person-centred. They respect and contribute to realise people's aspirations and preferences. People receiving care are empowered and informed to make autonomous decisions around care and daily life.</p>	
Health and social care work in an uncoordinated manner. Budgets, means and objectives are defined in silos. People in need of care struggle to understand the care ecosystem.	<p>People can access in timely manner all care services needed, ranging from health to social care and including palliative care</p> <p>A care plan to help health and social care services coordinate; they exchange information continuously</p> <p>Informal carers to be involved in the design of the care plan. They receive psycho-social support and training</p> <p>Health and social care authorities and all services work under a shared strategic planning: policies and budgets for health and social care are coordinated and pursue shared goals</p>	<p>Care is integrated. All health and social care services and professionals coordinate smoothly. Informal carers are involved and supported.</p>	
Care systems fail to prevent the deterioration of physical and mental capacities. Care practices sometimes aggravate such deterioration. Care policies target separately different age groups.	<p>Prevention and rehabilitation are core topics of the curricula and missions of health and social care workers</p> <p>Government programmes, funding schemes and service management pay specific attention to and create incentives for prevention and rehabilitation</p> <p>Elimination of practices that aggravate physical and cognitive decline, including restrains and inadequate medication prescribing</p> <p>Health and care policies integrate fully a life-course approach, thus demonstrating and enabling the prevention of care needs.</p>	<p>Care services ensure prevention and rehabilitation. Care policies have a life-course approach.</p>	
Physical and digital environments are not accessible for everyone. They hinder equal participation and inclusion.	<p>Policies and funding enable the adaptation of housing, transportation and outdoor spaces to make them accessible</p> <p>Accessibility criteria are enforced in all digital services</p>	<p>Communities are adapted to enable everyone to participate. The physical and digital environments are accessible for everyone.</p>	

The European Care Strategy: an opportunity to trigger change

The European Care Strategy, foreseen for 2022, can be an impactful tool to materialise many of the key changes identified above.

The Strategy can be a wake-up call to EU Member States to act and implement decisive changes in care. Whereas care is mainly a national competence, the EU can influence agendas and provide guidance on many of the policy, service-level and societal changes required.

An ambitious Strategy can produce positive impacts at two levels:

- 1) By putting forward an ambitious frame, data, evidence and a strong case for investments in care, the Strategy can trigger **a positive dynamic in which States converge upwards**. Peer reviewing, sharing of good practices and EU policy guidance can encourage States to **emulate** each other's practices and policies.
- 2) By including concrete flagships, objectives and a strong monitoring framework, it can **empower civil society and social partners** as key stakeholders to guide care reforms and steer progress.

What do we propose for the European Care Strategy?

The European Care Strategy must build a positive and compelling case for reform and investments in care, based on **a life-course approach** and the opportunities that better care systems offer to European societies. It should build on the approach to long-term care as a right, as proclaimed in the European Pillar of Social Rights.

- The Strategy should propose **indicators on access to professional care and support services** (measured in terms of met/unmet needs reported by people themselves), and also access targets. These should be disaggregated according to care settings, so as to monitor progress in improving access to home and community-based care, as mandated by principle 18 of the European Pillar of Social Rights.
- The Strategy should propose actions to build a shared understanding of quality of care and support across Europe. This should include a **European Quality Framework**, aligned with and linked to the European Quality Framework for social services of excellence for persons with disabilities announced for 2024 in the Strategy for the Rights of Persons with Disabilities 2021-2030.
- The EU should support and orientate long-term care reform in member states through the development of further **guidance, research and peer reviewing** on key aspects of care systems, including: the transition towards community-based care, social protection for care, integrated care, palliative and end-of-life care, the use of new technologies and support to informal carers.
- The Commission should develop a **repository of promising practices in long-term care** to inspire reforms and facilitate exchanges across Europe, with civil society involvement in both selection and evaluation.
- The Strategy should also launch a permanent **EU-level platform on care** composed of civil society-organisations to support and monitor implementation.

An ambitious EU Care Strategy should be anchored in the **European Pillar of Social Rights**¹⁰. This means that the Strategy should affirm **care of good quality as a social right** everyone should enjoy – and this includes implicitly the need to adopt a life-course perspective to care. In line with Pillar provisions, the Strategy should focus on making progress on access to home and community-based services.

It is indispensable that the Strategy is fully coherent with other EU policies, such as the **Strategy for the Rights of Persons with Disabilities 2021-2030**¹¹. This involves cross-referencing the provisions on care, social services and independent living to ensure both Strategies have the same level of ambition. There can be no different standards: **everyone must enjoy the same standard of care and support regardless of their age and disability.**

Older people raise their voices for care reform

In Denmark, our member Ældre Sagen has launched the campaign [Værdig ældrepleje NU!](#) (Dignified care for older people NOW!). The online campaign, which includes a [video](#), calls on coordinated professionals, support for socialization and participation and good personal care as key elements of dignified care.

The Slovenian Federation of Pensioners' Associations (ZDUS) has been actively involved in long-term care reform in the country. Influencing has included direct work with Parliament, including via the submission of [critical comments](#) and [amendments](#) to the reform under consideration.

The French Confederation of Retirees (CFR) has actively contributed to the reflections of the French government on care reform. Our member organisation has [called](#) on the care system to enable ageing at home, with an emphasis on prevention and the development of intermediary care settings. It calls on the meaningful involvement of older people in the reform process.

¹⁰ Read our [views](#) on the implementation of the European Pillar of Social Rights.

¹¹ See our [reaction](#) to the Strategy for the Rights of Persons with Disabilities 2021-2030.

The way forward

We have before us the opportunity to learn from the shortfalls of care systems exposed by the COVID-19 pandemic. The crisis has proven the need to build a society where receiving support allows to unlock the potential of a growing part of the population.

Let's join forces to make it happen.

To know more, check out our resources:

- Our [toolkit](#) on dignity and wellbeing of older people in need of care offers evidence and key arguments for service providers and policymakers to change care systems.
- Our work on COVID-19 includes a [paper](#) on the impacts on the human rights of older people, a [paper](#) on the recovery from the pandemic. A new report will be issued early 2022.
- Our [work](#) on human rights in older age challenges ageism and puts forward proposals for a society for all ages.
- Our [Ageing Equal](#) campaign highlights the impacts of ageism on older people's lives and calls for action to ensure equality across the life-course.

For more information

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