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“Us Two Together”

Creating an Autobiographical Visual Narrative about Dementia

‘Graphic medicine’ or ‘graphic pathography’, a subgenre of the autobiographical comic, enables patients or caregivers to relate personal encounters with disease, mostly to process these experiences. When I set out to create the graphic narrative *Wij twee samen* (“Us Two Together”, 2015), which deals with my father’s developing dementia and slow decline, the goal was to attract a broader audience’s interest. By using strategies and techniques that bridge the gap between fine arts, literature, design and comics, the autobiographical storyline evolved into a work of art that transcends the visual diary.

1. Introduction

The graphic narrative *Wij twee samen* (“Us Two Together”, 2015) deals with how my father’s devastating disease affected him and his surroundings over the last decade before his passing. In the book, visualisations of the characters’ actions are embedded in a verbal narrative told from a first-person perspective. When I set out to create this book, I wanted it to reflect my hybrid art practice and to bridge the autonomous with the applied arts, as a kind of literary art comic. This entailed some challenges that I will examine in more depth in this contribution to *DIEGESIS*. Specifically, I want to explain some of the strategies that I used to develop the storyline into an experimental and kaleidoscopic book in which a melancholic story, recognisable to those familiar with terminal illness, is primarily carried by portraits, abstract images and fragile texts. Moreover, I want to discuss how the experience of publishing *Wij twee samen* made me aware of the necessity to establish a distance between the author of an autobiographical narrative and her audience.

2. Comics, Autobiography and Graphic Pathography: A Survey

In the course of the 20th century, comics gradually evolved into an art form that combines aspects of fine arts and literature. The emergence of autobiography in graphic narratives has permitted authors to share their personal stories with the public.¹ One of the French pioneers of this genre, Edmond Baudoin (qtd. in

Groensteen 2014), did not even realise that autobiography had a preceding tradition in comics, when his autobiographically inspired book *Passe le temps* was published in 1982. However, as Paul Gravett (2014, 88-92) points out, Olaf Gulbransson (Norway / Germany) and Charlotte Salomon (Germany) already created graphic narratives about their lives in the 1930s and 1940s. Gravett also mentions a short – presumably autobiographical – story by an anonymous British soldier that was published in the mid-1950s. He adds that authors like Keiji Nakazawa (Japan) and Justin Green (USA) set the pace in the 1970s for an active practice of the autobiography in comics form.

Eventually, autobiographical comics proliferated in the United States due to groundbreaking publications by underground artists like Robert Crumb and the generations he inspired (cf. *ibid.*). Thus, Hillary Chute (2010, 14) notes that “a mode of comics narrative – exploring the self seriously – has [...] become dominant within literary comics”, and Dale Jacobs (2008, 59) observes “a significant increase in the number of autobiographies published and read in North America. Autobiography and memoir now constitute a sizable portion of the publishing industry”. To “draw attention to the specific conjunctions of visual and verbal text in this genre of autobiography”, Gillian Whitlock (2006, 966) coined the new genre term ‘autographics’.

In recent years, the autobiographical comic book has flourished, developing, amongst other forms, “a distinctive subgenre of graphic stories that we call ‘graphic pathographies’ – illness narratives in graphic form” (Green / Myers 2010, 574). Since 2007, the Graphic Medicine website “tries to denote the role that comics can play in the study and delivery of healthcare” (Williams 2007) by means of comics reviews, a blog and podcast. A special committee consisting of the founders of the website and several other international academics has been organising the annual conference “Comics and Medicine” since 2010. This conference “brings together worldwide scholars, artists, and clinicians working at the intersection of comics and medicine” (Abbasi 2015). Some of the members of this committee also curate the book series “Graphic Medicine” which Penn State University Press launched in 2015. Ian Williams (2014, 64), one of the driving forces behind these projects, argues that “the graphic medium facilitates a complex visual layering of subjective and objective experiences, bridging the gap between clinical facts and personal perception”. According to Williams, “autobiographical comics often achieve their power by emphasising the personal impact of a disease, [...] evoking empathy and identification” (*ibid.*, 73).

Most illness narratives have such an effect on readers, specifically those who recognise the experience. They can also fulfil educational purposes. In the preface to his comic book, Brian Fies (2006, viii) testifies that he received “letters from medical professionals and educators saying that *Mom’s Cancer* helped them understand their patients’ perspectives and asking permission to use it in their curricula”. However, from the point of view of the artist, comics also lend themselves for self-reflection. For this reason, many authors use the genre mainly to process their personal situation with a visual diary.

As an artist holding two Master's degrees – in Fine Arts and in Graphic Design – I have always positioned myself at the intersection of both practices. I have picked up strategies and techniques from these distinct fields of art and have been combining them, trying to bridge the gap between the fine and the applied arts. Under the pseudonym of Ephameron, I publish illustrations in international newspapers and magazines and travel the world to curate, and take part in, art exhibitions. My artwork explores a delicate and temporary side of the world in which I do not shy away from using autobiographical experiences as a starting point. Recently, I have also been working with artists from different fields (music, literature, fine arts) finding inspiration in collaborating, while looking into different ways of graphic storytelling. In the past, I have published two books containing a selection of snapshots, drawings and illustrations, each collecting several years of work, called *Love / Pain* (2006) and *Found+Lost* (2009), and one graphic novella entitled *Weg* (“Gone”, 2010). This last publication marks a turning point in my art career. The story contains text and images that run parallel to each other, yet are thematically intertwined. It was made in close collaboration with writer Pieter Van Oudheusden. During the process of working on this project, my interest slowly but surely shifted from contributing singular images or series of illustrations to creating a full-fledged graphic narrative by myself.

3. *Wij twee samen*: Creating a Graphic Pathography

Wij twee samen (see figure 1) can be considered an experimental graphic narrative, telling the story of the impact my father's disease had on him and our family. He suffered from a type of dementia – early onset primary progressive aphasia – which is situated in the brain area of language and orientation. My father passed away more than a decade after he received his diagnosis. Our family cared for him in my parental home until the end, and this journey inevitably became a source of inspiration for my art. I explored the theme of his illness in illustrations, short stories, artworks and installations for exhibitions. After collecting materials for a long period of time and trying to process my emotions, I decided to turn the story into a book and ended up working on it for five years, which were also the final years of my father's life. The result is a kaleidoscopic graphic narrative where even the layout of the book played a role in the storytelling.

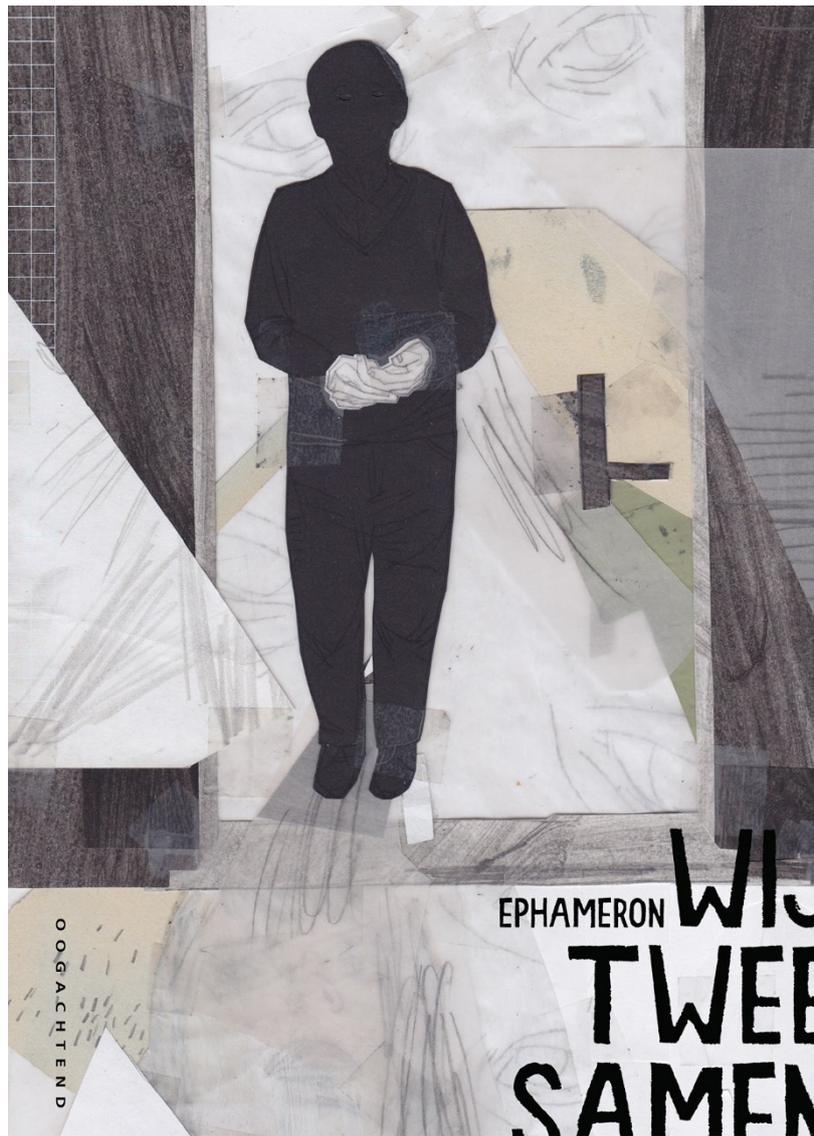


Fig. 1: Cover of *Wij twee samen* (2015)

However, some of the challenges I encountered while working on the book made me aware of the possibilities and limitations of autobiography. In this paper, I would like to outline some of the methods I applied to solve these problems and which continue to influence my current practice-based Ph.D. research in the Visual Arts. Because my art practice oscillates between fine arts, illustration, graphic design and comics, I knew from the beginning of the book's work process that I wished to combine these art disciplines in the project. I wanted to assemble several images in a sequence and add text to them to tell a story over a large number of pages, but I did not want to be restricted by pre-existing comics conventions.

I decided to work in phases. First I conceived a storyboard, then I determined the *mise-en-page* and developed a collage technique which allowed for changes throughout the process. Finally, the layout of the book was completed by arranging the text on and around the panels which were spread out onto the pages.

When I first started working on the storyline, I noticed that the fact that I was trying to recreate my childhood memories had a negative impact on the narrative. To only ‘write what you know’ and discuss your own experiences can be seen as a form of navel gazing. Autobiography is known to be a genre where readers are actively involved by means of ‘affiliation’, i.e. emotional engagement with the protagonist (cf. El Refaie 2012, 9f.). But allowing an audience to engage with one’s life story can be intimidating. According to Paul Gravett (2014, 88), “autobiographical comics have that story power to admit us into the sometimes problematic or distressing lives of others, people we may otherwise never know, and to find perspectives on our own”. In my case, to tell the story from my own perspective was making the book too personal, and I could not create enough distance from the subject to transform the project into the kind of visual literature I had envisioned. Some distancing effects needed to be added to avoid that my memories would become the focus of the narration. I did not want to create a representation of my father that was limited to my own perception of him. On the contrary, I longed to transcend my own perspective on his personality.

At first, I was using old family pictures as photographic references for my sketches. I also drew from personal recollections of my father to compile a biography that ended up depicting him in a favourable manner. This ‘perfect’ image clashed with what we were witnessing every day during his illness. In literature and film, it is often the extraordinary and sometimes enchanting moments of dementia that are documented: patients are still able to walk around and connect with the world, at times in an endearing or funny way. In my book however, I wanted to capture the last stage of my father’s disease, the stage where he could not communicate anymore and became immobile, which proved to be the most difficult period for us as a family. Since this final chapter of his life had nothing to do with the idealised photographic memories of my childhood, these initial sketches were dropped in favour of more realistic scenes and daily observations. Perhaps the images representing my father’s life before his illness are presented most directly on the endpapers of the book which depict objects my father used daily in his home study. They carry emotional value for his family as they remain intact, silent witnesses to a bygone era.

In the beginning of the process, I worked with text balloons. Early on I realised that this resulted in a narrative that remained too close to myself. Seeing myself and my family as characters that were speaking in bubbles also felt artificial. As soon as I decided to work with freestanding text that did not always link back to the images, the final outlines of the project became more clear. Having text and visuals run parallel to each other opened up new possibilities, because an interesting tension could be created where both could add more layers of meaning to each other (see figure 2).

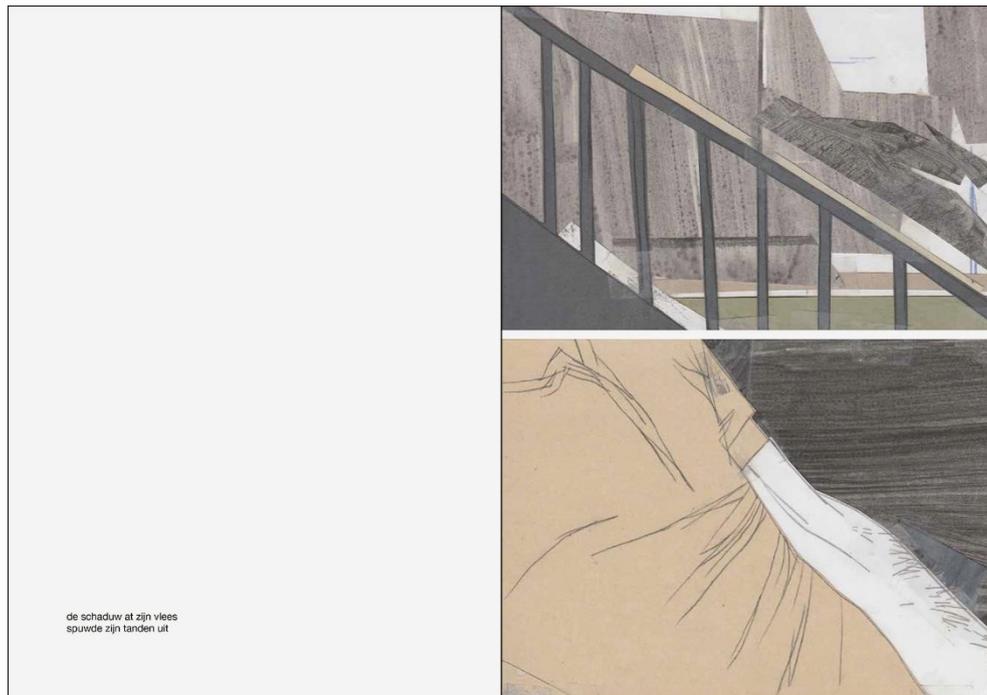


Fig. 2: Pages 156-157
[the shadow ate his flesh / spit out his teeth]

The dialogue between the characters was dropped, as I concentrated on describing their emotions and the daily scenes they were witnessing, as a poetic layer of text instead of a common daily conversation. I decided to keep the lines short and simple to avoid melodrama, and to use the sentences to guide the readers from panel to panel so that they would be able to piece the story together gradually. Instead of writing down the conversation between B and E as I had initially planned, I used a first-person narrator, who observed what was happening. This mode of authorial presence made it possible to look at the story more objectively and to combine text and image in an experimental way, as an artistic effect.

First draft²:

B: What would be your power if you were a superhero? I would like to become invisible.

E: I'd love to be able to look into the past.

B: Why not the future, that would be more exciting?

E: I would like to see my father before he became ill...

Final text:

my husband asks me if I'd like to be able to see into the future but
if I had a superpower I would want to look into the past
to be around my father again before he became ill
now, old memories have been replaced by new ones
and I've lost him forever in my mind
(Cardon 2015, 7-12)

Finally, on some pages I decided to use the comics convention of representing sound effects by sometimes adding transparent or coloured empty speech balloons in the pictures in order to highlight the loss of language in a subtle way.

It also proved difficult to draw myself as a character in the book, to be confronted with my own visual presence in the story. Unlike other (semi-)autobiographical authors like Alison Bechdel in *Fun Home* (2006) or Tim Enthoven in *Binnenskamers* (2011), I was not the most important protagonist of my graphic memoir. I therefore chose to only portray the character that represents me in the first few scenes, and to write the text in the first person. When I turned to the tactility of my images, I realised I was inadvertently leaving fingerprints on the painted paper and on the back of the sticky tape holding the paper collages together, which may be considered a visual mode of authorial presence as well. I chose to narrate my point of view verbally, while focusing on the other characters, my sisters and mother taking care of my father, in the images. As I was experiencing these events while I was working on the book, I was also writing in the present tense. This creates an intriguing condition since my character is present in the words, but not in the pictures (see figure 3).



Fig. 3: Pages 186-187

[he turns towards me and / tells me something I can't understand anymore]

Because I wanted the book to be about more than just my own experiences, I worked towards an open approach to the topic, and tried to make certain scenes recognisable to outsiders as well. In this way, the story could rise above the merely anecdotal and could become relevant to others who are familiar with terminal illness and / or dementia. Other authors share this ambition, like comic author Brian Fies. He starts the preface to *Mom's Cancer* (2006), about his family's struggle, with the quote "You are not alone" (viii). According to Williams (2012,

3), “he hoped that others similarly affected would find some comfort” in reading the story, just like I did when I set out to create my book. At the same time, I veiled my personal memories and hid them in the images. Thus, I could use them in a more abstract way for cathartic reasons without exposing myself. Examples of events readers can relate to in the book are images of my father trying to put something in his mouth, or a short sequence that looks like he is trying to hold something between his fingers. In reality, these objects only existed in his mind. This is a behaviour commonly associated with people suffering from dementia that already starts in the early stages of the illness (see figure 4).

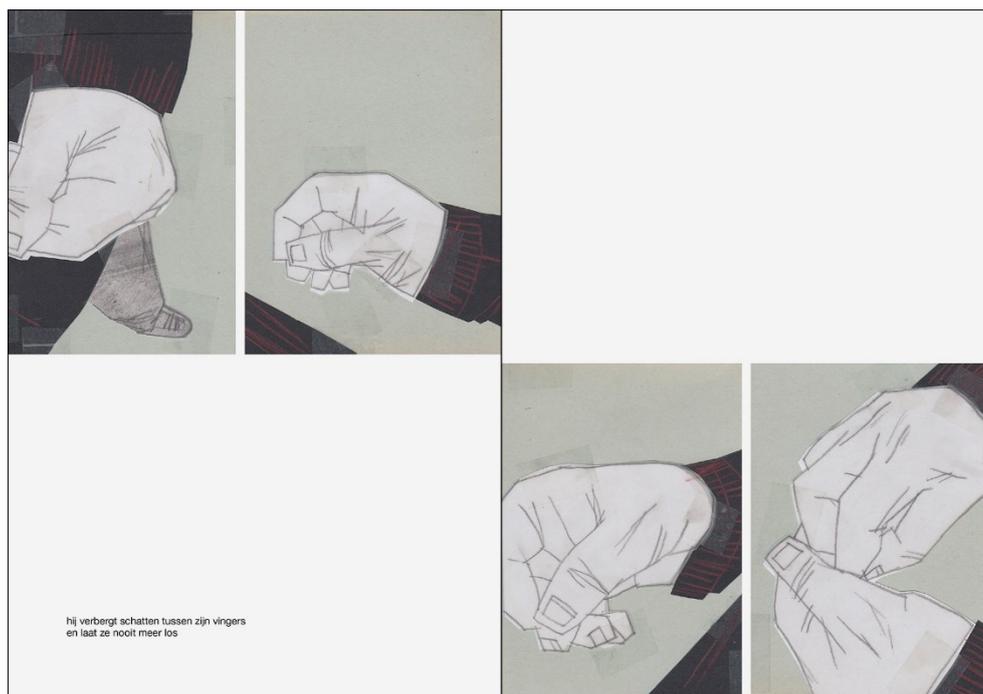


Fig. 4: Pages 48-49

[he hides treasures between his fingers / and never lets go]

At this point I was writing the story from the caregiver’s point of view, but I wanted to combine my perspective with a visualisation of the protagonist’s confusion. The story now became a graphic pathography (cf. Green / Myers 2010, 574) that tries to relate both the patient’s and the carer’s experience, similar to David B.’s *Epileptic* (1996-2003), in which the author narrates and visualises his brother’s illness. I wanted to link the aesthetics of my comic book to the disease – from using ephemeral, layered materials in my paper collages to transforming the text into a visual element representing the type of aphasia my father suffered from, which I will describe below.

It was a challenge to imagine how my father was experiencing the world during his journey. In the first half of the book I show him in an early phase of his illness, when he was slowly losing his language skills, yet was still able to join us on walks in and around the house and garden. This half revolves around his mental decline. The process is discernible in a few recurring spreads in the middle of the book, containing text on a painted background. The text becomes



Fig. 6: Pages 84-85

While working on the second half of the book, I was confronted with my father's sudden physical decline: his brain could not instruct him to walk anymore. His world was now limited to his bedroom and the ground floor allowing wheelchair access, and as a result his appearance changed dramatically. I documented this change and one way to visualise the decay was to create ambiguous images. For example, I avoided to show the physical decay by depicting parts of the body in a simplified manner instead of portraying my father's full figure in more realistic images. I also used a specific light blue card stock that loses its colour when it is exposed to sunlight. I left the pages out in the sun for a month so that their colours faded away, thus alluding to the disease's effects on the body.

The visual chaos and the surreal elements that I used to present my father's point of view also contrast with the empty areas on other pages. The abstracted images complemented by large, blank spaces set the tone for a slow-paced visual narrative. Consequently, the layout became an important tool in my book. Interpreting my father's sounds and movements, I created a background for his character using undefined shapes that allude to his perspective and represent the space that he inhabited. I drew what he was looking at and the scenes that he was facing, sometimes only applying two plain pencil lines to suggest a ceiling as seen from his bed. I zoomed in on small details that my father seemed to be focusing on, like a piece of red string wrapped around a pole in a field, or the striped pattern of his sheets. In the book, text is gradually reduced and images become larger and emptier while the borders of panels sometimes overlap and colour fades away, all to prepare for the inevitable end of the line.

In addition to the visual chaos in panels where objects, people and surroundings sometimes float around without connection, written words were also important for the representation of the development of my father's illness. Chute (2010, 6-10) states that handwritten text, because the same artist is drawing and writing the story, can evoke an "intriguing aesthetic intimacy" which can "work in tandem with the sometimes visceral effects of presenting 'private' images" in autobiography. Technically, there is also a difference to working with a pre-existing scenario: as I am writing and drawing at the same time, I can adjust either text or pictures, or both, during the process. This allows for flexibility in my decisions. In my book, several layers of text, for which I used different fonts, interact with each other and with the images (see figure 7).



Fig. 7: Pages 108-109

[can I come? / and laughs out loud / the same laugh from before / when everything was normal]

Firstly, I created a first-person voice for the character that stands for me. The neutral Helvetica typeface was chosen for this text. I used no capitals or punctuation for this narration, only lowercase text. Secondly, I incorporated the notes my father made in his diary, when he was still able to write at the beginning of his illness. Through the repetition of words and strike-throughs or underlining, functioning as indexical signs, the frustration of the character can be felt. In order to increase the emotional impact on the reader, I chose extracts which show the struggle in his handwriting, his search for words and letters, for example at the end of the first half where we can read 'Held me' instead of 'Help me'. My father's own handwriting, which I traced manually and turned into a digital font, was used for these notes that were laid out on a background of squared paper. Thirdly, I created an uppercase typeface that changes size throughout the pages. It functions as a visual representation of the protagonist's voice volume

when he gets angry or sad. This layer of text also visually represents my father's decline in speech: in the first half, words are slowly disappearing into syllables and sounds, but in the second part of the book, when his language is gone, speech and notes are left behind and only the narrator's voice remains.

In these three layers of text, each of which incorporates a particular focus, the pictorial aspect of the written words is brought to the fore: the text doubles as image, and works in symbiosis with the pictures. The layers of text literally overlap each other and the images in the book. Will Eisner (2003, 103) points out that images tend to dominate words in comics: "body posture and gesture occupy a position of primacy over text". In other words, if we look at an image, we will trust its content over the caption we read underneath. However, in comics, most of the time text will be read before examining the image it accompanies, so it remains important to keep a balance between both elements.

I wanted to both involve the readers and leave space for their own interpretations so that they could read, figuratively speaking, 'between the lines' – or, referring to the space in between comic panels, in the 'gutter'. Because of the sparse text and the large amount of blank areas in the book – echoing the use of white in the East-Asian painting tradition – I am asking a lot from the reader and I am aware of that. Some readers have commented that the book is somewhat inaccessible. However, as an artist, I want to provide a framework in which readers need to play a part too, by linking the panels in their own way, by using their imagination and filling in the blanks with their own life experience to complete the narrative and actively participate in the construction of the story. According to Elisabeth El Refaie (2012, 9), "comics typically achieve a high level of involvement on the part of their readers by inviting them to contribute to the process of creating meaning".

In 2007, Thierry Groensteen introduced the term 'iconic solidarity' (cf. 19). To describe this phenomenon, Ian Williams (2012, 22) wrote that "the human brain seems to work in such a way as to try to extract or impose narrative on juxtaposed images, even when none may exist. Comics use this innate propensity to their advantage. When one perceives two or more juxtaposed images, the brain assigns the sequence a narrative timeline". According to Crucifix / Meesters (2017, 644f.), in this way *Wij twee samen* "stimulates the readers' tendency to link ostensibly incomprehensible or uninterpretable forms in a never-ending quest for meaning".

Words in comics do not always correspond to what the accompanying picture is showing, and pulling the two elements apart can create additional meaning. I also used the opposite technique: when text and image complement each other, they can enhance each other's meaning, like in figure 8, where the sensation of touching is communicated through a combination of text and image, without showing the act.

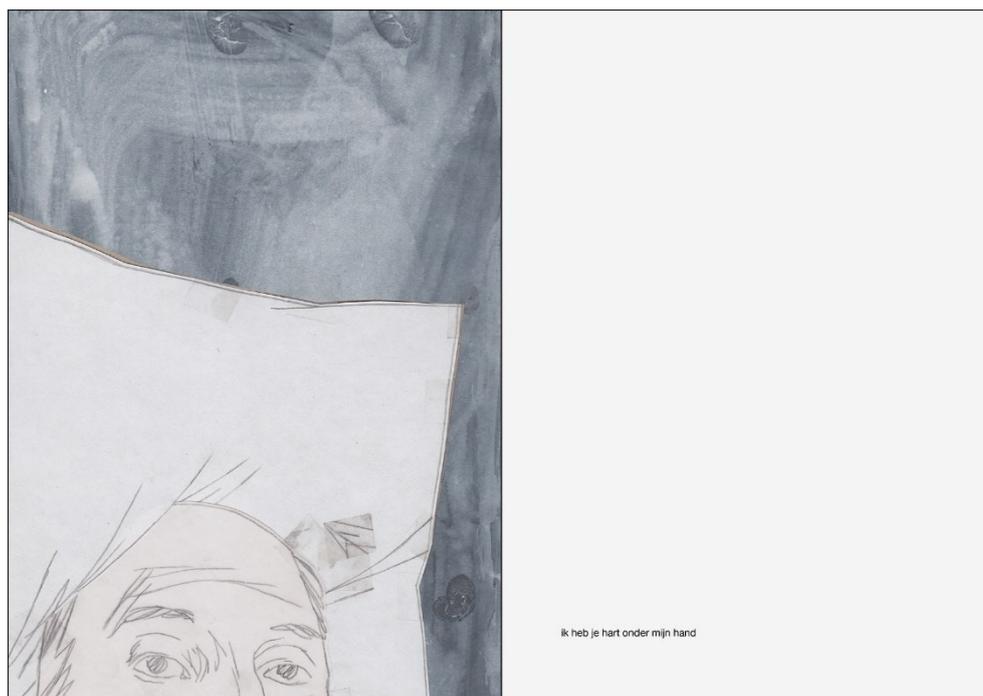


Fig. 8: Pages 188-189
[I've got your heart under my hand]

While reading a comic book, the reader is able to set his or her own pace, flipping back and forth between pages:

[...] comics is not a form that is experienced *in time*, as film ultimately is. That it cedes the pace of consumption to the reader, and begs rereadings through its spatial form, makes comics a categorically different visual-verbal experience for its audience. Releasing its reader from the strictures of experiencing a work in a controlled time frame can be a crucial, even ethical difference, especially in presenting traumatic narratives that may include disturbing images. Comics avoids the manipulation often associated with film – in which the camera might linger on an image of atrocity for too long, on the one hand, or wash over it casually, on the other – by allowing a reader to be in control of when she looks at what and how long she spends on each frame. (Chute 2010, 8f.; emphasis in the original)

At the book launch event of *Wij Twee Samen*, I tried to influence the reader's control over the reading process: I exhibited the 150 collages that I made for the book horizontally on tables (see figure 9). As framed and isolated images, they communicate the feeling of fragmentation even more tangibly than in the book. They were presented in their original size, which is slightly larger than their reproductions in print. A considerably greater tactility was also present through the visibility of the edges of the collaged paper, which are cut off in the layout of the publication. The tables were arranged into a labyrinth with some dead ends, so that the audience could experience the feelings and the confusion of my father. During the event, many visitors became trapped by each other while walking through the installation. They had to make an effort to follow the storyline because everything was jumbled up – just like my father must have felt in the end, when he did not understand the world anymore.



Fig. 9: Book launch exhibition view, February 12, 2015

4. Autobiography and Voyeurism

After *Wij twee samen* was published, I realised that I had previously neglected the impact that publishing an autobiographical story could have on the author. Where I assumed that finishing the book would be like moving on to the next chapter of my life, press and audience kept pulling me back to traumatic memories. The book had become a public testimony. While I was lecturing on the work process and traveling with an exhibition of the original artworks from *Wij twee samen*, the reactions that I received from people sympathising with me or criticising my depictions in the book made me experience the voyeurism that is linked to autobiography, the irresistible urge of strangers to look into the life of the author and to build an emotional connection or ‘affiliation’ with the characters in a story. I noticed that the readers were not only interested in identifying with a story, but also in sharing their own experiences with the author, as a way of confirming this identification.

However, I did not want to be reduced to being ‘the artist who lost her father to dementia’. It was emotionally hard to try and carry readers’ feelings and experiences on top of my own, especially since my father passed away only a few weeks after the book was published. This is why I decided that in my next project I was not going to write a story only from my own, individual perspective, but rather that I would incorporate fictional elements into the stories – thus transforming the autobiographical into the autofictional or semifictional. The new graphic short stories about motherhood that I am currently working on are experiments that call for a lesser degree of identification from the reader, and

from myself. I do not accomplish this by moving completely from autobiography to fiction, but by looking for multiple voices and collaboration by interweaving my stories with those of others.³

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How to cite this article:

Cardon, Eva: “‘Us Two Together’. Creating an Autobiographical Visual Narrative about Dementia”. In: *DIEGESIS. Interdisciplinary E-Journal for Narrative Research / Interdisziplinäres E-Journal für Erzählforschung* 6.2 (2017). 160-175.

URN: [urn:nbn:de:hbz:468-20171121-120256-9](https://nbn-resolving.org/urn:nbn:de:hbz:468-20171121-120256-9)

URL: <https://www.diegesis.uni-wuppertal.de/index.php/diegesis/article/download/286/448>



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¹ Cf. Joseph Witek (1989, 5): “It is clear that the comic book, a widely accessible and commercially available medium, is now being chosen as a form by serious writers. [...] Comic art is thus a literary medium in transition from mass popularity and cultural disdain to a new respectability as a means of expression and communication, and this new respect is evident first in the attitudes of the creators themselves.”

² Throughout this article, I will be using my own (preliminary) translations, since the book has not been published in English yet.

³ See Masschelein 2013 for a similar approach by Sophie Calle in her artwork *Douleur Exquise* (2003-2004).