



# Spoons on Fire: The Visualization and Communication of Pain by the Community of the Persistently Fatigued

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**Abstract:** *How can I ever convey how I suffer?* It is a question that has plagued many. The 'inexpressibility' of pain is particularly pertinent to those suffering from chronic conditions. Those who call themselves "spoonies" suffer from persistent fatigue and have gathered an online community based on a metaphor developed by Christine Miserandino. This essay will explore how this metaphor serves as a layered communicative tool to *spoonies* and how this group could be considered a subculture. I will link the linguistic expression to visual products by referring to images that have been posted to the online platform Tumblr. By discussing *spoonies*, I aim to provide a glimpse into the many methods people have employed to show the complex experience of pain. Concluding that the metaphor that was initially meant to communicate suffering to 'outsiders' of the experience of persistent fatigue, eventually morphed into an expression that primarily serves those suffering from persistent fatigue.

**Keywords:** Spoonies, Persistent Fatigue, Disability Studies, Metaphor, Subcultures, Pain Communication, Tumblr

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## Introduction

*"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."*

- Susan Sontag, *Introduction Illness as Metaphor*<sup>1</sup>

What would citizenship to Sontag's kingdom of illness look like? I imagined the country as a desert, where I—as an ill person—roamed aimlessly and alone. The comparison to a country was somewhat strange, I thought, because it appears to suggest there must be the unity of a nation, where I had only found loneliness. This essay involves a group of physically impaired people, those suffering from persistent fatigue otherwise known as *spoonies*, who did manage to find unity where I saw none. Online, the *spoonies* bond over their shared experiences and challenges. In this essay, I explore how the metaphor of spoons functions as a communicative tool and 'insider knowledge' for the group. This focus on metaphor is particularly interesting

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<sup>1</sup> Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, 3–4.

because, as Elaine Scarry described in *The Body in Pain* (1985), suffering is an incredibly hard experience to describe to others, it is ‘unsharable.’ She writes that “to have great pain is to have certainty; to hear another person has pain is to have doubt.”<sup>2</sup> Thus, we stand for a great challenge when trying to express pain. Leading this inquiry is the question: how do *spoonies* on Tumblr use the metaphor of spoons to tackle the challenge of the seeming inexpressibility of their suffering? In order to answer this question, I first explain the metaphor that gave the group its name and elaborate on how this conforms to Scarry’s challenge. Following this, I describe the group formation of *spoonies* by referring to Dick Hebdige’s characterizations of subcultures. Finally, I show how this metaphor finds visual expressions in memes and illustrations shared online. In my discussion of these visual expressions, I will show how this metaphor morphed from initially being used to communicate the experience of pain to others, to being used to communicate to fellow sufferers of persistent fatigue. These expressions, I argue, are completely illegible to those unfamiliar with the metaphor.

## The Birth of a Metaphor

When out to dinner with her friend, Christine Miserandino wound up discussing her illness. Lupus impaired her energy, resulting in her being able to do less than she would otherwise be doing. Recalling the event in a blog post, she writes remembering the struggle to find the words to express her impairment.<sup>3</sup> Then, suddenly, she found the answer right in front of her. She gathered the spoons on the table and explained to her friend how they exemplified her illness: an able-bodied person does not have to think about the choices they make, they do not ‘spend’ spoons consciously. A person with persistent fatigue has a limited number of spoons they can spend on activities. Every daily task costs a spoon, implying you have to be conscious of what you choose to do or not. Her friend was tasked to imagine her life as limited to a number of spoons and found herself struggling to do so. But why did Miserandino pick spoons in particular? She explains: “I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a “loss” of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.”<sup>4</sup>

This metaphor turned out to be of incredible significance to people suffering a similar fate as Miserandino. But why did it gain such popularity under this group? Part of the answer can be found in the work of Elaine Scarry. In general, the experience of being in pain can be extremely isolating.<sup>5</sup> In *The Body in Pain*, Elaine Scarry argues an innate quality of the experience of pain is its ‘unsharability.’<sup>6</sup> Her argument starts with the idea that being in pain gives clarity to the sufferer, but uncertainty to those who are told the person is in pain. This seemingly simple dynamic is complexified greatly if considered as woven through every aspect of social reality. It can have immense social and political repercussions for all parties involved, such as through public health policies.<sup>7</sup> To Scarry, it could even be said much of the sorrow of pain is ‘achieved’ in its unsharability. According to her, language always falls short, pain is ‘resistant’ to language.<sup>8</sup> Scarry wrote that in some cases, physical pain can even destroy

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<sup>2</sup> Scarry, *The Body in Pain*, 7.

<sup>3</sup> Miserandino, “The Spoon Theory.”

<sup>4</sup> Miserandino, “The Spoon Theory.”

<sup>5</sup> Note on terminology: pain is here understood in its broadest sense, both in Scarry’s work and in this essay. It is certainly not limited to physical sensation but also includes mental torment and—most importantly here—fatigue.

<sup>6</sup> Scarry, *The Body in Pain*, 4.

<sup>7</sup> Scarry, *The Body in Pain*, 7 and 13–14.

<sup>8</sup> Scarry, *The Body in Pain*, 2, 4.

language. In her account, we can see Miserandino face this challenge head on, but eventually succeed in trying to find an expression for it. Her simple solution of the metaphor of spoons proved to be effective in her personal situation. But the metaphor moved greatly beyond her: published on her blog 'butyoudontlooksick.com' in 2003, the metaphor went on to become the defining feature of the group of people suffering from persistent fatigue who call themselves *spoonies*.

## A Simple Term and the Judgment of Authority

The reader should observe the mundanity of the metaphor: it was thought of in the spur of the moment, employs everyday objects and the theory was published on an ordinary blog post. A metaphor can be understood as an expression that is essentially different from the thing it describes, but that does carry a common characteristic or resemblance which can help foster new understanding of the situation at hand.<sup>9</sup> The spoon metaphor managed to get enormous traction among those with persistent fatigue. As explained by Miserandino's anecdote of how she came up with the spoon theory, the tangibility of the metaphor makes it very easy to convey to bystanders. In such scenarios, it is ultimately this simplicity of the metaphor that makes it useful to the persistently fatigued.

Medical professionals have generally rejected an embrace of the metaphor that patients present in order to discuss their experience with these patients. Elena Gonzalez-Polledo and Jen Tarr, who extensively studied *spoonies* and their online world, have already pointed to the unwillingness of medical professionals to embrace self-defined expressions. They argued that where there would be an opportunity for effective communication and understanding between doctor and patient, there is instead a rejection by the figure of authority.<sup>10</sup> Within disability studies, there has been a larger sound of urge for the embrace of self-expression, which means so-called 'disability worlds' have to be acknowledged. This term refers to bringing the perspective of disabled people into every aspect of social life.<sup>11</sup> Persistent fatigue can be understood as an invisible disability, according to symptoms named by the Invisible Disability Association (2016).<sup>12</sup> This type of fatigue cannot be resolved with conventional solutions, such as rest or sleep (although these may help). It is chronic and often comes paired with other ailments such as headaches and dizziness.<sup>13</sup> The term applies to a wide range of people and is not bound to a particular illness. Those who identify as *spoonies* range from having lupus to chronic fatigue syndrome to Crohn's disease, but also autism or ADHD and more.<sup>14</sup> Uniting them is a complex experience of persistent fatigue that is much more than simply 'being tired,' meaning that the weight of this experience is not easy to understand for outsiders. Because of this, the embrace of the self-expression of the disability worlds of *spoonies* are also certainly needed. Particularly because it can be typified as an invisible illness, the self-expression by the small group of sufferers becomes one of the only ways we can come to understand the experience.

However, the self-expression of *spoonies* is not only useful to them. I think it is easy to see how spoon theory could find general application to all forms of energy deficiency and thus be beneficial as a figure of speech in general. Despite larger societal benefits, most centrally it

<sup>9</sup> Cambridge Dictionary, "Metaphor."

<sup>10</sup> Gonzalez-Polledo and Tarr, "The Thing about Pain," 1457.

<sup>11</sup> Ginsburg and Rapp, "Disability Worlds," 53–68.

<sup>12</sup> Invisible Disabilities Association, "From Defining Invisible Disability to Invisible No More — What is an Invisible Disability?"

<sup>13</sup> Conrad, "Consider the Spoons," 82.

<sup>14</sup> Gonzalez-Polledo and Tarr, "The Thing about Pain," 1446.

would help the persistently fatigued greatly in gaining societal understanding. However, the metaphor is not socially embraced: its value is not even recognized by most medical practitioners, let alone beyond that. There is a significant political dimension to what we accept as communication of symptoms and pain, with huge repercussions in terms of treatment for the ill.<sup>15</sup> Despite its failure to find general expression, the metaphor is currently still being used as a communicative tool within a very particular group of people: the persistently fatigued and those near to them. This group has gathered around the term ‘spoonies.’ They are defined by shared experience, not medical labels. How ‘spoonie’ is used is thus also at odds with conventional medical terminology and seems again a rejection of medical jargon.

In discussing the rejection of the term ‘spoonies’ by the general public and medical professionals, I have already begun to show the separation between dominant culture on the one hand and *spoonies* on the other. I believe that the position that *spoonies* take in online forums such as Tumblr shows they could be considered a subculture, according to Dick Hebdige’s terminology. According to Hebdige, subculture is subversive. They are groups that would otherwise be dismissed by society, but with rebellious gestures these subcultures refuse submission.<sup>16</sup> These groups are, to Hebdige, defined by their rejection of dominant culture. They organize based on their shared ideas and signify this rejection through cultural expressions.<sup>17</sup> Hebdige mainly explores post-war groups and it may be that our current day equivalents to subcultures function very differently, but they certainly have features in common. *Spoonies* are frequently dismissed, as argued above, but this feature of dismissal is also central to their discussions on online forums. Online, there is room for expressing frustration about outsiders’ lack of understanding.<sup>18</sup> Mundane objects are another key feature of subcultures for Hebdige.<sup>19</sup> In our case, spoons—those everyday household objects—become laden with new meaning that is only understandable for those ‘in the know’ due to the limited usage of the term.

There are obvious differences between the groups Hebdige references and the *spoonies*, but these could be largely attributed to the nature of the experience of disabled people. For example, the typical groups that Hebdige explores are punks, who are often very visually distinctive from dominant culture and gather communally to do activities related to their group’s values. Hebdige names the extreme ways in which punk attended concerts, for example, they were keen on breaking the barriers between stage and audience; this was a supposed revolutionary method to break hierarchies.<sup>20</sup> Physical activities and meetings opportunities like these are mostly inaccessible to the persistently fatigued, they rather gather in another way. The digital format of the *spoonie* community is highly accessible. Online, *spoonies* do have a very distinct form of expressing themselves in visual expressions. These expressions are not externally visible to outsiders though. Thus, the conventional understanding of ‘subversiveness’ that Hebdige stresses is perhaps not applicable here. As he says, the meaning of subculture is always in dispute.<sup>21</sup> In our case, subversiveness is to be understood in the power of language and expression. To be understood in your own terms is a political claim, one which the online community works towards. Koen Leurs discusses online forums in “Voices from the Margins on Internet Forums.” Regarding a different context, particularly forums of racial internet forums, he asserted that these platforms allow minorities to assert their own voice and to discuss their ideology and views on social reality. Online, one can share an account of oneself. This account reflects the individual’s agency to speak but is simultaneously embedded in a plural

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<sup>15</sup> Conrad, “Consider the Spoons,” 80–81.

<sup>16</sup> Hebdige, *Subculture*, 2.

<sup>17</sup> Hebdige *Subculture*, 17–18.

<sup>18</sup> Gonzalez-Polledo. “Chronic Media Worlds,” 7.

<sup>19</sup> Hebdige *Subculture*, 2.

<sup>20</sup> Hebdige *Subculture*, 108–111.

<sup>21</sup> Hebdige, *Subculture*, 3.

setting.<sup>22</sup> In this article, forums are asserted as having countercultural elements. This does not necessarily go to radical extends, but forums do empower users and they provide a space for self-expression.<sup>23</sup> This also applies to *spoonies*, who use forums to express the inexpressible. the metaphor is more than ‘just’ a linguistic tool, it has also been converted into many visual expressions in online platforms. In the next section, I will analyze visual expressions that are coupled with language, they are never ‘purely’ visual but always have text incorporated within them.

## A Metaphor Visualized

How the metaphor is used has remained rather abstract, so now I intend to give an impression of how the metaphor actually functions online within communities of *spoonies*. Tumblr is a website where users can post and repost images, texts, videos and more on blogs. On the website, small communities form around niche topics. As stated by the website, Tumblr is “where your interests connect you with your people.”<sup>24</sup> Thus, when looking for a place where *spoonies* discuss ideas and share their experiences, Tumblr might be an obvious place to look. Additionally, Tumblr is known to house many visual expressions on their platform.<sup>25</sup> Despite my focus on Tumblr, it should be said that similar communities exist other digital platforms such as Instagram as well.

My method for finding the pictures for my case studies was rather straightforward: I logged in on Tumblr, typed in the tag ‘Spoonie’, selected ‘most popular posts’, ‘last year’ and the ‘picture’ option and scrolled through the posts until I found an image that sparked interest and directly showed spoons. My selection is by no means a comprehensive overview of this discourse but only serves to exemplify how the metaphor is referenced too frequently and how current the posts are.<sup>26</sup> In my discussion of these images, I aim to show how the metaphor came to serve a purpose which can be said to be almost contradictory to its initial aims. The metaphor had been created to communicate the experience of persistent fatigue to ‘outsiders’ who were unaware of the effects of persistent fatigue, but the images I discuss employ the metaphor in ways that became completely illegible to these very outsiders.

This comic (**Figure 1**) confronts us with the daily reality of the illustrator. In the first panel we see him in bed with his tablet, drawing the very comic we now read. The captions read like personal confessions to the reader and are accompanied by pictures that can seem rather lighthearted for the heavy subject matter. The state of the maker never escapes the reader, so much so that we can never finish the comic because the maker was never able to finish it. This self-referential style of the comic shows how close the reader is to the maker. The informal image description achieves a similar effect. Spoon theory is referenced two times. In the second panel of the comic, we read “I have no spoons” accompanied by a sad-looking boy standing beside a bowl and cereal box. To an outsider of the *spoonie* community, this panel would be completely misunderstood. But to an insider, this would be an obvious comment on lack of energy. The final panel also references the theory. It shows a broken spoon together with the text “I don't even have the energy to finish this comic.”

<sup>22</sup> Leurs. “Voices from the Margins on Internet Forums,” 111–112.

<sup>23</sup> Leurs. “Voices from the Margins on Internet Forums,” 111–112.

<sup>24</sup> Tumblr, “Getting Started on Tumblr.”

<sup>25</sup> McCracken, *a Tumblr Book*, 309–310.

<sup>26</sup> A more comprehensive overview can be found in the works by Elena Gonzalez-Polledo and Jen Tarr, listed in the bibliography. Both articles focus on how the specific technology of Tumblr impacts its narrative. These papers are, by the internet's standards, now slightly outdated.



**Figure 1.** Ryegarden on Tumblr, description: “No art lately + no spoons + silly comic that has a sadder tone than planned but i hope other people can relate to” posted on 28 February 2023, Tumblr.com under #Spoonie. <https://www.tumblr.com/ryegarden/710543994267025408/no-art-lately-no-spoons-silly-comic-that-has-a?source=share>

The meaning of this comic would fall flat without knowledge of spoon theory, it has become like an icon for communicating hardship. This emphasis on communicating to peers is also apparent from the caption, which reads “silly comic that has a sadder tone than planned but i hope other people can relate to,” to which a fellow user (stripedshirtgay) responded “Extremely relatable! Sending love and good wishes for more spoons!”<sup>27</sup> Within the *spoonie* community, the spoon metaphor has been incorporated into the vocabulary so deeply it is assumed to be established knowledge. We have a clear in-group and out-group. Here, the reason behind the ‘secrecy’ of the icon is not a conscious desire to exclude others, which had been the case in Hebdige’s examples. It is rather the invisibility of the chronically ill which makes the comic unreadable to the outside world. Simply put: the spoon metaphor became an icon because it never became widely used outside of online spheres into medical and political terminology, but within the group it advanced deeply into their methods of communication. This calls to mind Hebdige and his comments on mundane objects. To him, the subculture raises the mundane objects to a double meaning. In addition to its conventional meaning, the subcultures “erect them into icons” and give them a symbolic dimension. I would be hesitant, to say we can speak of “tokens of a self-imposed exile” as he did.<sup>28</sup> Because here, exile is not exactly self-imposed. In his explanation of the functioning of the mundane object, he is very clear about the refusal of society.<sup>29</sup> If we take this first comic as an example, the meaning of spoons is not a symbol of refusal but of pain external to social influence.

A portion of the discourse in this group is dedicated to the reality of illness on which no one has any influence. But there is also certainly attention to the refusal, particularly in the *spoonies*’ critique of medical professionals and unawareness of outsiders. If we look at another illustrated image (**Figure 2**) we see a cat in bed, with a knife wrapped in its tail. Alongside it, we read “Low on spoons, but good on knives”. Again, here spoon theory functions only if you have insider-knowledge. The illustration is a lot more hostile than the last. Here, we could certainly apply the term ‘refusal’ as the illustration counters the commonly held belief that the chronically ill are helpless. This assumption is put in a different light by combining the confession one is low on energy with a statement of being in the possession of many knives, which are heavily

<sup>27</sup> Ryegarden and stripedshirtgay, “Tumblr post.”

<sup>28</sup> Hebdige *Subculture*, 3.

<sup>29</sup> Hebdige *Subculture*, 2–3.

coded as harmful objects. This is thus a juxtaposition of a utensil which admits weakness to one which signals a capacity of violence. So, although the spoon metaphor was previously used to convey a more depressing experience of illness, it also appears in a more empowering or even activist form. This latter aim also appears to be suggested in the bio of ‘Liberal Jane’, who is the illustrator of the illustration, in this she tells us she is “Currently fighting the patriarchy, making art & all that good stuff.”<sup>30</sup>



**Figure 2.** Liberaljane on Tumblr, description: “Low on spoons, good on knives”, 12 December 2022, Tumblr.com under #Spoonie. <https://www.tumblr.com/liberaljane/703398574503985152/low-on-spoons-good-on-knives-graphic-of-an?source=share>

The final image I discuss is a meme (see **Figure 3**). Again, awareness of spoon theory is a requirement for understanding the image. Nevertheless, the image is more layered than that. What Miserandino’s theory explains is solemnly the challenge of dividing units of pain, not the actual experience of doing the action. In the first example (the comic) I discussed, we already saw spoon references combined with the expression of having to do with pain, but this still did not address Scarry’s discussion of pain: to be told the other person is experiencing pain still means remaining in doubt. The meme combines Miserandino’s metaphor of being in pain with an experience of brokenness. Looking at the molten spoons, we can imagine the holder of the spoons feeling burnt out and crooked. Thus, there are two metaphoric layers to the meme: feeling as though you have a restricted amount of energy units to spend during a day and feeling burnt or broken whilst having to spend these energy units. The metaphoric expression of ‘being on fire’ is also a common descriptor for pain, here we see it fused with spoon theory.<sup>31</sup> Additionally, in this meme, the spoons we spend are all drastically different, which seems to acknowledge what can be seen as a small limitation in spoon theory: the energy we spend on activities is often very different in nature from each other, it might be too limiting in illustrating how we spend energy as standardized units. This is no judgement on spoon theory on my part, I rather aim to illustrate how this image takes spoon theory a step (or spoon) further. This meme effectively expresses the diversity of supposed ‘energy units.’

<sup>30</sup> Liberal Jane, “Tumblr Post.”

<sup>31</sup> For example, Elaine Scarry speaks on this: Scarry, *The Body in Pain*, 7–8.



**Figure 3.** Chroniclesofchronicillness on Tumblr, description: “Also called a really bad day lol”, 6 November 2023, Tumblr.com under #Spoonie.

<https://www.tumblr.com/chroniclesofchronicillness/733243093615247360/also-called-a-really-bad-day-lol?source=share>

Finally, I want to reflect on what all of these images have in common. Although the images range in type, from pixelated memes to colorful illustrations, they are all lighthearted in some sense. The boy in **Figure 1** one is surrounded by comically large piles of stuff and he consumes “cheap crap”; in **Figure 2** the vaguely threatening cat is executed in bright, flashy colors and surrounded by hearts; the final **Figure 3** is supposed to be amusing to the viewer, something which is even signified in the “lol” of the caption. This lightheartedness might perhaps be surprising, given the heavy themes discussed in the posts. As said before, this community depends in large part on providing consolation to peers which could explain the prevalence of humor and a lighthearted take on the metaphor. Another common feature of these posts is that they show how deeply the metaphor is incorporated in the communication of *spoonies*. Even if the posts on these forums make no direct reference to spoons, the identification with the name ‘spoonie’ shows awareness of the metaphor. The group reveals that the identification with this metaphor is extremely strong, regardless of whether outsiders accept it or not.

## Conclusion

In her book, Sontag aimed to show that “illness is not a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking.”<sup>32</sup> But can we ever be resistant to metaphorical thinking? In her book Sontag appears to conceive of the metaphor as a mostly negative thing for the ill, in the sense that illness serves as a metaphor for other phenomena and in doing so fails to aptly represent the experience. However, this might be an incomplete picture of the value and effect of the metaphor for the chronically ill, as the metaphor can also serve as a pivotal tool for the ill in communicating their experience. Such is the case for *spoonies*, who found spoon theory to be such an essential communicative tool that they named their group after it. In this essay, I sought to explore how the community of the persistently fatigued found expression for their experience through spoon theory. By analyzing images from Tumblr, I showed how the

<sup>32</sup> Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, 3–4.



metaphor was transformed from just a tool for communicating pain to loved ones to a symbol for community; centered on finding consolation with those suffering a similar fate and to guide discussion with peers. As a symbol within the group, it is certainly also used to communicate dissatisfaction about the lack of social recognition of the group. Thus, although spoon theory may be simple and looked down upon by figures of authority such as doctors, it is also deeply functional.

For now, the metaphor is not widely accepted, doctors—for example—have been mostly unwilling to adopt the metaphor in their communication with patients. Thus, it is strictly applied within groups of persistently fatigued people and their close acquaintances. There is a certain contradiction in place with this metaphor, where it was originally conceived as a tool to be widely shared to now being insider knowledge in an online forum that mainly communicates to peers. I think it is important to keep this transition of the term in mind, because this original intention is very much still alive. Many groups that are defined by symbols may be protective of their symbols and wish for them to not go mainstream. For *spoonies* though, social awareness of their suffering is of significant importance. It is beneficial for the *spoonies* if their metaphor is embraced by the mainstream. Perhaps if it goes mainstream, we as a society can take a step towards understanding what was previously deemed unsharable.

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## Images

Figure 1. Ryegarden on Tumblr, description: “No art lately + no spoons + silly comic that has a sadder tone than planned but i hope other people can relate to” posted on 28 February 2023, Tumblr.com under #Spoonie.  
<https://www.tumblr.com/ryegarden/710543994267025408/no-art-lately-no-spoons-silly-comic-that-has-a?source=share>

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