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# Me Time and Foreverism: L'Hic ET Nunc of Caregiver for People with Disabilities

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## Abstract

The communication of a disability diagnosis does not only concern the person directly involved, but is a critical event capable of producing profound effects on the entire support network, with particular reference to the family unit. In fact, it triggers a complex and articulated process of re-elaboration and renegotiation that affects multiple dimensions of daily life and social reality. In this process, the variable of time plays a central role and takes different forms, highlighting its polysemic and symbolically dense nature.

On the one hand, time manifests itself in its tangible and factual sense: the time devoted by the caregiver to caring for the person with a disability. This time, which is often pervasive, ends up taking away time from other areas of daily life, such as work, personal interests, leisure activities and maintaining social relationships.

On the other hand, time appears as an immaterial and conceptual dimension, linked to planning for the future. It is a future fraught with unknowns, in which the personal perspective of the caregiver and that of the dyadic relationship with the person being cared for are intertwined.

This paper aims to explore the psychological, social and symbolic-imaginary aspects related to the perception and management of care time, the ways in which carers involved in assisting people with disabilities plan for the future, and the role and function of support networks in the management and use of time.

Keywords: social capital, caregiver, me time, foreverism, social time concept.

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## 1. Introduction

The communication of a disability diagnosis is not something that affects only the person involved, but also determines a process of re-elaboration and renegotiation of various aspects of daily life and social reality within the support network in which they are involved (primarily the family).

This complex and multifaceted process of re-evaluation necessarily involves the dimension of time, which must be considered in the polysemic sense of the term and the symbolic universes it encompasses: a tangible and factual time, i.e. the time devoted to care by the caregiver towards the person with disabilities, which sometimes takes time away from other areas of daily life such as work, hobbies and passions, relationships and social interactions; an intangible and conceptual time, i.e. planning for the future, a personal future, the dyadic relationship with the person being cared for in terms of subsistence and social repositioning in the event of the carer's death or inability to continue providing care (particularly if they are a close family member).

In this perspective, the support network and the social support network possessed by the carer play a central role, as a relational sphere in which to find support, discussion and comfort in times of need or as a safe space.

The aim of this paper is to analyse the psychological, social and imaginary aspects of the perception of and relationship with caregiving time and future planning by carers who assist people with disabilities.

The first part of the paper is devoted to the "theoretical frame of reference", i.e. it will attempt to present a recent review of the main theories and research on the subject of caregiving and social support for people with disabilities. In addition, with the aim of guiding the reader in understanding the data and concluding reflections, some theoretical coordinates on the sociological concept of time will be presented, both in its short-term meaning and as a dimension of memory and long-term planning.

The second section of the paper will present the results and reflections that emerged from a qualitative survey conducted through dyadic interviews with 25 carers of persons with disabilities, residing in different regions of Italy, in order to understand the complex universe of the process of care and assistance for persons with disabilities.

## 2. Caregiving and social support networks for people with disabilities: an overview

Caregiving, in the context of disability, is a complex phenomenon that has attracted the attention of both sociology and psychology, as it represents a fundamental point of reference for understanding not only caregiving relationships, but also the social constructs that have historically developed around the figure of the disabled person. In the sociological tradition, the analysis of these relationships has been intertwined with the evolution of interpretative models of disability, taking on different theoretical configurations at different times in history.

In the early decades of the 20th century, people with disabilities were mostly relegated to the medical paradigm, which interpreted their condition as a pathological deviation from a given biological norm. In this view, caregiving was often conceived as an innate duty, linked to traditional family responsibilities, and the caregiver – when considered at all – was perceived as an ancillary figure to the work of the doctor, an informal support who participated in the "normalisation" of the disabled person. This model, in line with positivist medicine, tended to depoliticise disability, making it a technical object to be managed (Barnes, 1990).

However, caregiving can be understood in the light of reflections offered by feminist theory and disability studies as an intrinsically political arena in which structures of power and inequality are configured, reproduced or questioned. Thanks to this conceptual shift, the social model of disability, developed since the 1970s, began to emerge, redefining disability not as an individual characteristic, but as the product of social, cultural and environmental barriers that exclude people with physical or cognitive impairments. T. Shakespeare adds that every caregiving relationship involves an element of asymmetry, and that recognising this, while acknowledging dignity, is fundamental to authentic relational justice (Oliver, 1990; Shakespeare, 2006). J. Tronto (1993), within the theory of care developed in feminist thought, already highlighted how caregiving has been made invisible and devalued, as it is associated with female practices and socially marginalised individuals. In the case of caregiving for disability, this marginalisation is amplified: care is taken for granted, while caregivers face emotional tensions and ethical conflicts in balancing their time, their identity and the dependence of the other, leading to the assertion that "care is not simply a moral or domestic act, but a public practice that reflects and constructs power relations in society" (p. 103). At the same time, E.F. Kittay (1999) stated in her publications that care work must be recognised as central to the ethical and political structure of democratic societies because "we depend on each other, and this dependence is not an anomaly, but a fundamental condition" (p. 29). From this perspective, caregiving is not limited to responding to individual needs, but becomes a field of social tension, in which the dynamics of autonomy and dependence, visibility and invisibility, power and vulnerability are intertwined (Fine & Glendinning, 2005).

In recent decades, in Italy too, the thinking of authors such as Roberto Medeghini has contributed to broadening the debate, pushing for an interpretation of disability as a social and relational construct. Disability, these authors argue, is inseparable from the quality of the educational, emotional and social network in which the individual is embedded. In this context, the figure of the caregiver (often a family member) is crucial, but equally ambivalent: they are both a primary resource and a potential source of crisis, as they have to manage the emotional, temporal and economic burden of care on a daily basis (Medeghini, 2011).

The contribution of emotion theory to contemporary sociology has further refined the analysis of caregiving. Arlie Hochschild, with her concept of "emotional labour", has shown how caregiving requires intense emotional regulation, which can lead to a form of inner alienation when the emotions expressed do not coincide with those actually felt (Hochschild, 1983). This concept has been significantly developed in studies on family caregiving, where the moral pressure to "have to" care can coexist with feelings of frustration, loss and ambivalence.

One of the key theories concerns the concept of the "stress process model" (SPM)[1], which focuses on the physical, emotional and psychological pressures faced by caregivers. The latter is distinguished mainly by the dimension of time, which is a crucial aspect of the daily experience of caregiving. Research by Price et al. (2022) highlights how parents of children with chronic illnesses experience caregiving in a way that drastically transforms their lives, forcing them to renegotiate time and social expectations. Not only can the time devoted to actual caregiving take energy away from other areas of life such as work and social relationships, but it also creates a process of restructuring personal and professional ambitions (Kennedy et al., 2024).

The most recent sociological literature has brought new interpretative lenses to the experience of caregiving, both internationally and in Italy, highlighting the growing importance of social support networks as a resource for caregivers. These networks allow caregivers to share experiences and receive support, proving vital in times of crisis, as highlighted by Nguyen et al. (2021), who analyses the impact of caregiving on self-concept among caregivers, especially women. This work suggests that caregiving experiences can alter individual perceptions and family relationships, creating a new platform on

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[1] The Caregiving Stress Model is a sociological theory developed primarily by Pearlin et al. in 1990, which explains how stress develops and is maintained over time in informal caregivers, highlighting the factors that mediate or moderate the effects of stress on the caregiver's physical and mental health. It is based on a distinction between: primary and secondary stressors; personal and social resources; health outcomes.

which support dynamics can be rearranged. In China, Liu et al. (2024) highlighted how social support – understood not only as material help, but also as symbolic and relational recognition – significantly influences the psychological well-being of caregivers of adults with disabilities. The presence of a diverse support network reduces the risk of depression and isolation, showing that caregiving is not an individual activity, but a collective one, embedded in a fabric of reciprocity.

Reflections from this recent literature allow us to grasp a transformation in the figure of the caregiver: from an invisible and silent subject to a relational and political hub, embedded in more or less stable networks of meaning, affection and institutionalisation. In this context, disability cannot be understood outside the relational system in which it is embedded, and the caregiver emerges as an existentially and socially crucial figure for understanding current forms of interdependence.

In Italy, a recent study conducted by Beatrice Salsi (2023), focusing on parents of children with intellectual disabilities, found that the temporal dimension of care – in particular the uncertainty about the "after us" – generates a form of constant vulnerability. The parents' reflections range from an absorbing present to a future that is impossible to delegate, in the absence of institutional structures capable of taking on the continuity of care. This type of concern, the author observes, translates into a continuous effort to renegotiate identity and values.

At the same time, the Emilia-Romagna Region has promoted a research-intervention programme for the recognition of the role of family caregivers, launching an experiment that integrates public services and informal resources. The project – documented by Belluto et al. (2022) – highlights how regional policies can have a positive impact on the well-being of caregivers only if they are able to recognise their social function, avoiding placing the entire responsibility for care on them.

Time management also involves thinking about the future. Caregivers not only have to deal with daily challenges, but also plan long-term strategies, for example regarding the continuity of care in the event of unforeseen circumstances, such as illness or death of the caregiver themselves.

The prevalence of an "always-on care" model and the internalisation of caregiving as a long-term career are factors that influence the quality of life of the caregiver themselves and require reconsideration in the social and professional context.

## 3. The sociological concept of time: short-term and long-term dynamics

The dimension of time within the caregiving experience is of central importance and needs to be analysed in depth from a sociological point of view. It is essential to understand how time is assimilated and reorganised by those who perform the role of caregiver: it is no longer simply divided into “free” or “working” time, but is transformed into fragmented time, continuously redefined and determined by the demands of caregiving. The literature describes this transformation extensively: for example, qualitative research by Cuoco et al. (2024) shows that carers devote an average of more than thirty hours per week to care, distinguishing between “personal time”, “time for household management”, “time reserved for the person being cared for” and “time for social relationships”.

This articulation highlights how time is no longer experienced as a continuous flow, but as a series of segments that acquire meaning in relation to the burden of care and the needs of the patient. As Zwar et al. (2024), the intensity of care work – defined in terms of hours invested, tasks performed and perceived burden – affects the perception of one’s own ageing process and self-representation throughout life.

In other words, the time spent on caregiving changes the personal subjective experience of temporality: the caregiver may feel “older” or feel that they have “less time available” due to the constant commitment required by the role. Another significant element concerns the discontinuity between biological, social and personal time: those who provide care end up being involved in the time frames of the other, i.e. the person being cared for, and their own chronological organisation is redefined and often put on the back burner. The daily routine is thus structured into “micro-times” (individual care activities), “waiting times” (to obtain answers, services or resources) and “protected times”, which are, however, constantly renegotiated or sacrificed. This process of temporal negotiation can have a significant impact on the well-being, quality of life and social relationships of the caregiver: individual time is reduced, opportunities for socialisation diminish and opportunities for recovery remain scarce (Gérain & Zech, 2019).

In this sense, a sociological analysis of the concept of “time” is essential to understand the dynamics that lead to the concluding reflections of this study.

The concept of time and its perception has always been of great interest to the humanities, and in sociology, a robust and dense scientific literature has attempted to study the temporal element as a dimension of social reality and human experience.

For sociology, in fact, time does not represent a natural framework within which human actions and social dynamics stand out, but rather a central element that allows for the organisation, elaboration and re-elaboration of horizons of meaning in which to trace the analysis of the present, the codification and learning of past experience, and the anticipation and planning of the future.

In this perspective, time is restored to its symbolic, institutional and relational nature and function, which is necessary for understanding and analysing its role in human and social life and experience.

An important first distinction in the social analysis of time in human experience is between *micro-temporality,* i.e. the temporal rhythm of everyday life given by rhythms, routines, short-term planning and synchronisms, which has the function of organising and coordinating short-range human action and setting most interpersonal relationships on the micro-systemic side; and *macro-temporality*, which concerns "long-term" temporality, such as the analysis of the past and the analysis of social and cultural changes over long periods of time, which allow us to predict and anticipate future projections for both individuals and the community.

Zerubeval (1981) analysed micro-temporality, highlighting how calendars, timetables and "hidden rhythms" represent normative cultural frameworks that govern the social lives of individuals and establish "social temporal normativity", i.e. the human actions and stages that fall within the dimension of "being on time" as opposed to everything that is considered "out of time", normative aspects that vary – like all normative aspects – in relation to chronological height and different cultural contexts.

The relationship between micro-temporality and macro-temporality and how there is interdependence between changes in "longue durée" and normative temporal frameworks has been extensively investigated by Adam (1998) and Adam and Groves (2011), who proposes the concept of "timescape". According to the author, societies are traversed by complex and multiple temporal dimensions – for example, rhythms, sequences, durations, future plans, natural times, human times, etc. – which are composed and recomposed in specific temporal passages and which influence institutional, social and individual spheres in different historical periods. Adam's temporal interdependence between micro and macro is also supported at the institutional and social level by Luhmann (1995), who highlights – in his theory of social systems – the function of time planning, understood as "possible futures", as a continuous reworking of "temporal normativity" with the main aim of pacifying social anxiety about the future and reassuring new generations about the legacy of previous generations.

McAuley et al. (2006), on the other hand, highlight how the micro-macro temporality relationship also has effects on the biographical side of individuals, through the concept of the "timing" of people's lives: entering the workforce, starting a family, retirement, physical decline and death are "individual destinies" that are inevitably intertwined with biographical elements but also with social events and dynamics anchored in the specific historical moment in which the individual lives, highlighting in reality the individual's relative control over their own life timing.

Helga Nowotny (1994), in turn, emphasised post-modern temporality and the proliferation of personal times that were not contemplated in pre-modern society, a proliferation that has completely reorganised temporal normativity and individuals' living spaces. Furthermore, the author clearly highlights how there are "different temporalities" with respect to major social changes: while science, medicine and technology undergo relatively short temporal changes, social, political and legal elements change in a "lounge durèè" perspective, creating a temporal asynchrony that affects individuals' daily lives.

Virilio (1995), with the concept of *dromology*, identified the centrality of speed in late modern society, emphasising how technological acceleration imposes a remodelling of temporal rhythms and perceptions Miller (2018).

A further element that has profoundly changed the relationship between time and contemporary society is the digitalisation of society.

The spread of computer networks, the Internet and online platforms has produced an increasingly fragmented and accelerated temporality with a relatively short temporal processing speed compared to pre-digital society. Castells (2000) defined the digital society as "the timeless society", an era in which immediacy and simultaneity prevail over sedimentation and gradualness.

Rosa (2013) formulated the theory of social acceleration on the very theme of the processing speed of time, emphasising how the understanding of time and the increasing rapidity of social processes produce a paradoxical effect of "frantic stagnation" that paralyses decision-making processes, individual and social planning and creates an effect of "stagnation in the past and present" at the basis of the theories of *forverism* and *presentism*, which will be discussed in the following paragraphs.

## 4. The research process

The aim of this section is to describe the different stages of the research process that forms part of a PRIN project of national interest entitled "Social capital as resource of care practice in Italy: Caregiving and social support in pandemic time".

The research project has been designed as a composite research tool with different methodological approaches (mixed methods, qualitative and quantitative) that unfolds in two different, interconnected research segments: a) the reconstruction of the trust and cooperative networks that caregivers build and from which they can draw on different types of resources; b) a more detailed and in-depth analysis of the role of caregivers in Italy and the different mechanisms that determine their identity construction and operational processes, taking into account the particular historical and cultural moment experienced in the wake of the COVID-19 pandemic.

In order to investigate the construction of trust networks and the role and operations of carers of people with disabilities, 25 dyadic interviews were conducted in which the carer of the person being cared for and a reference person involved by the carer in the research experience were present. The reference person was someone who, in various capacities and on a completely voluntary basis, was involved in the process of caring for the person being cared for.

Each dyadic interview was preceded by the completion of a “Social Network Analysis” form with the aim of highlighting and examining the characteristics of the networks and relationships activated by the carers, with particular attention to both the structural and content aspects of the support relationships. In addition, the analysis focused on the morphology of the networks and the formal and informal resources implemented within the network. It also analysed the mechanisms regulating the relationships between the different components of the network, the perception of well-being, and the aspect of future planning and the evolutionary trajectories of the different relationships.

The analysis segment of this research work – with respect to the broader perspective of the general project – will focus on the last three aspects listed, namely the perception of short-term time, the dimension of planning and the future, and the role of the reference person involved in the care of the person with disabilities from the perspective of analysing the management and perception of time.

To this end, in order to understand the psychological, social and imaginary aspects of the temporal dimension of caregivers, the following research questions have been formulated: how do caregivers perceive the time available to them, and how do they organise their various activities based on their perception of time? How is the dimension of the future experienced, both in relation to one’s own plans and in relation to the evolutionary trajectory of the person being cared for, and what are the relationships between the two different perceptions of future time; how does the caregiver contribute to the management and perception of time in the short and long term.

The tool used was the dyadic interview, a particularly effective tool in the social sciences for analysing networks, relationships and intra- and interpersonal dynamics.

The interview is characterised by the simultaneous presence of two interlocutors who share an experience, a bond, or a specific social practice, who are asked to reflect, argue and narrate their common experience within a dialogical framework. The main strength of this tool is its ability to bring out not only individual points of view but, above all, relational dynamics and any converging – and diverging – points of view with respect to the focus of analysis and different experiences.

However, the data and narrative material should not be understood as the mere sum of the individual material collected, but as the complex and interdependent result of the interaction that took place during the dyadic interview.

Nevertheless, it is important to bear in mind the limitations and distortions that a composite interview may inevitably present: in some cases, certain personalities emerge more than others, and individual dialogical abilities may obscure and render invisible other positions; often – especially in an emotional relationship such as that between a caregiver and a person of reference – responses are set to a "desirability" effect within the dyadic relationship and would lose authenticity and spontaneity.

*Table 1. Caregiver of people with disabilities.*

| Countries | Gender | Age | Partial for gender | Total for countries |
|---|---|---|---|---|
| Campania | Female | 67,64,54, 52, 75,57,66,42,29 | 9 | 10 |
| | Male | 67 | 1 | |
| Latium | Female | 53, 26 | 2 | 2 |
| | Male | -------- | 0 | |
| Sicily | Female | 48 | 1 | 1 |
| | Male | -------- | 0 | |
| Piedmont | Female | 46,32,65,45,65,38,57 | 7 | 8 |
| | Male | 69 | 1 | |
| Basilicata | Female | 31 | 1 | 1 |
| | Male | --------- | 0 | |
| Veneto | Female | 53,60,72 | 3 | 3 |
| | Male | -------- | 0 | |
| Total Partial for gender | Female | | 23 | |
| | Male | | 2 | |
| Total | | | | 25 |

The dyadic interview covered various aspects, such as communicating the diagnosis of disability to the person being cared for, the support networks in place at the time of the interview, the impact of the diagnosis and care on family life, the role of the reference person in caring for the person being cared for and within the caregiver's support network, the role of institutions and association experience (where present), the perception of well-being in the present and the dimension of the future and planning.

The dyadic interviews were conducted from March to November 2024 in person, where possible, or online via the Meet platform.

The tables 1 and 2 show the socio-demographic data of the carers (table no. 1) and the reference persons (table no. 2).

*Table 2. Reference persons chosen by caregiver of persons with disabilities.*

| Countries | Gender | Age | Partial for gender | Total for countries |
|---|---|---|---|---|
| Campania | Female | 47,60,29,28,71 | 5 | 10 |
| | Male | 52,41,53,57,70 | 5 | |
| Latium | Female | 33 | 1 | 2 |
| | Male | 49 | 1 | |
| Sicily | Female | -------- | 0 | 1 |
| | Male | 53 | 1 | |
| Piedmont | Female | 52,57,44,37,51 | 5 | 8 |
| | Male | 37,79,47 | 3 | |
| Basilicata | Female | 45 | 1 | 1 |
| | Male | --------- | 0 | |
| Veneto | Female | 86 | 1 | 3 |
| | Male | 67,67 | 2 | |
| Total Partial for gender | Female | | 13 | |
| | Male | | 12 | |
| Total | | | | 25 |

The analytical approach was hermeneutic, a perspective that emphasises the centrality of the process of understanding content: the technique aims to construct meaning by restoring the complexity and richness of human experience and individual and collective experiences within social and cultural frames that restore meaning and perspective.

## 5. Data analysis and discussion

### ***5.1. Caregiving and short-term time: organising and conserving time***

Analysis of interviews and life stories of carers of people with disabilities revealed a general tendency to consider short-term time as something "precious", "rare" and, at the same time, something to be "protected" and "organised".

An analysis of the terms (both adjectives and verbs) referring to time shows that in the short-term management of time – i.e. everyday time – carers use terms that refer to two macro-dimensions: on the one hand, organisation: the caregiver reports that the entire day and the entire time schedule revolves around the act of care, an act that often engulfs all other activities and all other "times of life" of the person and the family unit; on the other hand, conservation: carers are particularly careful not to "waste time", which is considered a precious commodity and something that must necessarily be taken into account in organisational and functional aspects of the life of the person being cared for and the extended family.

The organisation of daily time revolves around the primary care of the person being cared for, the management of medical appointments and therapies, and the scheduling of any check-ups or day hospital visits; a time that fits in – often with difficulty – with their own lives and those of the extended family. The following interview excerpts testify to the complexity of the time planning process that caregivers of people with disabilities often have to face.

> "I am the mother of two autistic boys: XXXX1, the eldest, is twenty-one years old, and XXXX2 will be eleven in May. They are both different from each other, because with ten years between them, one needs to be accompanied to university or work experience, while the other needs to go to dance classes, therapy, homework, birthday parties, etc. So, many years ago, when XXXX1 was born, I had to give up working as I had done before because there are not many people here in the family. In fact, there is no one: because he, PR, has only one brother and he takes care of my father-in-law; my family is all in America (brothers, mother, etc.), so there was no support" (woman, carer, 48, Catania).

> "You have to tell XXXX what to do in everything, like getting dressed, 'brush your teeth", "eat"... You have to keep an eye on him because otherwise he does things hastily and carelessly, so you always have to keep an eye on him when it comes to personal hygiene, managing his tasks, managing his food; you have to give him certain fairly precise rules, otherwise he would spend all his time in front of the TV, tablet and everything else he has... So, very specific rules... and rules help me a lot... they help us... so XXXX has very specific and well-defined rules throughout the day" (woman, carer, 66, Salerno).

In most cases, as shown in Table 1, the caregiver is female and tends to be the mother of the person being cared for. The caregiver has gradually sacrificed her personal time in favour of caring for and managing the person being cared for, leaving her job or considerably reducing the time available for her own self-fulfilment. This is highlighted in the following interview excerpts.

> "I used to teach. Then, when I had my other daughter, I was doing more than one job. I left teaching to spend more time with my daughter. At the same time, I was working with my husband's sister in a party favour shop. I continued working like this, but I always kept her busy because she had therapy every morning, every day. Then I took XXXX to therapy in the afternoon, because that half hour wasn't enough... an hour of therapy. I was lucky because I had a good teacher: a good therapist, at the beginning, who let me participate with her and then told me how I should help her discover her feet, her hands..." (woman, carer, 60, Cagliari).

> "In the past, I always worked. Then, with the arrival of P.A., we put work aside. However, the idea of going back to work was there, but unfortunately now there just isn't enough time... even if I wanted to go back to work, I wouldn't be able to find a job that was easy to manage with the hours you have to fit in with XXXX... even when you go for a job interview, you start saying "but I can't work in the afternoon and in the morning after eight, because I have XXXX first"... and anyway, he needs to be looked after and taken to school... so it becomes a bit difficult to work... I miss working and being able to interact with people... anyway, work, I always say, work helps you to completely disconnect from your daily and family routine, and I think those who work are lucky, those who have the opportunity to work" (woman, carer, 38, Novi Ligure).

Further key elements – which we will also find important in subsequent analyses – are the diagnosis of disability and the age of the person receiving care: the type (and severity) of diagnosis necessarily implies a targeted and systemic organisation, and the organisation of care and life during an acute event that arises later would appear to be different from the planning and organisation of a chronic condition that arises in the early stages of life; Furthermore, the management of time and the rhythms of life of a person receiving care during their developmental years (up to the age of 18) differs from that of an adult.

> "Family management has changed, our lifestyle has changed. For example, we used to be able to go out in the evening and take our little one with us, but now, of course, we can't do that because we're afraid.

> She has her habits, she's much more delicate... so before going to a birthday party, we say, "Oh my God, wait, because I know that if she leaves the house, she'll catch a cold," and then the fears and anxieties begin. Yes, life has changed quite a bit: if we go shopping, we don't take the children with us; one stays at home with the baby and the other goes shopping, because crowded places are absolutely out of the question. It has changed us a lot" (woman, carer, 24, Rome).
>
> "XXXX has spastic tetraparesis. He cannot speak, he cannot hold his head up and his left arm and hand are rotating like this 'simulates the movement' and he moves it less; and his right leg also remains a little more bent because the tendons may be shrinking... So, in recent years, she has had great difficulty sitting up and therefore prefers to lie down, even in the wheelchair she uses to go out or to eat at home. She lies down almost as if she were in a cot... and often suffers from back pain: we realise this because at those times she doesn't want to stay in the wheelchair; she prefers to lie down, perhaps on the sofa with her legs dangling, just to take the weight off. She needs help with everything: if we wash her, she doesn't help in any way, she remains a dead weight, so she doesn't help to turn herself over; we have to lift her by her arm, turn her over, and that means two of us have to give her a daily shower: either PR and I do it, or PR and my husband, or my husband and I. In short, it always takes two of us" (woman, carer, 57, Salerno).

The interview excerpts highlight the different perceptions and organisation of daily time with respect to the person being cared for: while in the first case the person being cared for is a 2-year-old girl with Down syndrome and the rhythms and organisation of time planning are organised around the child's therapies and health needs, the second story is that of a carer of a 31-year-old person with spastic tetraparesis and is different in that the time spent on care is totally focused on managing physiological needs and structural body care.

As we will see in section 5.3, it is precisely the management and perception of short-term time that involves the reference person in a considerable and important way, often allowing psychological decompression from feelings of oppression and lack of time for the caregiver, acting as a real "time reservoir".

### *5.2. Caregiving and long-term care: between foreverism and presentism*

With regard to the perception of long-term time, i.e. the future and long-term planning, analysis of the interviews and life stories revealed a tendency to "procrastinate" when it came to planning their own future and that of the person they were caring for, focusing mainly on the day-to-day and immediate future.

Most of the people interviewed showed resistance and fear in addressing the topic of the "future" and often returned to talking about the present and the past without any mention of the future, except in a fatalistic dimension or one entirely entrusted to "fate" or "God's will".

While aware of the interpretative and methodological limitations, one above all being the small sample size that does not allow for generalisable interpretations, the common thinking of many carers would suggest, with the appropriate interpretative measures, a dual matrix of thought that is arousing particular interest in the philosophical and sociological scientific community and can be found in various areas of human and social reality: foreverism and presentism.

The term foreverism, coined by Grafton Tanner (2024), describes a contemporary cultural tendency to avoid endings, whether they be death, the end of relationships or the conclusion of projects. This perspective manifests itself in society through the pursuit of eternal youth, the use of technologies to prolong life and the denial of death.

Presentism, on the other hand, refers to the tendency to interpret the past through contemporary thought patterns and analytical lenses (Hartog, 2003), but has recently been highlighted by Zimbardo and Boyd (2008). This interpretative bias has also taken on connotations in human behaviour and in certain modes of social analysis that tend to focus exclusively on immediate experience, progressively reducing attention to and planning for future experiences.

Foreverism and presentism thus become interpretative paradigms of historical and philosophical disciplines, but also a cross-cutting phenomenon that reveals the growing difficulty of contemporary society in maintaining a dynamic balance between memory, the present and anticipation of the future.

Applied to caregiving, these concepts refer, on the one hand, to an individual's dedication to caring for a person with disabilities, a commitment that often extends beyond the caregiver's own life, and, on the other hand, to the cultural tendency that highlights a difficulty in dealing with death as an integral part of life and significantly procrastinates in designing a social and organisational structure around the person being cared for that does not necessarily contemplate the presence of the caregiver.

This paradigm – i.e. foreverism/presentism – could provide a further interpretative lens to explain why the "Dopo di Noi" projects are struggling to become stable and recognisable in the collective imagination of carers.

On the one hand, as highlighted in some life stories, the Dopo di Noi projects seem to be a reality still far from becoming stable in Italian society due to "structural" reasons related to the welfare state – such as lack of funds, cumbersome bureaucracy, gaps in the services offered – on the other hand, it is the families themselves who highlight the difficulty of planning a future for their loved ones that is different from a reality that does not fall within the family, but more often than not, carers tend to avoid talking about the future and remain firmly focused on managing the present.

The following interview excerpts highlight the points described above.

> "Should I be honest? I live very much in the moment; in the sense that I follow the debate about what will happen after we are gone, etc., and I don't know... I live very much in the moment, living in the present; I have always done so because if I start thinking about the future, I think it would become like a cloud over my head and would no longer allow me to live in the present. So we try to give her financial support so that in the future she can be financially independent, yes. Her situation is so serious that I don't even ask myself the question (i.e. what she could do) because it would distress me too much" (woman, carer, 65, Verona).

> "We have to live in the present. The future will take care of itself. New prospects will probably arise, but we are not making any predictions for the future. We definitely need to provide financial support for the future, that's for sure. We don't want to make predictions about 'what will happen' etc." (79-year-old male, caregiver, Verona).

> "Let's say that, as PR said, I'm afraid I can't predict XXXX's future. I am very scared because, unfortunately, I am very rational and pragmatic, and so, unfortunately, I am not very positive, but my life plan for XXXX is to get him into a job at the book garden, where he could be a theatre tutor or a... steward at events, or a presenter of... in short, something related to his, to his, let's say, his interests. I hope that C's future will be as long as possible so that I can help XXXX and NameF until the very end of my life, and what happens after we are gone is also, let's say, a bit of a question mark because, unfortunately, I did not expect NameF to have what he had, so I

> say...even though I'm doing everything I can not to burden him, I thought that NomeF would live longer than XXXX and so he could at least look after his safety and well-being. But, I mean, I'm scared that NomeF will die before XXXX, so let's say that this question about the future is my real fear. But what can I do? As long as I can, I just hope I don't get sick... that's all I want. I just hope I don't get sick and that I can do what I can do until... for a long time, I mean" (woman, carer, 44, Salerno).

### *5.3. Caregiving, point of contact and time: in search of Me Time*

Short-term time management and daily life seem to be the aspects that directly and significantly involve the caregiver.

Caring for the person being assisted gradually erodes the time available for the caregiver's own activities and well-being (Perucci & Negrogno, 2021).

Caregivers often experience a conflict between their duty to care for others and the need to take care of themselves: they often find themselves sacrificing themselves in order to devote themselves completely to the person being cared for. This precarious balance can lead to an increase in emotional and physical burden (Velloze et al., 2022), resulting in distress, emotional exhaustion and social isolation (Ramírez-Perdomo et al., 2024). Caregivers often experience guilt and stress related to the difficulty of reconciling the multiple identities and responsibilities that the role entails (Huang et al., 2022).

For example, Saunders and Groh highlight how widowed carers face a series of challenges once their caregiving role is over, embracing a period of "me time", which often translates into a journey of self-understanding and coping with loneliness (Saunders & Groh, 2019).

Analysis of interviews and life stories clearly showed that carers need a "reserve of time" to be able to carry out personal and social activities outside of caring for the person they are assisting. In this context, there are two concepts that can help to interpret the role of the reference person within the complex reality of caring for a person with disabilities: the concept of "Me time".

The concept of "Me Time", understood as time dedicated to personal well-being and psychological recovery, takes on crucial importance in the context of caregiving, especially when it comes to assisting people with disabilities. In fact, many of the carers interviewed highlighted – at various points – how the caregiver often represents a real "time bank", i.e. the person from whom they can draw time by replacing them in the care of the person being assisted, allowing the caregiver to devote themselves to their own needs, whether these are personal (e.g. going to the hairdresser or for medical tests), social (going out for pizza with another child's class group or with work colleagues) or administrative/bureaucratic (completing administrative procedures for oneself or other family members). It is clear, as in previous analyses, that the diagnosis and severity of the condition and the age of the person of reference are determining variables in the caregiver's request for time from the person of reference and in the emotional management and weight of responsibility with regard to the explicit request for "time for oneself".

The following interview excerpts clearly illustrate the relationship between carers and reference persons with regard to the request for "me time".

> "When he is free and does not have to work, he takes care of many things: he looks after the children if they need to go somewhere or if they have homework. In short, lots of little things; and then, thanks to Law 104, he gets a certain number of hours per month that he can use to assist disabled people in the family, and therefore his children. Thanks to this, I can manage a little even if I have a need (I have to cut my hair, take a shower). Many things are limited due to the availability of help" (woman, carer, 48 years old, Catania).

> "Ah PR, me? How does he help me? Yes, PR helps me, for example, if I'm ill and can't take XXXX to therapy or... I sometimes ask PR, I say "PR, please, can you take me to XXXX this afternoon?", and he comes, or "PR, we have... at the book garden, we have tonight, I don't know, the paper has to be thrown away, I couldn't do it, can you throw it away?". I mean, PR is really, as he said, like my husband, in the sense that we're not... but as if he were the male figure that is missing in our family, who is absent, and so he is our point of reference, both as a reference figure, let's say for XXXX. Because he spends several hours a day with XXXX every day" (woman, carer, 44, Salerno).

## 6. Final reflections

The dimension of time is a central element in the care and organisation of the various aspects of life for carers of people with disabilities.

Time is experienced on two distinct levels: contingent, present and immediate time, which requires systemic responses to the needs of the person being cared for and the entire family unit responsible for caregiving; and future, deferred, intangible time, which is often not considered and/or cannot be contemplated: the time of projection and long-term planning.

From the analysis of the interviews and life stories of the carers who participated in the research, it is clear that in their narratives and perceptions, short-term time is the focus of their daily perspective and of planning "close" to the present, while there is a clear resistance to planning for the future, to projecting the life of the person being cared for into the distant future, perhaps without the presence of the caregiver or outside the family's caregiving activities.

The first trend, aware of the methodological limitations and the non-generalisability of interpretations, would seem to fall within a matrix of contemporary thinking that combines aspects of "foreverism" and "presentism", i.e. the tendency of contemporary individuals to remain focused on analysing and remembering the past and the need to deal with the individual and social aspects of the present, completely disregarding aspects considered distressing, such as the future, the end of life, and life trajectory planning.

In analysing the temporal aspects of caregiving, the role of the reference person in short-term time planning and scheduling takes on particular importance.

The dyadic interviews and life stories of caregiver-reference person relationships have made it possible to highlight, using the interviewees' own words, how caregivers often use the help of the reference person as a "time bank" or "time reservoir", i.e. a resource of time made available to the caregiver "for themselves" (Me time concept) provided by personally replacing the caregiver in certain activities and at certain times of the day.

On a theoretical level, the two concepts of Me time and Foreverism/Presentism can create significant intersections in the context of the care professions and end-of-life preparation, raising ethical and practical questions: on the one hand, carers need time for themselves in order to provide quality care; on the other hand, the denial of the future, procrastination in planning for the "after us" and the difficulty in "letting go" of a loved one or a situation of great suffering can lead to degenerative effects on both an emotional-psychological and a social-structural level.

It is essential to highlight that policies supporting carers must consider their need for time for themselves as a crucial element in maintaining their mental health and ability to provide effective care.

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