

Link alla rivista: <https://riviste.unimi.it/index.php/AMonline>

Issue n. 32 (2024), *Quando la narrazione incontra la cura: Dialoghi interdisciplinari intorno alla malattia e al trauma*:

<https://riviste.unimi.it/index.php/AMonline/issue/view/2563>

Essay: Coppola, Maria Micaela. 2024. «Into the Land of Wonder: The Narrative Life of Dying Neural Cells in Dementia Stories». *Altre Modernità*, n. 32 (novembre):1-16.

<https://doi.org/10.54103/2035-7680/27240>.



Muratori, Micol. "Abbraccio." *Dissolving Forms*, tecnica mista su carta, 2024



# *Into the Land of Wonder: The Narrative Life of Dying Neural Cells in Dementia Stories*

by Maria Micaela Coppola  
(Università degli Studi di Trento)

**ABSTRACT:** This paper aims at engaging in dialogue with diverse perspectives on neuropathology by examining the intersections between biopsychiatric and narrative portrayals of dementia. Firstly, we investigate how neurocognitive disorder is depicted in narrative form (in prose and verse), emphasising the significance of “narrative brain scans” as sites of intersubjective exploration of this complex experience. Secondly, we emphasise the unique potential of dementia narratives in prompting contemplation of whether the disruption of consciousness can be questioned through imagination and storytelling. Ultimately, narratives of dementia serve to practice wonder and not knowing (Candiani), and challenge reductionist boundaries between life and death, presence and absence of consciousness. Employing Lewis Carroll’s *Alice’s Adventures in Wonderland* (1865) as a narrative framework, this paper embarks on a journey in search of wonder within narratives by Mariangela Gualtieri, Jonathan Franzen, and John Bayley, depicting progressive cognitive decline.

**KEY WORDS:** wonder; dementia stories; narrative psychiatry; Mariangela Gualter; Jonathan Franzen; John Bayley



## INTRODUCTION

“You,” your joys and your sorrows, your memories and your ambitions, your sense of personal identity and free will, are in fact no more than the behaviour of a vast assembly of nerve cells and their associated molecules. [...] You are nothing but a pack of neurons. (Crick 3)

The name of the molecular biologist Francis Crick is tied to the discovery of the double helix structure of DNA. Together with Maurice Wilkins, he was awarded the 1962 Nobel Prize in Physiology and Medicine. The words above epitomise Crick’s later research on theoretical neuroscience and the neurobiological basis of human consciousness. Taken from his book *The Astonishing Hypothesis. The Scientific Search for the Soul* (1994), this paragraph introduces his investigation into the connections between the brain and the conscious mind. “You’re nothing but a pack of neurons” is used here to put in a nutshell the so-called reductionist approach, which can be broadly defined as “a belief in the possibility of a mechanistic, analytical explanation of biological phenomena in terms of physics and chemistry” (Fuerst 242). If, as Crick writes, “a complex system can be explained by the behavior of its parts and their interactions with each other”, then “our minds—the behavior of our brains—can be explained by the interactions of nerve cells (and other cells) and the molecules associated with them” (Crick 7).

This paper focuses on a particular kind of brain, namely the brain affected by dementia, and its narrative representations. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), dementia is categorised as a neurocognitive disorder. The term ‘dementia’ is used as a general name for a syndrome characterised by organic brain disease, primarily caused by the buildup of toxic proteins, which form plaques and tangles around and within brain cells. This degeneration process results in the loss of neurons and synapses, leading to progressive cognitive decline and interference with independence in everyday activities. Dementia syndrome predominantly affects older adults, and particularly women. Currently there is no cure for this disorder. Despite progress being made towards disease-modifying therapies, drugs like lecanemab and donanemab have not yet been granted widespread clinical implementation or approval (Belder *et al.*).

Dementia—including Alzheimer’s disease (the most common form of dementia)—can impact various cognitive domains such as attention, executive function, learning, memory, motor-visual perception, language, and social cognition. In the later stages, with the brain engulfed by tangles of ill-functioning synapses and dead neurons, everything that defines a whole, conscious human being worsens: decision-making, problem-solving, relational competence, self-awareness are progressively lost. Additionally, the body becomes less mobile and autonomous, since dementia syndrome can also compromise bodily functions, including the ability to stand or walk, swallow, control the bladder, and regulate bowel movements.

The approach adopted seeks to engage in dialogue with different perspectives on this neuropathology by exploring the interconnections between biopsychiatric and narrative representations. Firstly, we will focus on narrative representations (in prose



and verse) of the brain affected by dementia, and we will examine how “narrative brain scans” can serve as sites of intersubjective observation of this complex experience. Secondly, we will explore the unique potential of dementia stories, which encourage readers to wonder whether the life of the neural correlates of consciousness could be ‘expanded’ through imagination and storytelling. Ultimately, we will see how stories of dementia can play a pivotal role in questioning the boundaries between life and death, presence and disruption of consciousness, by venturing into the realm of wonder and not knowing (Candiani). Lewis Carroll’s *Alice’s Adventures in Wonderland* (1865) will provide the narrative framework for this journey in search of wonder in tales by Mariangela Gualtieri, Jonathan Franzen and John Bayley, which account for progressive cognitive deterioration.

## NOTHING BUT A PACK OF NEURONS? INTERFACING BIOPSYCHIATRIC AND NARRATIVE BRAIN SCANS

If we examine Francis Crick’s complete passage, we can observe that he introduces his “scientific search for the soul”—as indicated in the subtitle of the volume—based on a literary reference, which in turn prompts a narrative twist:

The Astonishing Hypothesis is that “You,” your joys and your sorrows, your memories and your ambitions, your sense of personal identity and free will, are in fact no more than the behaviour of a vast assembly of nerve cells and their associated molecules. *As Lewis Carroll’s Alice might have phrased it: “You are nothing but a pack of neurons”.* (Crick 3; my emphasis)

So, Crick’s “scientific” argument is opened by evoking the character of Alice and Lewis Carroll’s fictional land of wonder. This narrative turn in Crick’s exploration of the neurobiological basis of human consciousness is particularly striking when considering that Carroll’s *Alice’s Adventures in Wonderland* is often regarded as emblematic of the nonsense genre, and as a story that emphasises the power of imagination and curiosity in the quest for knowledge, encouraging readers to challenge conventional reality by immersing themselves in a world teeming wonder and mystery. Indeed, I would argue that this passage encapsulates the potential for both reductionist and narrative approaches to mutually enhance one another.

Promoting the significance of narrative in psychiatry, Bradley Lewis’s analysis of how stories can shape clinical practice is pertinent to the present study as it bypasses the simplistic dichotomy between the current idealisation of biopsychiatry—which “articulates mental illness as a medical disease involving neurological pathology”—and antibiopsychiatry’s critiques of reductionism—which argue that “we are more than our bodies and brains [...]; we are also our experiences, our hopes, our dreams, our histories, our cultures, our politics” (Lewis 1). According to Lewis, a narrative approach to psychiatry can dismantle the dominant biological discourse, while fostering more multifaceted perspectives than the denunciations of reductionism made by antibiopsychiatry: “We need a new approach to psychiatry,” he argues, “that can hold in



tension the value of biological models (even when they are reductionist and oversimplified) while at the same time putting these models into a greater perspective” (2). In narrative psychiatry Lewis envisions a more complex model for conceptualising mental illness, which neither outright dismisses the biopsychiatric approach as reductionist nor unconditionally embraces the antireductionist stance:

we need an approach that recognizes the value of reductionist interpretative frames, including biopsychiatry, while avoiding the trap of simultaneously idealising it. Narrative psychiatry, along with its core theory of narrative multiplicity, provides just that approach. (15)

So, not only does Lewis reject the dualism between reductionism and antireductionism, but he also calls for a move from antireductionism to narrative multiplicity. By acknowledging a variety of metaphors, characters, plots, styles, paradigms, and discourses, narrative psychiatry can provide non-dogmatic interpretations of patients’ stories and human life:

The goal of narrative psychiatry is not to denigrate single interpretative solutions for their simplicity, nor is it to take single solutions and make them complex. The goal is to increase our appreciation of alternative solutions, be they simple or complex. The goal is openness to a range of options and to richness and variety of psychiatric experience. (16)

According to Lewis, the narrative turn for psychiatry can usher in new horizons by embracing the value of complexity without disparaging simplicity.

Starting from Lewis’s promotion of the role of the narrative in psychiatry, it could be interesting to see how narrative can investigate psychiatric pathology. In particular, I believe that stories of dementia can be sites of interface between the biomedical and narrative approaches to neurological disorder. They can be regarded as “narrative brain scans” (Coppola, “mente”), providing subjective and complex descriptions that can complement neuroimaging, and overcome the binary opposition of probiopsychiatry and antibiopsychiatry. A narrative brain scan entails an examination and description of the brain through narrative means rather than visual, adopting a subjective rather than objective standpoint, and involving diverse participants in the meaning-making process, including individuals who are affected by mental illness, caregivers, witnesses, and readers.

For centuries, narratives have served as tools for exploring and depicting brain functioning and human consciousness. In a radio broadcast titled “Craftsmanship” (1937), Virginia Woolf eloquently portrays the elusive, dynamic, and untameable nature of words, underscoring their connection with the mind:

They are the wildest, freest, most irresponsible, most unteachable of all things. Of course, you can catch them and sort them and place them in alphabetical order in dictionaries. But words do not live in dictionaries; they live in the mind. (Woolf 03:30-03:47)



According to Woolf, words are “irreclaimable vagabonds” that “rules of grammar and spelling” can scarcely restrain, living “variously and strangely” in the mind. Yet, paradoxically, it is precisely because words are brimming with echoes, associations, and memories that they serve as the means through which the mind can be observed and described, as if “peering over the edge of that deep, dark, and only fitfully illuminated cavern in which they live” (04:39-05:29).

Building upon this imagery, one could contend that narrative means offer a liminal perspective, allowing for the scrutiny and portrayal of the *chiaroscuro* areas of the mind, whereas scientific tools of inquiry into the mind strive to shed light, illuminate, and pinpoint specific areas or functions, thereby gaining insight into them (Coppola, “mente”). Narrative accounts of progressive cognitive disorders can immerse readers in brain worlds that remain, to some extent, unknown, obscure, and unaccountable, from both biopsychiatric and narrative perspectives. As for the former, empirical accounts of dementia syndrome are becoming more detailed, clear, and precise. Diagnostic tools such as tests and brain imaging have contributed to developing in-depth understanding of clinical cases, throwing light on the syndrome’s characteristics, symptoms, phases, causes, and risk factors. However, some aspects remain shrouded in obscurity: researchers are aiming at getting timely diagnosis, reversing cognitive deficits, as well as lowering the cost of tests and drugs, and improving their effectiveness. As for the narrative perspective, through dementia stories or, more generally, fictional psychiatric pathography, “vivid, persuasive and believable representations of the experience of sickness can be created, mental processes can be simulated, and emotive responses to suffering characters can be triggered” (Coppola, “Pathography” 63). Yet precisely because these narrative representations call for suspension of disbelief, open interpretations, shifting meanings, and empathy, they can be unsuitable for objective, evidence-based inquiry. So, to put it in a nutshell, neither neuropathology nor fictional pathography alone can fully capture the complexity of the subject.

Examples of nuanced narrative brain scans can be found in Mariangela Gualtieri’s poems included in the section titled “Ma” (37-48) in *Le giovani parole* (2015). In the following excerpt from an untitled poem, the combination of cognitive decline with impairments in physical functions, which is typical of neurocognitive disorders, is vividly portrayed in poetic form:

[...]  
Ci volevano gambe per lei e spinte  
alle ruote di ferro che la portavano.  
La mamma affogava nel tempo  
lasciava pezzi di abilità  
e ingegno e memoria, tutto  
sbriciolava lento, si allagava  
la mamma, spettinata come non mai  
si dileguava in parte in parte  
ogni giorno diluiva il suo essere lei  
nell’indistinto della specie.



E io accompagnando quel suo  
disimparare il mondo  
studiavo l'ultima scena  
recitando con lei. [...]¹ (Gualtieri 45)

In this case, the poet and readers witness time taking away “pieces of skill/ and ingenuity and memory” (pezzi di abilità/ e ingegno e memoria”) from the mother, for whom everything is “crumbling slowly” (“sbriciolava lento”). Due to an unspecified cause, whose characteristics suggest cognitive deterioration, the mother’s sense of selfhood and humanity are fading away, becoming indistinct and out of focus. In biomedical terms, it is a process of retrogenesis, by which the order of acquisition in typical development is reversed. In narrative terms, this process is depicted as “unlearning the world” (“disimparare il mondo”), which extends beyond mere brain functioning and beyond the afflicted subject. Rather, it involves both the mother and the poet—who appear to be interdependent—as well as the readers. For all those engaging with this story of cognitive decline, living and dying equate to rehearsing a common script.

Narrative brain scans can fill in the blanks left by neuropathology, shifting the focus from the disease’s mechanical processes to the suffering subjects—whether patients, relatives, caregivers, healthcare workers, or readers—and to their unique and intersubjective experiences of illness. They redirect attention to the individual, family, and socio-cultural contexts in which these experiences unfold. However, while narrative brain scans offer valuable insight, they cannot provide a comprehensive understanding on their own. For instance, they often lack specialised language, evidenced-based methods, and the clinical distance that are crucial for accurate diagnosis and effective treatment, as well as for gaining scientific knowledge and objective understanding, which can counteract stigmatisation and denial.

In my opinion, another example of narrative neuroimaging is “My Father’s Brain” by Jonathan Franzen (first published in *The New Yorker* on September 10, 2001), where bio-medical and narrative brain scans, empirical studies, and collective memories intertwine. In this essay, which is the opening piece of the collection *How to Be Alone* (2002), Franzen provides a narrative portrayal of the brain of his deceased father, affected by Alzheimer’s disease. He builds his argument starting from a personal memory, and weaving it into a compelling story:

Here’s a memory. On an overcast morning in February 1996, I received in the mail from my mother, in St. Louis, a Valentine’s package containing one pinkly romantic greeting card, two four-ounce Mr. Goodbars, one hollow red filigree heart on a loop of thread, and one copy of a neuropathologist’s report on my father’s brain autopsy. (Franzen 7)

---

¹ “Legs were needed for her and pushes/ to the iron wheels that carried her./ The mother was drowning in time/ leaving pieces of skill/ and ingenuity and memory, everything/ crumbling slowly, flooding/ the mother, dishevelled as never before/ disappeared little by little/ each day diluted her being she/ in the indistinct of the species./ And I accompanying that/ unlearning the world/ was rehearsing the last scene/ putting on an act with her. [...]”. Unless otherwise noted, all translations from Italian into English are my own.



This introductory paragraph displays the fundamental components of storytelling: characters, plot, theme, setting, point of view, and conflict. These elements shape Franzen's piece, which seamlessly blends argumentative, fictional, biographical, and autobiographical notes. Furthermore, it functions as a case study, akin to Oliver Sacks's concept of "deepen[ing] a case history to a narrative or tale" (x): the description of the disease, initiated from a memory and a brain autopsy report, sets the stage for the tale of the sick subject (Earl Franzen) and those close to him, who also grapple with Alzheimer's disease alongside him. The recollection of receiving a copy of the neuropathologist's report from his mother triggers the act of storytelling. This comprises the stories about the patient and his family, scientific descriptions of the neurocognitive disorder, and reflections on dominant conceptualisations of Alzheimer's disease in Western culture. Initially, these accounts are juxtaposed. The language of the autopsy report is detailed and specialised, precisely delineating specific areas of the brain and their physical attributes; while Franzen employs common language that relates to everyday experience. Upon reading the report's opening lines, Franzen recalls feeling compelled to translate evidence and data into ordinary terms:

I remember [...] sitting down to read it. *The brain* (it began) weighed 1,255 gm and showed parasagittal atrophy with sulcal widening. I remember translating grams into pounds and pounds into the familiar shrink-wrapped equivalents in a supermarket meat case. (7)

Franzen's 'translation' from pathological neuroimaging to narrative brain scan is essential for extracting his father's unique and complex story from the objective, straightforward description of his brain's withered and widened sections, which could belong to anyone with the same condition.

This translation process expands beyond language alone: it encompasses the conceptualisation of illness and ill people. Franzen argues against "the medicalization of human experience, the latest entry in the ever-expanding nomenclature of victimhood" (19). He seeks to transform a general condition that goes under the name of Alzheimer's disease into the unique story of Earl Franzen, his father:

Conditions have symptoms; symptoms point to the organic basis of everything we are. They point to the brain as meat. And, where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self [...]—to reduce our beloved personalities to finite sets of neurochemical coordinates. Who wants a story of life like that? (19-20)

Moreover, in rejecting the reductionist approach and calling for a different kind of story, which does not merely "point to the brain as meat," Franzen's brain scan embraces the potential for revision and creativity in the narrative reconstruction of events: "What I want (stories of my father's brain that are not about meat) is integral to what I choose to remember and retell" (31). The act of transliteration implies the enactment of the core elements of storytelling. Only through this approach can a story that questions the





limits of pathological reports be crafted—a multilayered story, which can acknowledge that “we are larger than our biologies” (33).

Nevertheless, it is crucial to recognise that the postmortem brain autopsy is the starting point of Franzen’s larger-than-biology tale: his reaction of “putting the report back in its envelope without reading any further” (7) triggers reflections and memories that re-create his father’s brain within the context of the author’s own story, as well as that of his mother and family. It also “excites the amateur scientist” (10) in him, prompting him to eventually read the whole report, quote sections of it, and refer both to empirical studies and mainstream discourses on Alzheimer’s disease. Thus, whereas his mother avoids direct confrontation with the pathology, burdened by the stigma surrounding it, and simply states that her husband died “after long illness” (10), Jonathan Franzen acknowledges Alzheimer’s disease, and names it. By doing so, he is able to confront its significance, and challenge the implications of the disease and of his father’s death. He navigates contradictory terrain, where the human brain is simultaneously described as “a web of a hundred billion neurons,” the complex “organ with which we observe and make sense of the universe,” and “a lump of meat” (10). Similarly, Franzen’s essay displays many nuances: it functions as autopsy report, tale of an unnamed “long illness”, detailed account of the symptoms of Alzheimer’s disease, unique story of a father, collective narrative of a family, and history of Western cultural attitudes and silences regarding this syndrome.

Hence, these types of dementia brain scans sidestep the reductionism vs narrative dichotomy, envisioning a more complex approach to investigating and telling the story of the human brain. By interfacing the two approaches it is possible to simultaneously provide evidence and give visibility to the general condition, as well as account for the one, particular story, for its multiple perspectives, protagonists, and endings.

## “ALICE’S EVIDENCE”: DEMENTIA STORIES AND THE PRACTICE OF WONDER

In the last chapter of her adventures, titled “Alice’s Evidence,” Lewis Carroll’s Alice endeavors to present evidence against a death sentence. Biopsychiatric approaches also hinge on gathering evidence. For instance, by recording observations, collecting data, taking measurements, replicating responses, verifying hypothesis, or defining general laws, they demonstrate that the last chapter of the life story of dementia patients equates to a death sentence for consciousness. Conversely, narrative investigations entertain the possibility that some form of consciousness might persist as the brain approaches death. They do so by employing the powers of wonder and storytelling to create fictional worlds, formulate astonishing hypotheses, and trace paradoxical interconnections.

The practice of wonder, as defined by Chandra Candiani in *Questo immenso non sapere* (2021), appears pivotal in the current analysis of the power of narrative to unveil new perspectives on dementia syndrome, integrating those of biopsychiatry:



Una buona pratica, preliminare a qualunque altra, è la pratica della meraviglia. Esercitarsi a non sapere e a meravigliarsi. Guardarsi attorno e lasciar andare il concetto di albero, strada, casa, mare e guardare con lo sguardo che ignora il risaputo e vede ora. [...] Si può andare a trovare un piccolissimo pezzo di prato, un pizzico di prato c'è sempre, anche in città. E guardare, a lungo.<sup>2</sup> (Candiani 9)

The practice of wonder is conceptualised as an exercise in embracing the unknown, which can be honed by observing one's surrounding closely and attentively, and then perceiving and seeing, as if for the first time, the non-human environment. Thus, a new world is made visible:

Si apre un universo minimo. Infinite vicende, mutamenti, arrivi, partenze, forme sempre più piccole man mano che lo sguardo si limita a vedere. Esercitare la meraviglia cura il cuore malato che ha potuto esercitare solo la paura.<sup>3</sup> (Candiani 9)

Paying heightened attention and relinquishing the well-known while embracing the unknown: these practices are integral to wondering, which possesses a transformative power, altering the way individuals engage with reality. As Candiani suggests, through the practice of wonder one becomes familiar with the unexpected, realising that the less one knows, the more open one is to new experiences and quests (8). Wonder also holds a healing power, stemming from the confrontation with the fear of not knowing: "Training wonder heals the sick heart that has only been able to train fear" ("Esercitare la meraviglia cura il cuore malato che ha potuto esercitare solo la paura", 9). Wondering involves accepting that we can be in the world without the compulsion to understand and control (11).

Angus Fletcher also describes wondering as an eye-opening process, prompted by observing the non-human world with fresh eyes, and posing questions without expecting definite answers. In his words, wonder is "life through the eyes of a child. It's the first glimpse of a flower, or the discovery of oceans, or the parting of clouds at the high touch of heaven." As such, wonder ignites a "sense of greater possibility" (16). Fletcher's analysis resonates in this context as it bridges wonder with narrative, and integrates empirical and narrative approaches. Firstly, Fletcher posits literature as one of the most potent avenues for evoking wonder, attributing to it two great powers: the "power of narrative, or, more colloquially, of story," which interconnects events, and the power of "the stirring of emotion" (5). He identifies the underlying mechanisms through which literature can 'make' wonder, highlighting two core components of narratives: the plot twist, characterised by a seamless progression of events propelling the story forward, and the stretch, "the taking of a regular pattern of plot or character or

---

<sup>2</sup> "A good practice, preliminary to any other, is the practice of wonder. To train oneself to not know and to wonder. To look around and let go of the concept of tree, road, sea, and look with the eyes that ignore the well-known and see now. [...] One can go to find a very small piece of grass, a pinch of grass is always there, even in the city. And to look, for a long time."

<sup>3</sup> "A minimal universe opens up. Infinite events, changes, arrivals, departures, smaller and smaller shapes as the gaze merely sees. Training wonder heals the sick heart that has only been able to train fear."



storyworld or narrative style or any other core component of story—and extending the pattern further” (17).

Secondly, Fletcher intertwines literary and scientific innovations, both of which have contributed to humanity’s progress over the centuries. He weaves together works such as Homer’s *Iliad*, Shakespeare’s *Hamlet*, or Angelou’s *I Know Why the Caged Bird Sings*, with neurosciences and evidence-based research. Drawing from this broad array of references, he claims that while scientific and technological inventions have aimed at “domesticating” our physical environment to our will and needs (7), literary inventions have grappled with the complexity of being human. This process is conceptualised as a wondering quest:

To be human is to wonder *Why?* As in, *Why are we here? What’s the purpose of our hours? Does this life mean anything?* And to be human is to have irrational desires, and uncontrollable passions, and griefs that split us into pieces. Or to put it in the frank language of our scientific present: to be human is to be saddled with the problem of having a human brain. A brain capable of asking vast questions that it cannot answer. A brain fuelled by emotions that proper us forward but that also cause us to crave things that harm, and to fear things that don’t exist, and to rage against age and death and other parts of our nature that can’t be escaped. (7)

Thus, literature and narrative wonderworks can play a significant role in posing questions, challenging well-established answers, and embracing the inherent contradictions of the human condition.

As I will argue, engaging with narrative brain scans of dementia sufferers can be an exercise in the practice of wonder, allowing individuals to embrace the unknown and to see the human brain from unconventional perspectives. This power of dementia stories is particularly evident when examining end-of-life tales, which defy evidence-based definitions of life vs. death, presence vs. absence of consciousness. Given the characteristics of dementia, individuals in the advanced stages, as well as their caregivers, occupy a liminal space between knowing and not knowing, awareness and loss of awareness. By engaging with dementia stories, readers can also inhabit this liminal space. Dementia narratives compel readers to stand on unsettled terrain, offering a vantage point from which to closely observe a mysterious brain world, and address issues on life and death.

In the following poem (untitled) by Mariangela Gualtieri, the speaking I describes such a liminal ground, where mother-daughter roles are reversed, and life and death are suspended for both:

Ogni giorno partorivo la mamma  
aggiustavo sul guanciale le forme  
di questo suo stare rovinato.  
con parole rimpicciolite  
modellavo il suo corpo disteso  
agitavo lo stagno del suo sangue.  
Dal suo pozzo sillabava lenta lenta  
come fosse da molto lontano.



Partorivo la mamma, la tenevo  
di qua. Lei che piano mollava  
scivolando sul fondo fangoso.  
Che fatica allora che lungo sgravare  
che infinito lento precipitare  
che terminata festa  
e come la mia vita parcheggiava lo slancio  
all'ombra di quel feto dipinto  
d'un'infanzia sghemba e pesta.

Questa fanciulla mamma rovinata  
ogni parola resta imprigionata  
in un gorgoglio di vento e di tormento –  
il suo nome, il mio nome, ogni nome  
è fuoco spento.<sup>4</sup> (Gualtieri 41)

The mother's implacable dying process mirrors in reverse the physical and cognitive development of a child. The mother has become the simulacra of a foetus, representing the story a "crooked and trampled childhood" ("d'un'infanzia sghemba e pesta"). As such, she depends on others but, unlike a newborn child, she cannot develop into a full human being. Lying on the bed, her vocabulary is shrinking and her far-away voice can be hardly heard, uttering unintelligible syllables. The mother seems to have completely lost her free will and decision-making skills: she is "gently letting go" ("piano mollava") and, like an object, she is "slipping down on the muddy bottom" ("scivolando sul fondo fangoso"), in which she is trapped. Her "infinite slow plummeting" ("infinito lento precipitare") is inexorable. The active role is played by the poet-caregiver, who strives to delay the dying process, to keep the mother in the world of the living, by inhabiting, willing or not, the same "muddy bottom." Their selves are mutually dependent on each other. Their lives are suspended in indefinite time and space. The mother's condition is erasing their names and identities, as well as those of witnesses, who can observe and participate in this experience through the poem.

Observing dementia from within its "muddy bottom," questions are raised: if, as Crick claims, we are "nothing but a pack of neurons," does a sense of awareness of the self and of others survive in late-stage dementia patients? When neural cells progressively die, leaving the body to survive, what remains of human consciousness? And, as John Bayley writes, "with the brain gone can the body take over the power of decision?" (211). Dementia stories that refer to the last stage of the disease address these issues in ways that complement biomedical accounts. These gather evidence that the deterioration of brain cells and networks progressively disrupts key consciousness

---

<sup>4</sup> "Every day I gave birth to mother/ I adjusted on the pillow the shapes/ of her ruined staying./ With shrunk words/ I moulded her lying body/ I stirred the pond of her blood./ From her well she syllabised little by little/ as if from very far away./ I gave birth to mother, I held her/ on this side. She who was gently letting go/ slipping down on the muddy bottom./ What an effort then, what a long unburdening/ what an infinite slow plummeting/ what a taken-off bloom/ and how my life parked its momentum/ in the shadow of that painted foetus/ of a crooked and trampled childhood./ This ruined maiden mother,/ every word remains imprisoned/ in a gurgle of wind and torment –/ her name, my name, every name/ is extinguished fire."



traits, such as memory, decision-making, problem-solving, communication, recognition of emotions, behavioural regulation, free will, as well as awareness of themselves and of the environment. From a pathological perspective, dementia can be defined as “a disorder of consciousness,” as it impairs the two major components of consciousness, “arousal (*i.e.*, the state of consciousness) and awareness of the self and the environment (*i.e.*, the contents of conscious experience [...])” (Huntley *et al.* 1). As the disease progresses, neurodegeneration in brain networks augments, and the dysfunction of aspects of consciousness is more pronounced. In the advanced stages, “[f]or caregivers of someone with advanced AD [Alzheimer’s disease], there is uncertainty as to what the person with AD is now able to experience, and feelings of grief for the loss of the person they knew, described as being akin to a premature bereavement” (2). In narrative brain scans of late-stage dementia this long series of deaths can take more complex forms and unexpected directions.

The following poem by Mariangela Gualtieri depicts this final stage, when the sufferer’s consciousness seems to be completely lost, and only the body is left of her:

La mamma è una grande larva buona.  
La giro nel letto, la metto a sedere  
La imbocco, la lavo, le cambio il vestito.  
È formica regina, piena di uova.  
Ha perso voce e parola.  
Un silenzio cala sulla sua faccia.  
Ma questo suo sorriso allora  
è una vittoria vera di millenni  
un’inspiegabile aurora rosa  
improvvisa, accesa, dentro casa  
in un tempo che pesa e scocca piano.  
La mamma è la mia nave-scuola.  
M’insegna l’immobile attesa  
come rendere tutto di sé pian piano  
le gambe le mani la vista la voce  
e ancora, per un soffio, un boccone  
un po’ di luce, abitare un bene.<sup>5</sup> (Gualtieri 42)

The mother’s body and brain have regressed to the immature state of a larva, having lost basic cognitive functions and the ability to perform primordial activities of living. However, against all evidence, like a larva, she is able to undergo some sort of metamorphosis and return emotional signals with a sudden smile. This could be explained as a purely mechanic physical reaction, or even as the fleeting sign of paradoxical lucidity—“an episode of unexpected communication or connectedness in a person who is believed to be noncommunicative” (Ney *et al.* 3167)—that can be

---

<sup>5</sup> “The mother is a great good larva./ I turn her in bed, I sit her down/ I feed her, I wash her, I change her clothes./ She is queen ant, full of eggs./ She has lost voice and words./ A silence falls upon her face./ But this smile of hers then/ is a true victory of millennia/ an unexplainable pink dawn/ sudden, bright, inside the home/ in a time that weighs and ticks softly./ The mother is my training ship./ She teaches me the still waiting/ how to render all of oneself slow slowly/ the legs the hands the sight the voice/ and more, for a breath, a mouthful/ a bit of light, to inhabit a well-being.”



triggered by a familiar voice. On the contrary, this episode is perceived by the caregiver as “an unexplainable pink dawn/ sudden, bright”, which interrupts the monotony of “a time that weighs and ticks softly” (“un’inspiegabile aurora rosa/ improvvisa e accesa, [...] / in un tempo che pesa e scocca piano”, 42). Ultimately, a sick mother’s smile can teach a lesson in waiting and well-being.

Dementia tales offer accounts of paradoxical lucidity, as also exemplified in John Bayley’s biographies of novelist Iris Murdoch (1919-1999). Bayley tells the story of Iris Murdoch’s extraordinary life, spanning years spent together as young lovers, wife and husband, Alzheimer’s sufferer and primary caregiver, and lonely widower, across three books—*Iris: A Memoir of Iris Murdoch* (1998), *Iris and the Friends: A Year of Memories* (1999), and *Widower’s House* (2001).<sup>6</sup> The following extract is taken from the second volume, published a year after Murdoch’s death. The passage describes the final days of her life:

And then between one day and the next it became all but impossible to get her to eat or drink. I coaxed her in every way I could think of, but she seemed abruptly to have given up being a good if sometimes difficult child, and became a sadly but politely determined adult. Politely and smilingly she declined to open her mouth to have a teaspoon or the edge of a cup put in. As if she had decided it was no longer worthwhile. (Bayley 211; my emphasis)

We can observe the dementia sufferer in the last phase of retrogenesis, when cognitive abilities resemble developmental stages seen in infancy. However, Bayley reports a sudden final shift from child to adult. He depicts a “determined” person, and tentatively assumes (“as if”) that she might have been able to understand her condition, make the decision to end her life, and plan how to do it. This hypothesis starkly contrasts with neuropsychiatric studies, which provide evidence of disrupted executive functioning, emotional regulation, or cognitive flexibility in subjects affected by dementia. Nonetheless, Bayley’s wondering takes readers on a different track:

With the brain gone can the body take over the power of decision? It looked like it. What Pascal said of the heart may be true of the body too? Like the heart it has its own reasons, which reason knows nothing about? If no one interferes, it knows how to do the right thing at the right moment?

And that is surely very comforting? For whom do I mean? For the onlooker of course, the carer. The patient is already far off. In a dark country where they have their own ways of knowing things. And doing things. (211)

It is interesting to note the abundance of question marks in this passage: Bayley raises doubts on whether the moment of transition from life to death could be the ultimate expression of an enduring consciousness, or whether the human body could have unknown abilities. At the same time, he is aware that these hypotheses can be a consolation for onlookers only. The practice of wonder, in these cases, cannot involve the afflicted subject, but, paraphrasing Candiani, it can heal the sick heart of those who witness and bear witness to suffering.

---

<sup>6</sup> The three books have been published in one volume, *The Iris Trilogy* (2003).



Similarly, in “My Father’s Brain,” Jonathan Franzen practices wonder when recalling the last phase of his father’s life and “his apparent persistence of will” (30). Recording the “downward trend” (30) leading to death, the novelist opens to the possibility that his father could have been willing and determined: “in April 1995, he stopped eating. Maybe he was having trouble swallowing, or maybe, with his remaining shreds of will, he’d resolved to put an end to his unwanted second childhood” (35). Earl Franzen’s death bed is akin to Candiani’s “minimal universe” (“universo minimo”, 9), where wonder can be trained. There, the father’s persistence of will is also Jonathan’s own persistence of will:

Hour after hour, my father lay unmoving and worked his way toward death; but when he yawned, the yawn was *his*. And his body, wasted though it was, was likewise still radiantly *his*. Even as the surviving parts of his self grew ever smaller and more fragmented, I persisted seeing a whole. (36)

Moreover, Franzen’s practice of wonder is strictly connected with his urge to tell this story:

I still loved, specifically and individually, the man who was yawning in that bed. And how could I not fashion stories out of that love—stories of a man whose will remained intact enough to avert his face when I tried to clear his mouth out with a moist foam swab? (36).

Wondering and storytelling, presence and absence of consciousness are tightly interconnected in these stories of dementia. This intricate network lies at the core of *Alice’s Adventures in Wonderland*, which has served as frame for this exploration of the narrative life of dying neural cells. So, it should not come as a surprise that the final step of this narrative journey is “Alice’s Evidence,” the last chapter of Lewis Carroll’s tale. Like Alice at the end of her quest, dementia stories spur readers to explore different, unreal (that is, beyond reality as we know it) dimensions of un-consciousness. When Alice shouts “You are nothing but a pack of cards!” to the King and Queen of Hearts, she awakes from the fantasy world back to ‘real’ life. Then, she tells her sister her “wonderful dream” and “all these strange Adventures of hers that you have just been reading about” (Carroll 182). When Alice runs off, she leaves her sister (and readers) alone. Her sister starts thinking of “little Alice and all her wonderful Adventures,” till she too begins “dreaming after a fashion,” and telling her wonder-filled story. Similarly to Alice’s, the sister’s act of wondering has transformative power: “[t]he whole place around her became alive with the strange creatures of her little sister’s dream.” The White Rabbit, the March Hare, the Queen, or the Mock Turtle—all the strange, non-human creatures of Alice’s Wonderland are conjured up in her sister’s dream. The latter wonders whether Alice could be a trustworthy storyteller: “So she sat on, with closed eyes, and half believed herself in Wonderland, though she knew she had but to open them again, and all would change to dull reality” (184). At this point, the sister imagines and tells the story of a hypothetical future, when Alice, now a grown woman, “would gather about her other little children, and make their eyes bright and eager with many a strange tale, perhaps even with the dream of Wonderland of long ago” (184). As the story goes, the



practices of wondering and storytelling are inextricably linked to one another: in the face of dull reality and sorrows, they can help picture alternative worlds and “many a strange tale.”

Likewise, as we have seen, dementia stories offer means for exploring uncharted areas of the brain, and wondering about the limits of human consciousness and life. When sorrow and “dull reality” burst into the life of sufferers, caregivers, and readers, tales of dementia can function as training grounds for wonder, encouraging us to venture into this unknown territory, survey its landscapes, imagine, and perhaps even half-believe in the wonder-filled narrative life of dying neural cells.

## WORKS CITED

Bayley, John. *The Iris Trilogy. A Memoir of Iris Murdoch*. Abacus, 2003.

Belder, Christopher R.S., et al. “Preparing for Disease-Modifying Therapies in Alzheimer’s Disease.” *The Lancet*, vol. 22, Sept. 2023, pp. 782-783.

Candiani, Chandra. *Questo immenso non sapere. Conversazioni con alberi, animali e il cuore umano*. Einaudi, 2021.

Carroll, Lewis. *Alice nel paese delle meraviglie*. Traduzione di Aldo Busi. Testo originale a fronte. Feltrinelli, 2008.

Coppola, Maria Micaela. “La mente in chiaroscuro: Note per una definizione delle *psychological humanities*.” *Elephant & Castle. Laboratorio dell’immaginario*, n. 22, giu. 2020, pp. 4-22.

---. “Psychiatric Fictional Pathography: The Alzheimer’s Brain in Lisa Genova’s *Still Alice* and Samantha Harvey’s *The Wilderness*.” *Textus. English Studies in Italy*, vol. XXXII, no. 2, 2019, pp. 61-76.

Crick, Francis. *The Astonishing Hypothesis: The Scientific Search for the Soul*. Simon & Schuster, 1994.

Fletcher, Angus. *Wonderworks. The 25 Most Powerful Inventions in the History of Literature*. Simon & Schuster, 2021.

Franzen, Jonathan. “My Father’s Brain.” *How to Be Alone*, Fourth Estate, 2002, pp. 7-38.

Fuerst, John A. “The Role of Reductionism in the Development of Molecular Biology: Peripheral or Central?” *Social Studies of Science*, vol. 12, no. 2, 1982, pp. 241-278.

Gualtieri, Mariangela. *Le giovani parole*. Einaudi, 2015.

Huntley Jonathan D., et al. “Understanding Alzheimer’s Disease as a Disorder of Consciousness.” *Alzheimer’s & Dementia: Translational Research & Clinical Interventions*, vol. 7, no. 1, 2021. <https://doi.org/10.1002/trc2.12203>. Accessed 24 Feb. 2024.

Lewis, Bradley. *Narrative Psychiatry. How Stories Can Shape Clinical Practice*. The Johns Hopkins University Press, 2011.

Ney, David B., et al. “The Ethical Implications of Paradoxical Lucidity in Persons with Dementia.” *Journal of the American Geriatrics Society*, vol. 69, no. 12, 2021, pp. 3617-3622. <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.17484>. Accessed 24 Feb. 2024.





Sacks, Oliver. "Preface." *The Man Who Mistook His Wife for a Hat*, Picador, 2007, pp. ix-xiii.

Woolf, Virginia. "Craftsmanship," BBC radio broadcast, April 29th, 1937. <https://www.youtube.com/watch?v=E8czs8v6Pul>. Accessed 24 Feb. 2024.

---

**Maria Micaela Coppola** is associate professor of English Literature at the Department of Psychology and Cognitive Science of Università degli Studi di Trento (Italy). She has published on 20th-century and contemporary women writers in English, lesbian literature, and feminist cultural periodicals. Her most recent publications are on fictional accounts of dementia syndrome, the psychological humanities, and narrative medicine. She is co-coordinator of the Centre for Interdisciplinary Gender Studies and director of the Language Centre of Università degli Studi di Trento.

<https://orcid.org/0000-0002-9377-6355>

[mariamicaela.coppola@unitn.it](mailto:mariamicaela.coppola@unitn.it)

---