



English language

CHARTER OF RIGHTS OF ELDERLY PEOPLE AND DUTIES OF THE COMMUNITY



Monsignor Vincenzo Paglia

Charter of the rights of elderly people and community duties

By the Commission for the reform of health and social care for the elderly population, Ministry of Health

- Monsignor Vincenzo Paglia, President
- Prof. Leonardo Palombi, Secretary
- Prof. Mario Barbagallo
- Signora Edith Bruck
- Dr. Velia Bruno
- Prof. Silvio Brusaferro
- Dr. Maite Carpio
- Prof. Giampiero Dalla Zuanna
- Prof. Paola Di Giulio
- Prof.ssa Nerina Dirindin
- Dr. Simonetta Agnello Hornby
- Prof. Giuseppe Liotta
- Prof. Alessandro Pan
- Dr. Gianni Rezza
- Dr. Andrea Urbani
- Prof. Paolo Vineis

Index

Introduction

Why a charter of the rights of the elderly and the duties of the community

The context

The right to protection of the dignity of the elderly person

The rights to responsible assistance

The right to an active relationship life

Conclusions

The charter of rights of elderly people and the duties of the community

Preamble

Card value

1. For Respect for the Dignity of the Person even in the Third Age
2. For responsible assistance
3. For an active life of relationships

Stories

Introduction

When in September 2020 Minister Speranza appointed the Commission for the reform of health and social care for the elderly population, the epidemiological picture of the Covid 19 pandemic was dark and full of unknowns. Above all, the worrying observation that dominated at a global level was that the elderly, particularly those in residential facilities, represented the main victims of the disease. In nursing homes, retirement homes and RSAs, a real massacre was taking place, aggravated by the conditions of isolation in which the sick lived and, unfortunately, died. Therefore, it is also a tragedy for families, children and grandchildren who would not have been able to see and hug their loved ones again due to the separation imposed in these environments.

A new approach was needed and a new look at that age of life which everyone now reaches, a happy but challenging goal of human progress and development of the last two centuries. For this reason it was decided, in tackling the program of a radical reform of assistance, to start from a review and enunciation of the principles for the defense of the rights and for the respect due to the elderly - a population now well above 20% of the population. total in Italy and Europe, but growing everywhere in the world.

Hence the need to write the Charter of the rights of the elderly and of the duties of the community, so that all generations could find themselves in an alliance for a future guaranteed in dignity and future services which we will all arrive at tomorrow, even today's young people. The Charter had to inspire the reform and had to become, in our intentions, the cultural, political and programmatic vehicle for a radical paradigm shift, which placed the elderly at the center of social and collective life.

For this reason it was placed at the beginning of the entire substantial document produced by the Speranza Commission and delivered to President Draghi in September 2021. Furthermore, it was a question of proposing to the entire society, to all generations, their duties so that the rights of the elderly. Hence the union, in the title, of "rights" with "duties". The Charter, also in this respect, wants to inspire a new way of conceiving society in an articulated way between generations. The prime minister, on that occasion, declared: "The work carried out by the Commission is extraordinary" stated President Draghi. "This is - he added - an initiative of enormous social and ethical importance. Italy must guarantee the rights of the elderly, respect for the dignity of the person, in all conditions. Social and health care must be adequate and responsible. Therefore the Government will support the intervention proposal presented today."

In fact, in the following months, the Commission for policies in favor of the elderly population was born, chaired by the Undersecretary to the Presidency of the Council Garofoli, with headquarters in Palazzo Chigi, in order to give substance and concreteness to the proposed reform. The reform is inspired by the principles of the Charter and aims to involve young people and all generations in a battle that restores a new dimension to living as an elderly person in respect, dignity, but also in a less marginalized and less isolated life.

Ultimately it is a precious message that Italy, one of the oldest and longest-lived countries, transmits to the whole world for a common destiny that is more humane and respectful of those who are older.

Vincenzo Paglia

Why a charter of the rights of the elderly and the duties of the community

Monsignor Vincenzo Paglia - President of the Commission

The context

The pandemic has brought out the contradiction of a society that on the one hand knows how to extend people's lives, but on the other fills them with loneliness and abandonment. Covid-19 has eliminated thousands of elderly people because we had already abandoned them. And we owe them a very serious debt. It is essential to remove at the root the serious shortcomings of an unbalanced, unjust, burdensome healthcare system, which itself causes so many victims. We need to overturn a paradigm. But this is only possible if we have a new vision of old age.

The demographic revolution that has occurred since the middle of the last century has brought to light a new continent, that of the elderly. Not that there weren't older ones before. But today is the first time in history that we have experienced "mass old age": millions more elderly people. An unknown continent, inhabited by people for whom there is no thought, neither political, nor economic, nor social, nor spiritual. It's an age to be invented. In short, we need a new vision of old age. Longevity is not a simple temporal addition, it profoundly changes our relationship with the whole of life.

Faced with this new scenario, the Commission deemed it appropriate to draw up a Charter that outlines some inspiring principles of the new perspective of care for the elderly. The Charter does not only talk about the rights of the elderly, but at the same time it indicates society's duties towards them. In this way the life of the elderly is connected to that of society, showing the inevitable link between everyone, even between different generations. The Charter concretely declines the indications contained in some international documents, such as the Recommendation of the Committee of Ministers CM / Rec (2014) 2 to the member states of the Council of Europe on the promotion of the human rights of older people adopted on 19 February 2014 and the European Charter of the Rights and Responsibilities of Elderly People in Need of Assistance and Long-Term Care drawn up in June 2010 in the framework of the European DAPHNE III Program against abuse of older people by a collaborative group of 10 countries as part of the project EUSTACEA.

Some might say that talking about rights is a pious illusion, the reality is quite different. The elderly are often seen as a problem for the country (just think of social security, hospital, pharmaceutical and other spending). Unfortunately, we forget that the elderly have not only more than earned the necessary social security and welfare relief, but are often the protagonists of assistance, for example towards their grandchildren or their spouses of the same age. And let's not forget that they represent a rather considerable share of the market, and the work associated with it, estimated by some at over 200 billion per year.

The vision of the elderly proposed by the Charter presents them as a possible driver of inclusive and sustainable development of the country. In short, the elderly can go from being a problem to becoming an opportunity for the growth of our social and economic model. Using a term and a concept dear to the Jewish tradition, the deepest intent of the card is to promote a true process of *Tiqqun Olam*: repairing the world around the most fragile. Not only repairing their dignity and guaranteeing the protection of rights, but giving new life to that social, human, family and friendship fabric torn apart by the phenomena of individualism, the impoverishment of the family, demographic decline and the abandonment of the territories that has marked Italy of the 20th century.

The Charter articulates three contexts of rights and duties in as many chapters: 1) respect for the dignity of the elderly person, 2) the principles and rights for responsible assistance, 3) protection for a life of active relationships.

The right to protection of the dignity of the elderly person

The first chapter of the Charter, dedicated to the protection of the dignity of elderly people, establishes two important principles: «1.1 The elderly person has the right to determine himself in an independent, free, informed and conscious manner with reference to life choices and the main decisions that they concern him. 1.2 It is the duty of family members and those who interact with the elderly person to provide him, due to his physical and cognitive conditions, with all the information and knowledge necessary for free, full and conscious self-determination".

Rights and duties here combine to work towards a context where freedom of choice is not an empty word, a right on paper. And at the same time one of the biggest problems of elderly life is identified: the deprivation of the possibility of choosing. The comment on the two articles explains it well: «In old age we often enter a cone of shadow, apparently determined by health conditions and frailty, but in reality the expression of a prejudice of ageism, according to which elderly people no longer have ability to make autonomous decisions, as well as the ability to independently manage one's own life. It is necessary to distinguish an assessment of physical or cognitive dependence from the presumed inability to make decisions, often transformed into implicit disqualification.

The fact that an elderly person has lost some physical and instrumental abilities to live daily life (washing, eating, using money, means of transport, etc.) must not automatically turn into a judgment of inability to decide, and be automatically replaced by the decisions of the family, caregivers or support administrator, abuses which occur for example when the elderly person is prevented from choosing the type and quality of food, from having their own identity documents or electronic payment".

I make a note here starting from the debate on the green pass, on the mandatory vaccination, which has animated the pages of the newspapers in this time of pandemic, due to the concern about the limits to personal freedoms. Well, there wasn't a single line about the much more radical lack of freedom among the elderly, especially institutionalized ones. A recent investigation by the New York Times, dated September 11, 2021, describes the use of antipsychotic drugs systematically administered to the elderly

guests of nursing homes, the mechanisms for circumventing the law, the reasons and effects. This is a tragic use of chemical restraint, extended to 21% of nursing home residents in the United States. One of the shortcuts used, for example, is to diagnose schizophrenia, used in 1 in 9 elderly people in these facilities, while at the general population level the figure stops at 1 in 150, a huge discrepancy. Over 200,000 seniors in US nursing homes have received diagnoses and "treatments." The phenomenon is not new if you consider that it was investigated by a senatorial commission from 1976 with the eloquent title: "Nursing Home Care in the United States: Failure in Public Policy".

Chemical restraint is also widespread in Italy. Its exact dimensions are not known, but it represents a truly scandalous example of deprivation of personal freedoms. It is the abyss into which many elderly people fall in structures, especially illegal ones, which use chemical restraint to solve the problems of staff shortages, opacity of the organic plan, use of precarious employment between different retirement homes and so on. The Commission for the reform of care for the elderly, through the Charter, wants to reaffirm the rights of the elderly, denouncing abuses and envisaging the new horizon in which the future of the elderly should be placed. The condemnation of restraint is also clear in the art. 3.6 "The elderly person has the right to safeguard their psycho-physical integrity and to be protected from all forms of physical and moral violence and improper forms of physical, pharmacological and environmental restraint, as well as abuse and intentional or unintentional negligence".

The relevant comment even proposes the possible solution: «The fight against all improper forms of physical, pharmacological and environmental restraint appears particularly important.

This protection should be ensured regardless of whether violence, abuse or neglect occurs at home, within an institution or elsewhere.

The most effective form of prevention of this type of abuse is not represented by the use of mere forms of technological control such as the use of video cameras, but by the possibility of cultivating the life of relationships and interaction with the outside by elderly people: the presence of visitors and volunteers constitutes the best protection against abuses that can occur in closed spaces".

These considerations pushed the Commission to propose a way to reform the RSAs. I quote here a passage from my presentation of the reform plan to President Draghi on 1 September: «1) the RSAs must be residences open to the family, to volunteers, to civil society, having within them the possibility of hosting day centres, of telemedicine, centers providing local services and integrated home care. The degree of openness and exchange with the outside world becomes one of the accreditation and quality assessment criteria of the individual structures. This is intended to avoid the fearful and widespread condition of isolation and loneliness in the future, which unfortunately occurred with the Coronavirus pandemic. As part of the care continuum and in relation to hospitals, RSAs can take on a role in transitional care, with a view to the final reintegration of the rehabilitated and stabilized elderly person into their home. 2) Precisely for this change in function, the standards of personnel, mandatory equipment and the healthcare, nursing and rehabilitation staff necessary for the proper functioning of the RSA are reviewed. 3) Such

advances will require a review of the tariff system on the one hand but also transparency and the obligation to publish the staff roster on the other".

Three changes are therefore promoted: the absolute requirement of the opening of the structure to the outside as an accreditation criterion, the change in the function of residential care as part of a continuum in dynamic equilibrium as a transitory moment and not as a terminal station, the rigorous control and transparency of the organic plant, as well as its appropriate enhancement. Fighting illegal construction also means demanding that all structures are open and totally transparent, accessible and permeable, in and out. One of the most significant violations of the elderly person's freedom of choice is the physical impossibility of meeting or leaving these structures, within a regime that can correctly be defined as prison.

I would now like to return, for a second example, to articles 1 and 2 which protect the elderly's freedom of choice. Where to live your old age? This is one of the fundamental choices to be protected: that of staying at home. Too often it is the relatives who decide, or even the support administrators, who too casually sometimes take on skills that reduce the elderly person to the role of an implicitly forbidden person. But even worse, too often the choice is dictated by the total lack of home care services, or by the economic impossibility of accessing them. If on the one hand the vast majority of elderly people choose to stay at home, we see that many obstacles combine to make this difficult, even arduous or impossible in the presence of illnesses and disabling conditions, or the difficulties and wishes of relatives and guardians. What does the Charter say about this? Article 1.9 sets out the principle according to which «The elderly person has the right to remain in his home for as long as possible».

This is a profound reform which is already evident from the title: "the home as a place of care for the elderly". The reason is simple and I believe incontrovertible: for those who are advanced in years, the home is the place of their affections and their memory, of history and experiences. Losing it means losing your memory, as Camilleri wrote, abandoning your roots and, ultimately, yourself.

However, it happens that the elderly often lose their home for family reasons, for economic reasons, especially due to lack of services. The Commission has explored, in collaboration with ISTAT, the topic of the conditions of the over 75s. Without dwelling on the results of the study, now published, I would only observe that in that age group there are over a million elderly people with serious motor and activity difficulties physical and instrumental aspects of daily life, without family help, public or private, living alone or with an elderly spouse. What freedom of choice do these people have if we do not protect them with adequate social support at home? Think of architectural barriers, houses without elevators, steep mountain centers, in short, the difficulties of those who live without accompaniment. For these reasons the Commission recommends an unprecedented strengthening of the so-called ADI, Continuous Integrated Home Assistance. Article 1.10 provides that «In the event of lack or loss of their home, the elderly person has the right to access adequate economic benefits in order to have an adequate home». The relevant comment explains that «the right of the elderly person to remain in their home, as well as to move freely both in private and public spaces, requires a growing commitment to the removal of architectural barriers, an intervention very often conditioned by regulations and complex and cumbersome administrative procedures, which in fact

end up undermining people's right to mobility. The right to a home and housing must also take the form of the right to immediate access to a home at a subsidized rent in the event of eviction or homelessness. It is not uncommon for the occurrence of improper hospitalizations associated with economic causes or other social problems, which lead to personal suffering and inconvenience for the elderly and unjustified economic costs for the community. The lack of and inadequate support from social and health services often translates into an objective violation of the right to live in one's own home: think of the hundreds of thousands of elderly people limited by architectural barriers, the most common of which is the lack of an elevator. for those who live on high floors."

Much more is contained in the first section but, in summary, I have indicated the two extreme examples that describe this first chapter well: from the right not to suffer violence, abuse and restraint to the possibility of being able to stay at home and choose how and with whom to live. The necessary radical reform starts from these needs.

The rights to responsible assistance

The second chapter, in its first two articles, also outlines rights and duties for responsible assistance by stating that «2.1 The elderly person has the right to participate in the definition of care paths, types of treatment and to choose the methods of providing care health and social care. Health and social care institutions and workers have the duty to present to the elderly person all the options available for the provision of health and social care".

There is a right to knowledge of the possible alternatives, the pros and cons of each, in the modern complexity of therapeutic paths. It could be said that even in the field of assistance it is necessary to formulate an informed consent, an indispensable safeguard against the risk of incorrect information when not openly counterfeit, or simply the lack of it. It is exactly in this direction that the following articles move by providing that «2.3 The elderly person must be guaranteed the right to informed consent in relation to health treatments as provided for by current legislation. 2.4 It is the duty of doctors and healthcare professionals to provide the elderly person with all the necessary information and professional skills in relation to their physical and cognitive conditions. 2.5 The institutions have the duty to adopt adequate and effective measures to prevent abuse."

The examples reported in the relevant comment are illuminating in this regard: «there are frequent cases in which the support administrator's consent is improperly requested for the provision of healthcare treatment even where the elderly person is capable of expressing it, as are the cases in which information on the state of health is provided only to relatives and not to the elderly people concerned or to other subjects indicated by them".

The following articles aim to guarantee the elderly care of the same quality offered to younger people; that care settings do not paradoxically produce disability or loss of self-sufficiency; that therapies and assistance always have also

recovery goals and return to previous health and life conditions. Providing home care represents a guarantee in itself: we know well how institutionalization represents an intrinsic factor of physical and mental disability: the so-called bed rest, the states of confusion that inevitably accompany separation from home, the immobility to which one is forced, the change in diet, the different sleep rhythms, the poverty of the activities that can be carried out, the objective social isolation, just to mention the most significant variables. This is the rationale of the following articles: «2.6 The elderly person has the right to high quality care and treatments suited to their personal needs and desires. 2.7 The elderly person has the right to appropriate and effective access to any healthcare service deemed necessary in relation to his or her state of health. 2.8 The elderly person has the right to be looked after and cared for in the environment that best guarantees the recovery of the damaged function. 2.9 It is the duty of the institutions to combat any form of age-selective healthcare and assistance."

Unfortunately, the trend, widespread in other European countries, of denying quality care to the elderly is also gaining ground in Italy. The pandemic has revealed worrying trends in this sense: from the "contract" that Dutch doctors propose to their elderly patients - long ventilation or euthanasia in the case of COVID - to the limitations on access to intensive care put in writing in Switzerland and Spain for patients over 75. The gallery of horrors would be very long. An eCancer Medical Science study reveals that only half of older people in Europe receive the excellent cancer care reserved for younger people. And paradoxically, neoplasms are much more common in old age! However, it is not even necessary to bother about the pandemic and the choices that accompanied it or the forms of cancer. Unfortunately just consider the ordinary, at least in English hospitals, based on data from the Parliamentary Service Ombudsman and the Daily Telegraph: Elderly patients are left without food or water, their wounds remain open and dressings are not changed, patients are not washed, there is a woefully inadequate way of cleaning them, leaving people soaked in urine or lying in bed in their feces, in the absence of pain medications, with incorrect therapies, or people left on the floor after falling, and so on.

The Daily Telegraph article describes such abuse as the norm in English hospitals and confirms what many families have known and complained about for years. The data reported is from 2010, well before the pandemic, and certainly not in an emergency regime. There is an embankment to be rebuilt to avoid falling into similar horrors and losses of humanity. The paper tries to draw guarantees for everyone: that there is no shortage of treatments, that they have the aim of healing, when possible, that care is always taken to alleviate all forms of suffering and pain. This last point was considered so important by the Commission that it was actually included in the first chapter, where we find the following text: «The elderly person has the right to access palliative care, in compliance with the principles of preservation of dignity, control of pain and suffering whether physical, mental or psychological, until the end of life. No one should be abandoned on the threshold of the last passage."

It is accompanied by the following comment: «The growing aging of the population, the evolution of the epidemiological picture and the progress of medical science make the need to guarantee elderly people adequate access to palliative care and renewed human, social and spiritual. As highlighted by the international reference literature, alongside the general elements on which palliative care is based (early identification, multidimensionality of evaluation and treatment, continuity of care and individualized planning of treatment and assistance pathways), it is necessary to consider

the specificity of the needs expressed by elderly patients and the ways in which these needs manifest themselves. In this sense, it must be considered that loneliness is always a harsh condition, but in moments of weakness and illness it is even more so. With pain it is unbearable; we prefer death to suffering alone. The request for euthanasia often starts here. Family members, social bodies, the community, have the duty not to delegate the needs of the dying person to the medical dimension alone, but to accompany him worthily and affectionately in the final stages of life."

The fight against pain runs through all three chapters of our text: it is at the same time a right, protection of assistance and care, human and social accompaniment in the awareness that pain cannot and must not be experienced in solitude. From this desire that belongs to everyone, simply to be cared for in the best possible way, and accompanied in the various difficulties of life, comes the Commission's proposal for a new model of care, close to homes, attentive to social issues, concerned with prevention, search for synergies. We understand it better by examining what is reported in the third section of the Charter.

The right to an active relationship life

The incipit of the third section is entirely dedicated to the guarantee of a life of relationships, the freedom to choose the form of coexistence, the fight against discrimination and the support of those who take care of the elderly, stating that «3.1 The elderly person has the right to have an active relationship life. 3.2 The elderly person has the right to live with whoever he wishes. 3.3 Institutions and societies have a duty towards elderly people to avoid any form of imprisonment, ghettoisation, isolation which prevents them from interacting freely with people of all age groups present in the population. 3.4 It is the duty of the institutions to guarantee support to families who have elderly people within them and who intend to continue to encourage cohabitation. 3.5 Institutions and societies have the duty to guarantee the emotional continuity of elderly people through visits, contacts and acquaintances with their relatives or with those with whom they have emotional relationships".

Three extremely important themes intertwine here: the awareness that the elderly person in his fragility depends even more on relationships and affection, on a network of daily contacts that surrounds and supports him, the fight against every form of marginalization and exclusion, support for those who support it. Too often we have forgotten the real pandemic of loneliness and social isolation that preceded the COVID 19 pandemic and which with the virus literally exploded in residences. The right not to be alone (and the duty not to leave us alone) coincides in the elderly and frail with the right to health and even to life. The scientific literature is full of studies that demonstrate the strong association between loneliness and cardiovascular diseases, loss of autonomy, dementia, depression and many other disorders in the over 65s. This is why it is even more serious that many are left alone amidst social neglect. which quickly and inexorably becomes a healthcare question. Family members and caregivers are also often left alone, those numerous and precious supports who however have to carry on the rest of the family, work and provide for the needs of their loved ones without help.

Conclusions

These three concerns have found great space in the Commission's reform proposal. The basis of the care continuum that we have designed, in fact, is made up of network and monitoring services for the most fragile and the oldest, the 4 million over 80s who we would like to see all involved. I report here an excerpt from the summary document: «These (network) services essentially consist of a multidimensional evaluation procedure per year (thus bringing us closer to the European standard of many virtuous countries) which allows us to define, where necessary, a personalized care plan, and therefore the entry into the continuum and also into digital tracking. Three further elements characterize this low intensity but maximum diffusion service:

to. the facilitation and launch of social inclusion processes for a systematic fight against loneliness and social isolation, digital inclusion (use of programs and software, telemedicine elements) and cultural inclusion (courses, apprenticeships, cultural events, etc.)

b. Health education, health promotion and prevention

c. Help and support in emergency situations (heat waves, pandemics, natural disasters, etc.)

Study and experimentation through well-structured sector studies could confirm and quantify the benefits known in the literature, namely the good reduction in the use of emergency rooms and hospital admissions, care in RA or RSA and the best life expectancy in conditions of self-sufficiency. The planned experimentation will involve a large sample and will represent a first step in the process of implementing the entire continuum and the digital tools and systems to be introduced."

Another point to which we have dedicated a lot of energy is that of the "Day Centres" for those suffering from dementia or other chronic disabling pathologies, designed with the dual function of entertainment and care centres, I would say of urban but also social redevelopment, with a function already "restorative" and already of hospitality for these people. These structures also support families and caregivers, who could receive the relief of 8 hours a day during which their loved ones are cared for and a peaceful space of freedom opens up for other tasks.

Finally, the proposal commits the entire health and social system to an effort towards transparency and the fight against illegal activity, so that situations of real exploitation of the elderly in "illegal" homes (sometimes real concentration camps) without accreditation rules are no longer tolerated. , without transparency and without controls. We do not want to forget the horrors seen during the pandemic and indeed we want to make it an opportunity for profound change and momentum towards a home-centered care system.

The Charter outlines that mature civil sense of rights and duties that a "high" society and democracy must be able to offer to their elderly citizens. It is not a utopian proposal. Starting from the most vulnerable, putting them at the center of attention, will favor inclusive and widespread development: the elderly are also a crossroads of economies - the digital one, the service one, the green one and the consumption one.

Charter for the rights of older people and the duties of the community

Preamble

The Italian Constitution does not provide for specific protection of the rights of elderly people. Its drafting in years in which the problems of the Third Age were less relevant in today's public debate contributed to ensuring that there was no precise reference on the topic in the Constitutional Charter, which limited itself to providing welfare measures in the case of old age. Also for this reason, in more recent years and in various ways it has been decided to remedy this lack, for example by introducing art. 3 among the non-discrimination factors is age.

However, the attitude of the European Union institutions was different. The Charter of Fundamental Rights, signed in 2000, dedicated a specific article to the rights of elderly people, art. 25 for which "The Union recognizes and respects the right of elderly people to lead a dignified and independent life and to participate in social and cultural life". This is an effective regulatory basis from which to move for in-depth reflection and an innovative proposal that responds to the growing and irreparable needs expressed by elderly people.

Furthermore, it must be said that the explicit absence of the topic in our Constitution does not prevent us from finding secure foundations to which to anchor the definition of the rights of elderly people, starting first and foremost from the principles of solidarity and equality. The elderly person is naturally part of social groups and in relations with the members of these groups the "mandatory duties of political, economic and social solidarity" enshrined in the art correspond to the rights of elderly people. 2 and the task imposed by art. 3 to the Republic "to remove economic and social obstacles which, by effectively limiting the freedom and equality of citizens, prevent the full development of the human person and the effective participation of all workers in the political, economic organization and social development of the country".

Therefore, the Constitution, although it does not expressly speak about elderly people, nevertheless requires that adequate promotion and protection of their rights and the fulfillment of duties towards them be ensured.

Card Value

The Charter for the rights of elderly people and the duties of the community, the result of the work of the Commission for the reform of health and socio-medical assistance for the elderly population established at the Ministry of Health, compared to a mere

abstract statement of the rights of elderly people and the duties of the community intends to take a further step in a twofold sense: if on the one hand it aims to have an impact on the legal system by presenting to the legislator fundamental principles and rights which can find formal recognition in specific regulatory acts, on the other hand it offers operational and organizational indications to institutions and operators called upon to take care of elderly people.

The Charter intends to concretely express the indications contained in some international documents, such as the Recommendation of the Committee of Ministers CM / Rec (2014) 2 to the member states of the Council of Europe on the promotion of the human rights of older people adopted on 19 February 2014 and the European Charter of Rights and Responsibilities of Older People in Need of Assistance and Long-Term Care drawn up in June 2010 in the framework of the European DAPHNE III Program against abuse of older people by a collaborative group of 10 countries as part of the EUSTACEA project.

Finally, the Charter serves the purpose of facilitating knowledge for elderly people of their fundamental rights and increasing their awareness, as well as the duties that weigh on those who enter into relationships with them.

These are objectives that could be pursued immediately through a translation of the contents of the Charter into a directive from the President of the Council of Ministers to inspire and guide the action of public administrations, as well as in a possible agreement in a Unified Conference to share them with regions and Local societies.



CHARTER OF RIGHTS OF ELDERLY PEOPLE AND DUTIES OF THE COMMUNITY

1

To respect the dignity of the person even in old age

1.1

The elderly person has the right to determine himself in an independent, free, informed and conscious manner with reference to life choices and the main decisions that concern him.

1.2

It is the duty of family members and those who interact with the elderly person to provide them with all the information and knowledge necessary for free, full and conscious self-determination due to their physical and cognitive conditions.

Examples and considerations

In old age we often enter into a shadow, apparently determined by health conditions and frailty, but in reality the expression of a prejudice of ageism, according to which elderly people no longer have the capacity for autonomous decision-making, as well as for management independent of his own life.

It is necessary to distinguish an assessment of physical or cognitive dependence from the presumed inability to make decisions, often transformed into implicit interdiction.

The fact that an elderly person has lost some physical and instrumental abilities to live daily life (washing, eating, using money, means of transport, etc.) must not automatically turn into a judgment of inability to decide, and be automatically replaced by the decisions of the family, caregivers or support administrator, abuses which occur for example when the elderly person is prevented from choosing the type and quality of food, from having their own identity documents or electronic payment.

1.3

The elderly person has the right to preserve their dignity even in cases of partial or total loss of their autonomy.

1.4

The elderly person has the right to be called by name and treated with respect and tenderness.

1.5

The elderly person has the right to privacy, decorum and respect for modesty in acts of personal and body care.

1.6

The elderly person has the right to be supported in their residual capacities even in the most compromised and terminal situations.

1.7

The elderly person has the right to access palliative care, respecting the principles of preservation of dignity, control of pain and suffering, be it physical, mental or psychological, until the end of life. No one should be abandoned on the threshold of the last passage.

Examples and considerations

The growing aging of the population, the evolution of the epidemiological picture and the progress of medical science make the need to guarantee elderly people adequate access to palliative care and renewed human, social and spiritual support increasingly relevant. As highlighted by the international reference literature, alongside the general elements on which palliative care is based (early identification, multidimensionality of assessment and treatment, continuity of care and individualized planning of treatment and assistance pathways), it is necessary to consider the specificity of needs expressed by elderly patients and the ways in which these needs manifest themselves.

In this sense, it must be considered that loneliness is always a harsh condition, but in moments of weakness and illness it is even more so. With pain it is unbearable; we prefer death to suffering alone. The request for euthanasia often starts here. Family members, social bodies, the community, have the duty not to delegate the needs of the dying person to the medical dimension alone, but to accompany him worthily and affectionately in the final stages of life.

1.8

Those who interact with older people have a duty to

adopt respectful, honourable, thoughtful and courteous behaviour, and pay attention and pay adequate attention to the reports and observations made by elderly people.

Examples and considerations

A very widespread habit, especially in healthcare settings, is addressing elderly people in an impersonal and disrespectful manner. Calling the elderly person with falsely confidential names or replacing the name with an identifying number are two apparently opposite ways of relating, but both denote a lack of respect for the elderly person. This is a lack that often manifests itself in the lack of attention paid to the external appearance of the elderly person: the exchange of clothing between those assisted, the use of poor and impersonal clothing fall into this type of abuse.

1.9

The elderly person has the right to remain in his home for as long as possible.

1.10

In the event of lack or loss of their home, the elderly person has the right to access adequate economic benefits in order to have an adequate home.

1.11

It is the duty of institutions to guarantee adequate services to elderly people in the face of particular physical and health conditions or the existence of architectural barriers.

Examples and considerations

The right of the elderly person to remain in their home, as well as to move freely in both private and public spaces, requires a growing commitment to the removal of architectural barriers, an intervention very often conditioned by complex and cumbersome regulations and administrative procedures, which in fact end up undermining people's right to mobility. The right to a home and housing must also take the form of the right to immediate access to a home at a subsidized rent in the event of eviction or homelessness. It is not uncommon for the occurrence of improper hospitalizations associated with economic causes or other social problems, which lead to personal suffering and inconvenience for the elderly and unjustified economic costs for the community. The lack of and inadequate support from social and health services often translates into an objective violation of the right to live in one's own home: think of the hundreds of thousands of limited elderly people

by architectural barriers, the most common of which is the lack of an elevator for those living on high floors.

1.12

The elderly person has the right to the protection of their income and assets for the purpose of maintaining an adequate and dignified standard of living.

1.13

It is the duty of the institutions to guarantee the elderly person forms of income integration in the event of partial or total poverty or inadequate economic resources.

1.14

It is the duty of the institutions to guarantee the effective freeness of healthcare and social and healthcare services.

Examples and considerations

There are multiple and recurring abuses regarding the use of economic and patrimonial resources by elderly people. In this regard, the intervention of the support administrator does not always appear appropriate, and often turns out to be more of a moment of protection of the assets than of the person.

With respect to the financial guarantee of essential levels of healthcare, the use of social services by elderly people is strongly conditioned by the availability of adequate financial resources on the part of the body called upon to guarantee their enjoyment.

Furthermore, the social and health services provided by public institutions often fail to satisfy the care needs of elderly people, who are therefore forced to resort to private providers resulting in high and not always sustainable economic costs.

This entails on the one hand the opportunity to reform the income criteria to define economic support for elderly people, and on the other a constant commitment by children to take care of their elderly parents who are in conditions of poverty.

1.15

The elderly person has the right to ask for support and help from people they trust and choose in making financial decisions.

Examples and considerations

Especially when suffering from cognitive problems, older people need support to improve their levels of "financial literacy" in order to allow them to understand the legal and financial implications and make informed decisions about health problems, the death of a relative or moving to another country, a care facility. This is particularly important because it allows the elderly person not to lose control of their finances and to be as independent as possible in their daily life.

1.16

The elderly person has the right to receive adequate support in making his decisions, including through the appointment of a person he trusts who, upon his request, and in accordance with his will and preferences, assists in his decisions.

Examples and considerations

It appears increasingly necessary to make elderly people informed and aware of the right to be able to choose a person they trust to make their own decisions and to look after their interests also with regard to crucial aspects of their lives such as health. The recent establishment of the figure of the "trustee" who can be indicated in the DAT (advance declaration of treatment) moves in this direction, a person who does not necessarily have to be a relative, nor the support administrator, but who can be freely indicated in the declaration. This choice could contribute to spreading its use more widely throughout the country and making the signing of declarations by older people effective.

2 For responsible assistance

2.1

The elderly person has the right to participate in the definition of care pathways, types of treatment and to choose the methods of providing health and social care.

2.2

Health and social care institutions and workers have the duty to present to the elderly person all the options available for the provision of health and social care.

Examples and considerations

The exercise of this right is not facilitated by the different, not always adequate, choices made regarding health and social care. For example, if the patient chooses to remain at home instead of resorting to hospitalization in social and healthcare facilities, all healthcare costs must be borne by the patient or his/her family due to the insufficient offer of home healthcare and integrated care services. An economic commitment by public institutions aimed at ensuring freedom and equality of choice between the different forms of health and socio-health care appears desirable if not necessary. The choice of the care environment must be made in accordance with the wishes of the elderly person receiving care, and in harmony with their needs and financial resources. Cases of abuse are not rare, such as the practice of transferring elderly people in need of rehabilitation care to post-acute and long-term care departments, a transfer often carried out without the consent of the interested party.

2.3

The elderly person must be guaranteed the right to informed consent in relation to health treatments as required by current legislation.

2.4

It is the duty of doctors and healthcare professionals to provide the elderly person with all the necessary information and professional skills in relation to their physical and cognitive conditions.

2.5

Institutions have the duty to adopt adequate and effective measures to prevent abuse.

Examples and considerations

There are frequent cases in which the consent of the support administrator is improperly requested for the provision of health treatment even where the elderly person is capable of expressing it, as well as cases in which information on the state of health is provided only to relatives and not to the elderly people concerned or to other subjects indicated by them.

2.6

The elderly person has the right to high quality care and treatments suited to his or her personal needs and desires.

2.7

The elderly person has the right to appropriate and effective access to any healthcare service deemed necessary in relation to his or her state of health.

2.8

The elderly person has the right to be looked after and cared for in the environment that best guarantees the recovery of the damaged function.

2.9

It is the duty of institutions to combat any form of age-selective healthcare and assistance.

Examples and considerations

Assistance and care for elderly people should be guaranteed at home as far as possible, as this is the environment that best stimulates the recovery or maintenance of the damaged function, providing every health and social benefit deemed practicable and appropriate. The hospitalization of the elderly person in a hospital or rehabilitation facility should take place for the entire period strictly necessary for care and rehabilitation, having clear that the return to one's home is a priority objective.

2.10

Health and social care workers have the duty to maintain the independence and autonomy of the elderly person in need of care.

2.11

Health and social care workers have the right to obtain professional training suited to the needs of older people.

Examples and considerations

Some healthcare practices, such as lifting patients out of bed only when the service staff is available, encouraging people to be bedridden to avoid falls, up to the adoption of forms of restraint, effectively limit and do not promote autonomy of elderly people. These behaviors are often justified by citing work organization reasons that end up prevailing over respect for the person.

3

For an active life of relationships

3.1

The elderly person has the right to have an active relationship life.

3.2

The elderly person has the right to live with whoever he wishes.

3.3

Institutions and societies have a duty towards elderly people to avoid any form of imprisonment, ghettoisation, isolation which prevents them from interacting freely with people of all age groups present in the population.

3.4

It is the duty of the institutions to guarantee support to families who have elderly people within them and who intend to continue to encourage cohabitation.

3.5

Institutions and societies have the duty to guarantee the emotional continuity of elderly people through visits, contacts and acquaintances with their relatives or with those with whom they have emotional relationships.

Examples and considerations

The possibility of an active relationship life is not guaranteed not only when people are confined to their homes or in care facilities with a reduced possibility of meetings and visits, but also when the care facilities are separated from the life of the neighbourhoods. Therefore, it must be a commitment on the part of institutions and communities to foster a fruitful relationship between young people and the elderly at every level and to stimulate the many forms of integration.

3.6

The elderly person has the right to safeguard their psycho-physical integrity and to be protected from all forms of physical and moral violence and improper forms of physical, pharmacological and environmental restraint, as well as abuse and intentional or unintentional negligence.

3.7

Those who interact with elderly people have the duty to report any form of abuse, violence and discrimination against them.

Examples and considerations

In order to decisively combat any form of violence against elderly people, the introduction of aggravating sentences could be considered in the case of moral and physical violence, mistreatment, deprivation of basic care, threats, extortion, humiliation, intimidation, economic violence or financial, especially if they occur in a protected environment or in care or assistance facilities. The fight against all improper forms of physical, pharmacological and environmental restraint appears particularly important.

This protection should be ensured regardless of whether violence, abuse or neglect occurs at home, within an institution or elsewhere.

The most effective form of prevention of this type of abuse is not represented by the use of mere forms of technological control such as the use of video cameras, but by the possibility of cultivating the life of relationships and interaction with the outside by elderly people: the presence of visitors and volunteers constitutes the best protection against abuses that can occur in closed spaces.

A further prevention tool is represented by the right of elderly people to choose the places and people with whom to live, also through the promotion of home care and cohousing services as possibilities within everyone's reach.

3.8

The elderly person has the right to participate actively in social life also through flexible forms of work suited to his conditions and possibilities or through voluntary activities.

3.9

The elderly person has the right to retain the possibility of accessing cultural and recreational services, as well as to express their thoughts and increase their culture, even in the presence of psychophysical limitations.

3.10

It is the duty of the institutions to guarantee digital inclusion, e-learning and facilitation of learning services through IT means.

Examples and considerations

The guarantee of this right requires the exercise of public protection by bodies and administrations, called upon to find suitable solutions to avoid processes of marginalization.

To this end, institutions must provide suitable aids, not only those provided for visually impaired or hearing impaired people or for mobility, but also for social and digital participation activities.

Furthermore, the concrete and verifiable possibility of access to day centers represents an indispensable form of protection of these rights.

The right of the elderly person to carry out the activities he prefers, including work and apprenticeship, must not be overlooked, albeit through suitable and actually practicable and available forms. In fact, a widespread prejudice leads to the belief that elderly people are incapable of activity and commitment. Scientific evidence emerges that active aging in old age, capable not only of ensuring greater survival, but also a slower decline, determines a more contained demand for social and health services and a better quality of life.

3.11

The elderly person has the right to preserve and have their beliefs, opinions and feelings respected.

Examples and considerations

The right to exercise religious practices by elderly people is thwarted by the lack of places of worship, as well as by the recurring choice to close religious services in places of reception and care.

3.12

The elderly person has the right to move freely and travel.

3.13

The institutions have the duty to adopt measures to facilitate the mobility of elderly people and adequate access to the infrastructure intended for them.

Examples and considerations

The urban environment is not without impediments and barriers for the mobility of elderly people, who suffer, like other fragile people, considerable limitations in traveling on means of transport, in public places and places open to the public. Therefore, the removal of every form of limitation on freedom of movement must be a growing and constant commitment on the part of all public institutions.



STORIES

Stories | 1

When others decide....

Mario was 82 years old and had some physical limitations. To get around he needed the support of a walker and some help going to the bathroom. He had a decent retirement income after 40 years of work. He had also obtained recognition of the carer's allowance and lived in a council house that had been assigned to him when he was still young and his son was only 15 years old.

A few years ago his son had moved to live with him because he had been evicted from the house where he lived with his family. One day the son begins to tell his father that cohabitation between them was no longer possible, that both he and his wife had to go to work and could not take care of him during the day. He suggests the retirement home to him, but Mario tries to resist.

His son's proposal, which by now was already more than a proposal, upsets him and to assert his rights he opposes it with all his strength, sometimes even letting his quarrelsome nature resurface. Mario adopts these attitudes because he is aware that in reality he will not be able to thwart his son's proposal which was now a decision made. He cries, he despairs but he is forced to do what his son tells him to do: he takes with him a bag with some clothes, a telephone, glasses and sets off, without speaking, with his son to an isolated house that borders the countryside and overlooks a busy road. Upon his arrival, an assistant greets him and shows him the room he was supposed to share with two other people. Some elderly people look at him, someone greets him.

So his son remains to live with his family in the public house in Mario's name and he, no longer considered part of the family, is forced to live in a facility among strangers, isolated from everyone and everything.

All he has left is his cell phone to maintain some contact. So he calls someone he knows and tells his absurd story which seemed like a nightmare from which he could no longer wake up. He says that he felt bad there, uncomfortable, that they didn't eat well, in fact the food was insufficient and he was always hungry.

After a few days, the son, having learned of his phone calls, goes to the institution and takes the phone away from his father. He tells the director that it was best not to keep him because those calls agitated him and made him feel bad.

Mario was no longer able to tell anyone these things, they closed him in silence.

Stories | 2

How much does it cost to make an elderly woman dress well?
Stories of ordinary abuse.

Adalgisa had worked in cabarets since the age of 20. She liked singing, dancing and boasted to everyone that she had also met actors who later became famous. Everyone complimented her because she had a beautiful voice and a physique, which as she herself said: "not for nothing but I made everyone's heads turn". She was very sophisticated in clothing and always said that, once the war was over, she was finally able to start buying new clothes and following the fashions of the time. She always recounted these same scenes as she sat, rolled up in the sheets, in the orthopedic bed of the 4-bed room of the RSA where she had been hospitalized for two years because "she could no longer be alone". "But you can't walk? Why don't you get up?" Adalgisa makes the gesture of lowering her voice and asks her interlocutor to come a little closer. "Let's speak softly here, even the walls have ears. You see, I've always dressed in a certain way, you can't imagine who knows what, but never a hair out of place, a stain on my dress... here they make me dress in a tracksuit because they say it's more comfortable. But who is it more comfortable for? For them. I wear the tracksuit, and I think this one I'm wearing isn't even mine, I was saying I've never used the tracksuit in my life, I've never liked it and I've never even done gymnastics, I already moved around quite a bit while dancing. Here, however, everyone in overalls, men and women, sometimes cuts your hair so short that you even struggle to recognize a person's gender. With the suit we are all the same, obviously I didn't serve in the military, but here it's worse than a barracks. I never receive visitors but it's better this way because I would be ashamed to be seen in these conditions. I would love to have an elegant dress and go out for a walk in the city." How much does it cost the State, society, to make an elderly woman dress well?

Stories | 3

How much does it cost to make an elderly woman dress well?
Stories of ordinary abuse.

Fulvio is 79 years old, he worked as an engineer, he designed elevators. He has been to work in Switzerland and Holland. Subsequently he became manager of a company in La Spezia and when it took out contracts in Rome he willingly moved to the capital.

His pension allows him to live comfortably but when the first health problems arise he is advised by his grandchildren to move into a house

of "very good" rest located outside Rome.

Fulvio was very uncertain and in the end he allowed himself to be convinced, thinking that after the first period of treatment he would recover his energy and return home. Yes, because he had a beautiful house in the Piazza Sempione area. In the same period, his nephews presented a request for administrative support for Fulvio because they thought it would be better to have someone alongside him in financial management and in daily choices. He only learned of this initiative when he received a summons from the Civil Court of Rome. His nephews downplay it and insist that it will be an important help to him. They thought that, knowing their uncle's extravagances, a stranger would be better as a support administrator rather than themselves, to whom their uncle never wanted to listen.

So a lawyer is appointed who suddenly enters his private life, even into the most remote corners.

Well, Fulvio thinks, now I want to assert my rights and I will explain that first of all I want to go home, maybe I will pay a family assistant to help me. So he prepares a nice speech but in the first meeting he doesn't perceive much willingness to listen from the lawyer who, having shown the appointment decree, is in a hurry to have the debit card, the documents and the house keys delivered. Fulvio thinks that maybe it wasn't the right day, maybe it was just the first meeting and continues to think that if the judge decided like this it means that this will be the way to assert one's rights and requests.

But after the first meeting Fulvio no longer manages to have the opportunity to speak again with the support administration. He asks the retirement home management to call him but they say not to worry because he will show up. Fulvio protests and they tell him to be careful what he says because they would have reported everything to the lawyer. Then he tells everything to his friends who come to visit him every now and then. We don't know how, they manage to talk to the support administrator and, in response, he warns them against continuing to take care of Fulvio and creating false expectations for him. He adds that he doesn't want to take on the responsibility of bringing Fulvio back home and therefore this current situation is the best, obviously best for him.

Fulvio's friends point out to him that he owns a beautiful house where, thanks also to his income, he could live well. The support administrator does not want to listen to reason and reiterates that it is fine as he has already decided. They insist on saying that Fulvio's will is different. The lawyer flies into a rage: "But what will and will, we have to be realistic and then I don't have to account to you for the reasons why I took this decision. I have nothing else to add". Fulvio talks to everyone only about his house, about being able to go out but he is no longer able to talk to his support administrator and never meets him. He cannot understand how it is possible that a stranger, never seen before, can decide everything about him, without listening to his will.

Stories | 4

Regarding the choice of support administrators... an exemplary story

Giovanni is almost 90 years old and has a very clear mind. In particular, one thing is clear: that he doesn't want to go to institute. He repeated it to everyone also to always repeat it to himself. The future certainly worried him. He was in good health but had no relatives, only a kind neighbor who did his shopping and other errands. And that he always rewarded. His house was very well organized but on the third floor without a lift it had become difficult for him to go out. One day a small hole in the backyard was fatal to him. He fell and fractured his femur.

Thus began a journey he had always feared. The neighbor who comes to visit him confides in him her worries about returning home: she couldn't have helped him more than she did. She also speaks to the doctors and the social worker at the hospital, explaining that she can do very little and then there is also the problem of managing the pension, household expenses and everything else and he has no one. For this reason the services decide to immediately make a request for a support administrator. Not that Giovanni was unable to decide how to manage the money and his future but he is 90 years old and the simplest thing, in the absence of a relative, seems to be to entrust him to an institutional figure.

Meanwhile, once the acute phase has passed, they also decide to transfer him to another facility. Not really a rehabilitation because he is an elderly person, he will go to post-acute rehabilitation: lower intensity of rehabilitation care. So he only does a few minutes of rehabilitation a day and then spends the rest of the hours in bed: no one gets him up. It is easy to imagine how this rehabilitation does not help him to significantly recover his motor skills.

One day a doctor from the facility approached his bed and explained to him that it was preferable for him to continue his treatment by moving to another facility a little outside Rome, but very good, towards Velletri. For the transfer he would have had to sign the form that she insistently handed him: "here you have to sign here".

Giovanni hesitates, he doesn't understand, he would like to talk about his future to prepare for his return home, he would like to have explanations about his health conditions, ask why he still isn't walking... and many other things: in short he would like to talk to someone. But time has now run out for him, the doctor is in a hurry and has already started to turn to another patient. All he can say is: but I would like to go home. The doctor looks at him with a pitying look that leaves

to understand that he was rambling: "But of course he has to stay here now." Giovanni finally signs, without knowing what it was about. He had given consent for a transfer to an RSA. After that signature, months pass without anyone explaining anything to him anymore. He waits to continue the rehabilitation treatments but every day for some reason they are postponed. One day a stranger shows up near his bed: good morning, I'm the lawyer Bianchi, I have been appointed as his support administrator. I will take care of her pension and what she needs.

Giovanni begins to see a way out. "Well I would like to go home I've already been here for 5 months". The lawyer responds without room for replies: "It's still too early to go out, we'll talk about it again. In the meantime, I will take care of paying the fees for this institute. We will see. I will return to visit her when I can because it is far from Rome here." Giovanni asks for a sum of money because he has nothing with him and he might need something. The lawyer's response is even more lapidary: "But what are you supposed to do here with the money? You don't lack anything, they take care of everything." Giovanni is still waiting for someone to explain to him why he has to stay in there.

Stories | 5

Appropriate care in the appropriate environment: the home.

As often happened to unmarried women of the past and despite the malicious judgments that surrounded them, Maria, now 88 years old, was a strong, independent and resolute woman. And he still is, despite his advanced age and the many vicissitudes he has had to go through. She has always lived alone, but this has not stopped her from having a very satisfying social and professional life. A cultured, studious woman, as soon as she finished high school, she had enrolled in a typing course in order to start working as soon as possible and support herself independently. These were certainly not times of great opportunities, then, for women who wanted to embark on a brilliant professional career. And so, still young, having completed her training, she was hired by the Christian Democrats, where she soon made her mark. He met Aldo Moro and entered his secretariat, where he remained for a long time. His was a very active and very satisfying life. He bought himself a beautiful house in Rome, near Piazzale Clodio, the neighborhood of those who practice law and where he still lives. Two years ago, already very old and long retired, Maria began to have significant health problems for which she needed a continuous series of tests. Nothing particularly specialized or sophisticated, just the need to repeat some analyses, such as measuring the blood count value, to keep the situation under control.

Even though she didn't lack a certain financial availability and she did it

requesting a home service, she was told that she would have to resort to hospital admission. And after the hospital, as in an uninterrupted vicious circle, here was the transfer to an RSA, where she had to spend many months and where perhaps she was destined to remain forever. Everything for frequent and regular blood count checks!

It seemed like a Kafkaesque situation with no way out. Meanwhile, in the RSA, Maria's health was worsening: she had fallen into a depressive state and was beginning to feel confused. Furthermore, it seemed that her relatives had no interest in her returning to her home, quite the opposite.

It was only thanks to a sensitive and attentive social worker, who later became her support administrator, that Maria managed to return to her home five months ago, where she now lives with a Romanian caregiver, sweet and energetic at the same time, who she calls "my little girl".

Stories | 6

The drama of COVID 19: stories of isolation and newfound freedom

Aurelia is 85 years old and for 5 years she has lived in a retirement home in the center of a populous neighborhood of Rome. He has a very rich relationship life. Every day she goes to visit her friends, goes around the shops and has long conversations with the shopkeepers in the area who don't know her, she goes to seek advice from her doctor who has also become a trusted person. The pandemic arrives and the doors of the institute close: you can no longer leave. Even when the period of greater restrictions on the movement of people has passed, it is not possible to leave the institute. Anyone who leaves can no longer return. Aurelia feels oppressed by this situation but is aware of the emergency that the whole world is experiencing and of the tragedy that has overwhelmed the lives of many. He complains a little but tries to resist waiting to see the end of this terrible epidemic. But with the new wave of the pandemic, the virus also entered the retirement home where she lived: almost all the elderly people and the elderly nuns in the home fell ill. Aurelia is also positive, but fortunately she manages to overcome the disease without having to be hospitalized. Instead, other elderly people in the institute and even the elderly nuns are forced to be hospitalized and some never return, perhaps six, and die.

Aurelia is shocked and, when infections begin to decline and restrictions begin to ease before the summer, she asks to go out just as all Italian citizens were allowed to leave their homes and move around freely.

She was told again that she was not allowed to leave and that if she did she would not be able to return. So after a few days pack your bags,

book a room in a bed and breakfast and cross the door of the institute to regain your lost freedom. She did it.

Stories | 7

When the real illness is loneliness, and when friendship and closeness could make the difference

Marisa and Antonio were a close-knit couple. A long and overall happy marriage, although with the regret of not having had children. Retirement and old age had increased the hours spent together. The affection was the same as always and they kept each other a lot of company. Every now and then they told each other that they were lucky because they were not alone and loneliness is so bad when you are weak and no longer young.

Antonio was a good and caring man, tender towards his partner, even when, as she grew older, she began to feel the signs of illness. He faithfully assisted her in her infirmities. At their home, as long as it was possible. However, over time Marisa showed increasingly alarming signs of confusion: prisoner of her nightmares and fears, she almost didn't notice others. Who could her husband count on? He too had aged and lacked the necessary support. In the end, out of desperation, he had to accept the prospect of hospitalization.

Marisa had been hospitalized far from their home, outside the city, thirty kilometers away. Antonio, however, continued to visit her every day. He couldn't do without her, he felt alone and, above all, she was the only affection he had left. So every day he took the bus that went along the state road, among the hills covered with olive trees. He endured the curves and bumps, indifferent to such beauty, closed in his thoughts.

One day, right in front of the gate of the institute, his heart could no longer take it. He died of a heart attack right there, a few meters from his wife, who never knew or understood what had happened to him. He was now eighty-five years old.

Marisa continued to invoke his name. Sometimes she felt betrayed; more often he imagined that something bad had happened and he despaired. No one wanted to waste time explaining to her what had happened. His sobs mingled with the voices of many other patients. After a short time she too died. Alone.

Stories | 8

Mary's letter

Many years ago, a passionate letter-appeal from an elderly woman hospitalized in an institution was published in numerous national and local newspapers which seems to summarize the meaning and purposes of the document well. It seems significant to us to place it at the conclusion of our work due to its expressiveness and clarity.

I am almost seventy-five years old, I live alone in my house, the same one I stayed in with my husband, the one my two children left when they got married.

I have always been proud of my autonomy, but for a while it hasn't been the same as before, especially when I think about my future. I'm still self-sufficient, but for how long? I realize between myself that the gestures become a little less casual day by day, even if they still tell me: "If only I were like her at her age...". Going out to do the shopping and keeping the house is making me increasingly tired.

And then I think: "What will my future be?". When I was young the answer was simple: with your daughter, with your son-in-law, with your grandchildren. But how do you do it now, with small houses and families where everyone works? So even now the answer is simple: the institute.

It's annoying, everyone says it, but everyone also knows, and doesn't say it, that no one would want to leave their home to go and live in an institution.

I really can't believe that a bedside table is better, a narrow space, a completely anonymous life at home, where every object, a painting, a photograph, reminds and fills even a day without much news. I often hear people say: "We put him in a nice institution, for his own good." Maybe they are sincere, but they don't live there.

Let's also admit that we don't end up in one of those TV news places, where they even have a hard time giving you water if you're thirsty, or they mistreat you just because they feel frustrated with the work they do.

But I really don't think that an institution is the answer to those who are a little unwell and, above all, alone.

Is finding yourself suddenly living with strangers, unwanted and unchosen people really a way to overcome loneliness? I know well how to live in an institution. It happens that you want to rest and you can't because you can't stand the noise of others, the coughs, the habits that are different from yours.

They say that when you get old you become exaggerated. But it is not an exaggeration to imagine that if you want to read there are those who want the light off or that if you want

see a programme, or watch another one or it's not on time.

In a shelter even the most banal problems become difficult: having the newspaper every day, repairing your glasses immediately when they break, buying the things you need if you can't go out.

It often happens that they exchange your underwear with someone else's after the laundry and then you can't keep anything of yours. What's worse - assuming that eating isn't bad - is that you can't decide almost anything: when to get up and when to stay in bed, when to turn on and off the light, when and what to eat. And then, when one is older (and is more embarrassed because he feels less beautiful than he once did), he is forced to have everything in common: illness, physical weaknesses, pain, without any intimacy and any shame.

There are those who say that in the institute "you have everything without burdening anyone". But it's not true. You don't have everything and it's not the only way to avoid bothering your loved ones.

An alternative would be: Being able to stay at home with some assistance and, when you feel worse or get sick, being able to be helped at home for the time you need. In fact, there are many of us who could stay at home even with just a little help, or with home healthcare. And it's not true that all this costs too much. These services cost three or four times less than my eventual admission to a long-term care facility or an institution. It happens that you end up in an institution and you didn't even decide it. I don't understand why you respect the wishes of a will and yet you aren't listened to while you're alive if you don't want to go to an institution.

I heard on TV that here in Italy thousands and thousands of billions have been allocated to build new institutes. If I lived in a shack I would be happy too. But I have a house and a bed, I already have my "bed place", there is no need to create new kitchens to prepare lunch for me, you can use mine. I don't need you to build me a new big room to watch TV, I already have my own TV in my room. My toilet still works fine. My house, if anything, only needs a few handrails and handles on the wall: it would cost you much less.

What I want for my future is the freedom to be able to choose whether to live the last years of my life at home or in an institution. Today I don't have this freedom. For this reason, even though I am no longer young, I still want to make my voice heard and say that I don't want to go to institute and that I don't wish it on anyone. Help me and all the elderly to stay at home and die among their belongings. Maybe I will live longer, I will definitely live better.

Maria.

