



# DiGeSt

Journal of Diversity and Gender Studies

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*DiGeSt Journal of Diversity and Gender Studies, Volume 7, Issue 2*

Print ISSN: 2593-0273. Online ISSN: 2593-0281

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DiGeSt is hosted by Ghent University Website: <https://ojs.ugent.be/digest>

# A visitor in your house? Letters about non/normative family lives from sisters becoming mothers

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## Abstract

Two women have become mothers. They both make art. They both grew up in a family with a sibling labelled as disabled. Ted, a visual artist, has made photographic and video work about her youngest sister. Marieke, an ethnographic filmmaker, created a short film about her eldest brother which fuelled her PhD about non-normative family lives. Intrigued by motherhood and sisterhood they have taken to writing letters, through which they bring their memories, thoughts and artistic creations into life. The present arts-based study is about entangled motherhood—i.e., the entanglement of mother-sister-daughter roles and the intergenerational entanglement of the present, past, and future—in the context of encounters with difference and care. By writing letters as a way of situating themselves within the world, they intend to open up new forms of knowledge production, moving away from medicalized and binary ways of studying (growing up in) families with a labelled family member.

## Keywords

Art-based research; Disability, Family; Norms; Entanglement

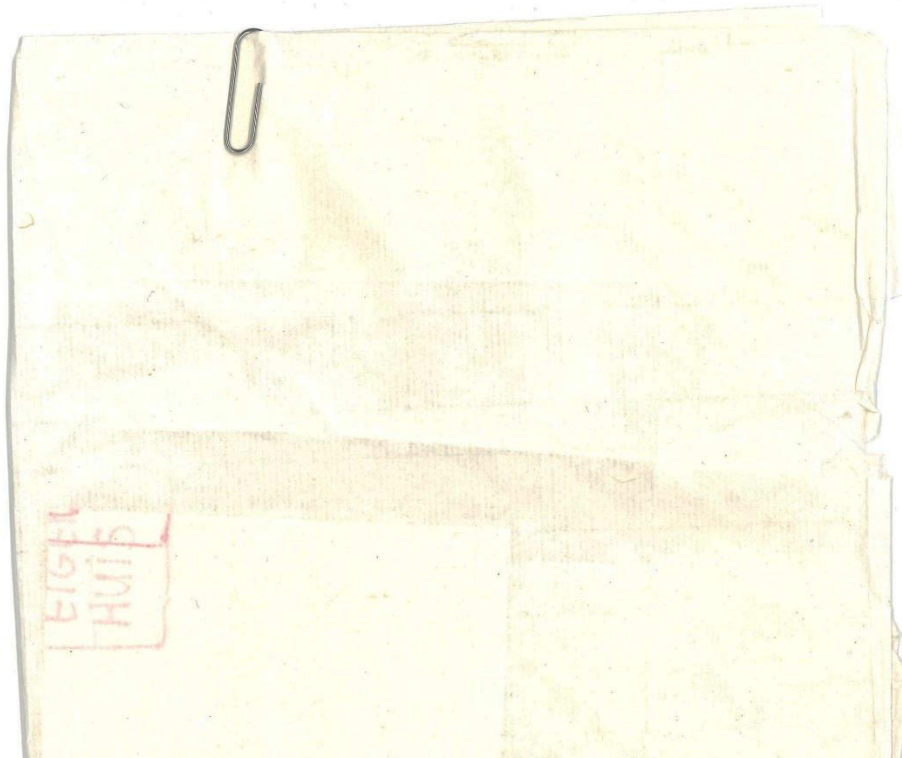


Figure 1. About what is present between the folds...

### **Introduction: Writing Letters and Entanglement**

Never before had there been a more intriguing business card on my<sup>1</sup> desk. In block letters, it said 'TED OONK photography and visual artist'.<sup>2</sup> I received your card in the context of the photo/video project of you and your youngest sister. I see similarities in how I created an animated documentary with my eldest brother.<sup>3</sup> Your sister and my brother were born with a disability label. Your sister's label is well-known, my brother's is rare. Your artistic family project first touched me through the image below. Your sister is standing on the edge of the swimming pool in her swimsuit. She looks at the lens as if she is looking straight through you, without any hesitation. An image etched in my memory.

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<sup>1</sup> First person usage refers to the first author, Marieke Vandecasteele.

<sup>2</sup> More information about Ted Oonk's artistic work: <http://tedoonk.nl/>.

<sup>3</sup> Link to Marieke Vandecasteele's shortfilm *Lode's Code*: <https://vimeo.com/197209791> (for password, contact [marieke.vandecasteele@ugent.be](mailto:marieke.vandecasteele@ugent.be)).



Figure 2. *Swimming pool* (still from Ted Oonk's videowork)

Who are you and why do you create what you create? I wanted to meet you and you accepted my invitation. We met regularly. You told me about your research in your artistic work, which coincided with your life as a sister and I shared about my work as an arts-based researcher, which also coincided with my life as Lode's sister. We sought ways to connect. Eventually we started writing each other, and we continued this exchange for two years.

Letter writing became a safe platform, a methodology to create a dialogue. Letter writing's status as a natural way of reflecting can be traced historically across human societies and cultures around the world (Barton & Hall, 2000). Despite its widespread occurrence, letter writing is seldom used in academic work (Harris, 2002). But it can expand research otherwise done in standardized ways. Letters are a unique data format which assembles the writer's thoughts, feelings, and observations – ranging from theoretical to deeply personal. Moreover, letters form a dialogical chain in time (Salmons, 2018). You follow your own rhythm, more easily than in conversations. Writing and receiving letters is separated by time. It requires detox time, withdrawal from the (expectation of) immediate satisfaction in the form of an answer. A letter can impose time to wait for its arrival, and might come as a surprise. Letters are time-bound, dialogical documents that enable writers to jump and create layers and allow time-space-position entanglement. Letters provide space for silence. Letters somehow facilitate the sharing of intimate topics (Harris, 2002). Letter writing comes close to what Patricia Leavy describes as poetic research:

Poems, surrounded by space and weighted by silence, break through the noise to present an essence. Sensory scenes created with skillfully placed words and purposeful pauses, poems push feelings to the forefront, capturing heightened moments of social reality as if under a magnifying glass. (Leavy, 2015, p. 77)

We see letter writing simultaneously as data collection and analytical tool (Harris, 2002). We see it as affective research. As researchers, we are driven by what touches us and that which we seek to integrate. As researchers, we are also continuously touching others, even if it cannot be put down in words. It is research in which our own subjectivity is welcomed. As Bronwyn Davies (2014) writes:

We as researchers, are part of, and encounter, already entangled matter and meaning that affect us and that we affect in an ongoing, always changing set of movements. This idea of entanglement affects not just what is possible to see but what is possible to be and do, epistemologically, ontologically and ethically. (Davies, p. 735)

The writing of letters transcends describing or writing about past events. The writing itself is research (Gibs, 2016). Over the course of our letter exchange, Ted and I both became mothers for the first time. Parenthood does not exist on its own. It is connected to the life we are living now, how we structure it, and how we carry with us our past of having grown up in a family ourselves, our material environment... Connections we are conscious or unconscious of to varying degrees, and which we would like to capture by Karen Barad's concept of 'entanglement'. In *Meeting the Universe Halfway*, Barad approaches all living (human and nonhuman) matter as being/becoming entangled. She insists on the connection of everything with everything. And when everything is relational, the world is continuously negotiating. We can only fix moments in time and unfold them temporarily. It compels us to think beyond static identities. The concept of 'entanglement' disrupts the idea of an individual human subject. The different positions of being-sister, being-mother, being-daughter are all connected and, hence, not entirely separable. We neither intend to unfold this relational chain completely, nor do we believe it is possible. We do wish to explore this chain collectively. During our letter conversations we shared fragments of our life experiences and loose fabrications of our memory and our imagination, simply because it worked. We write this paper from the idea that the past continues to live in the future and that the future is created by the past. The past can also be re-written at all times:

An ethics of entanglement entails possibilities and obligations for reworking the material effects of the past and the future. The 'past' is always already open to change. There can never be complete redemption, but spacetime-matter can be productively reconfigured, as im/possibilities are reworked. (Barad, 2010, p. 266)

We embraced letter writing as a journey during which we dared to be vulnerable, and moved our own conceptualisations around sister-/mother-/daughterhood. Meschonnic refers to the transformative power of writing, as a way of acting on the world and situating ourselves within things (Meschonnic, et al., 2011). In what follows, we share excerpts from eleven letters.

### Letter excerpts

Dear Ted,

I am quite ashamed for the many times I have attempted to complete this letter. I had nearly given up and was about to search for another communication channel, but I am happy that I haven't. The slowness and the unpredictability of letters are somehow charming and exciting. It is something you can look forward to and long for, exactly because you cannot take it for granted... which seamlessly brings us to our project.

I am waiting on the platform for the train to come. Waiting... it is usually quite an annoying experience... the emptiness that overtakes you... but now that I have discovered writing, writing without the expectation of a definite end product, I enjoy not being efficient for once, I am free to roam around and get lost in my thoughts. It reminds me of my pregnancy, waiting for my child. Both of us having a sibling with a disability and both of us having become mothers recently... I feel drawn to this similarity... what if we make it the axis of our research project? Letters of sisters becoming mothers? I wonder... what is it like for you to be Pim's sister while now also being a mother?

Dear Marieke,

Everything has changed. Everything I had and did is different now, with my child. I can go to my art space but Mies (my son) is in my head and time is limited. I can't work through the night anymore. I can't do anything the way I was used to do it. I get it, when people say that it's sometimes a mourning process you need to go through. That you need to say goodbye to life without children. I experienced it. And flashbacks have pulled me back to that feeling up until today. As if the childfree image wanders around as a ghost. Those moments scare me... I am afraid I'll become like my mother; unable to let go of my mother role. I have to admit that getting a child of my own has triggered many questions and memories about how I was raised. And that I don't have the answers, or that I am often lost in eternal doubt. It may be connected with my nature... or simply with motherhood?

I vividly remember the birth of my younger sister, Pim. She is the youngest of four sisters, I am the eldest. I found it very strange in the beginning to notice how everyone was sad when Pim was born, apart from us, the sisters. We didn't know yet that something was going on. Only after two or three years it became clear to me that there was something that would never go away. As a sister you get time to get used to your sibling. It went slowly. When we were kids, we used to play with each other all the time. A fight now and then, but always closely connected with all the sisters. We played in the garden. We went on little adventures together, and we pulled Pim along even though she couldn't speak yet. She lay on a blanket next to us. We did our thing and she joined us, quite naturally actually...

I have enclosed a photograph made by my mother when Pim was born. Pim was still a visitor, unknown to anyone, and about whom you might hope that she would stay only for a short while and then leave. You don't expect much from a visitor, but then the visitor became their daughter... She was parked shortly, but she belongs with us forever now. My parents had high expectations, they hoped she would be able to read and write well...

Letters from sisters who became mothers... a beautiful title. I have two questions for you. As a sister: do you feel responsible for Lode? As a mother: is sisterhood inferior to motherhood?



Figure 3. *Visitor* – Letter from Ted to Marieke (photograph from Ted's family project *This is not about you*)

Dear Ted, Thank you for the beautiful image you have given me, of your little sister in her pram. It is recognisable yet different. The word 'visitor', your chosen title and present in the picture, echoes strongly... Remarkable, how your sister has not been parked at number 4, but is seen as a visitor. Also the word 'parking' catches my attention. Parking something is a phrase referring to the act of temporarily not continuing with something. Locking it up for a while, not knowing how to deal with it, as a family.

I recognize myself in your story about gradually growing as a sister in learning how to deal with the strange visitor who has just entered your familiar nest, and about the gaze of the world outside, staring and reminding you that you are not a normal family.

About how you played on a blanket with your sisters. How you simply pulled your sister along... Yet I see how different our nests are. Your father is an expat and you all moved many times. I have always lived in the same house. You have the Dutch nationality but live in Belgium because of your Flemish partner. I am the youngest myself whereas my brother with a label is the eldest. I have never known a time without Lode; a very different position to start from. You come from a real sister nest... and I don't, I have two brothers. My oldest brother, Lode, talks and moves non-stop (at his happiest). Don't ask him to sit still on a chair for five minutes. You tell me that your sister uses

language sparingly. I have always felt really responsible for the extra support that Lode needs. In my family I was given the name 'little witch', the little witch who might have already been the extension of the 'great witch', our mother. It is Lode's language; we have noticed that fantasy is the best way to reach him. As the little protection witch, I saw it as my task to make Lode happy. He fell seriously ill a few times when I was little, and the idea that we need to help each other and pull the same cord as one family became strongly present. Ever since I remember, my parents have told me that I was born as a therapist... a message which probably steered my choice to study special needs education and support.

I realized, however, that I would need to create space to be able to become a mother myself by changing my role. Whatever I used to do was no longer feasible in combination with a partner. I have chosen to build up my own life and leave the house we grew up in. Despite my shifted role as a supporter, I do not feel less like a sister to Lode. Not less-sister, but rather different-from-before-sister... How do you look at your role(s) as Pim's sister?



Figure 4. *The sisters' blanket* – Letter from Marieke to Ted



Dear Marieke,

Thank you for your letter. When I read it, I felt snippets of sentences and stories moving through me. My thoughts were unstructured. I wished to respond immediately but life got in the way, so please forgive me if this piece is slightly unreadable.

I'll start with what has stayed with me after reading your letter, and that is your caring role in the family. How you describe that you were really convinced that your support was essential and that your parents were expecting this from you. It made me reflect on my own relationship with my sister and my parents, and our completely opposite story. How I have experienced it, my parents have always chosen very consciously to keep the care, the financials, the thinking completely at a distance. I did pick up Pim from school for three years and took her home by train because her school was in the same city where I was studying. When Pim turned 18 there was this piece of paper, shoved under our nose. We needed to sign a judicial power of attorney form, declaring that we as sisters would take care of Pim if our parents were gone. I didn't really think about it back then and just signed it, but actually, now that I write it down... how strange that we had never been part of the discussions around Pim and the decisions my parents sometimes needed to make and then suddenly had to decide on something as essential as power of attorney.

I guess they consciously chose to leave us out, trying not to put a burden on us and creating a childhood as normal as possible, very noble of course. But somehow, we already had a different kind of childhood, hadn't we?

Dear Ted,

In your previous letter you wrote that our parental families clearly differ, with your parents consciously choosing to leave you out of all decisions around your sister whereas my parents did not. I want to add to this, however, that my involvement was limited; my parents always were in charge. They enjoyed having an engaged daughter and I always enjoyed taking up this role... although I felt their disappointment after my graduation, when I started to divert from their expectations and I made clear that I could not be Lode's personal assistant (I am too close with him and his context) and that, more than anything, I wanted to stay his sister... Can we see the actions of our parents to shield us from decisions about our siblings as them creating limited space for us as sisters to engage and co-decide? Could our parents be afraid we might have a different perspective, and could that be the reason for not drawing us in the dialogue? Is difference not allowed to exist? When I look at your photographs, which you have made yourself or which you have selected from your mother's album or which your sister has taken from things she values following your suggestion, then I get the idea this is your creation to set the feeling of being parked (what you feel within your family) in motion. It tells the viewer: 'Look, I am here, and I am not ashamed. You can look at me. I may be different, but I exist.' I see it as a journey of two sisters, where you ask yourself the questions who you are as sisters and which desires you have as young women.

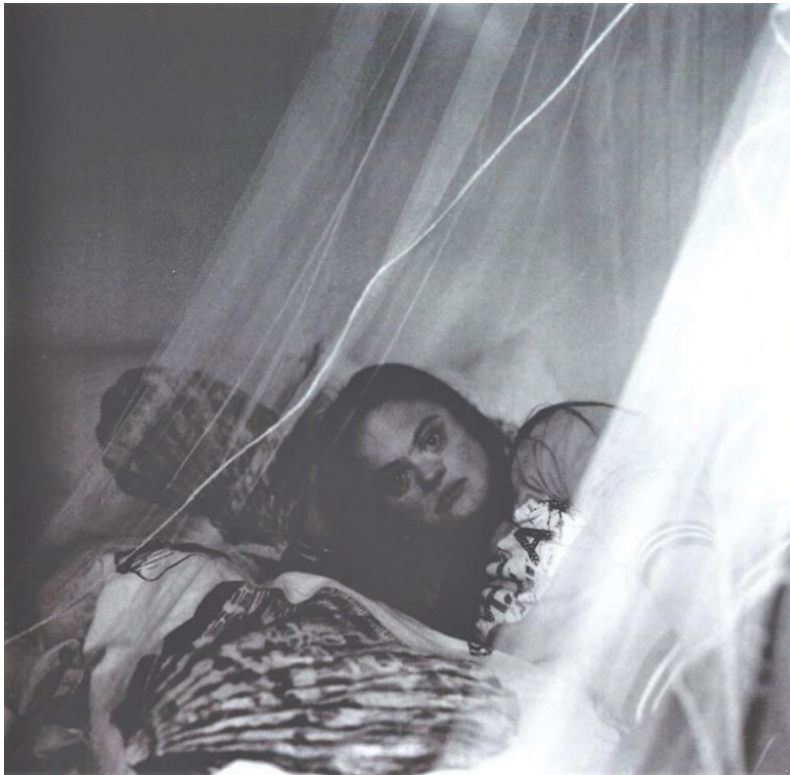


Figure 6. *House of my own* – Letter from Ted to Marieke (photograph from Ted's family project *This is not about you*)

Dear Marieke,

Probably there are many things that happened once and were never processed, which will hit you back twice as hard when you find yourself raising a child yourself. I notice that I have been so intensely raised with the idea you need to be strong and persevere that I now continue and do everything to avoid showing that I am vulnerable and that I sometimes don't know what to do, and that I don't consider my problems worthy of help.

I don't know what I want, take care of Mies, be there for him, or actually doing my own thing. It makes me feel guilty, thinking: how did my mother succeed, why was she able to be a stay-at-home mom? I find it so difficult, mentally, to give up aspects of my old life. Also the idea you bring Mies to daycare where he needs to survive on his own. This week I read something in the newspaper about dropping babies in daycare too early as a result of mothers needing to take up their jobs again three months after birthgiving. I could sense every fiber in my body telling me that Mies got upset by the noise etc. He was not ready for it until much later. But I was also happy that he was gone for a short while. While writing this, I feel tears welling up. Wishing to be there yet not always.

Expectations make you live less in the present. It sounds pathetic, but because of Mies I am compelled to experience it. Looking at him without expectations. Certainly now that I start to see that he does things differently and that my suspicion is becoming slowly confirmed: Mies is a high-spirited child with an introvert side, two characteristics that collide so roughly in my head that it short-circuits my brain multiple times a day. For a very long time I thought: 'Just be like other kids, relaxed, sleep like a good child for once, play independently. But I have had to let it go, it doesn't work for him. I need to follow him, place myself second. Expectations overboard and see what is. Expectations are so destructive, not only in families but also in how we look at each other.

Tom and I visited a sleep coach recently because the past half year Mies has been laying awake for hours. The coach invited me to reflect on what I wanted to teach my child. I blurted out: *'Look, I grew up in a women's house. I don't know anything about boys and about how boys grow up. I only know which men will be loved later in life, and which men are women-friendly. That is what Mies needs to become. I want him to be integer, kind and soft. By hugging him and showing how the first woman in his life interacts with him, I am laying the foundations.'* How naive, as if I can determine in detail what kind of man he will become. But my answer clearly contained a connection to what I was given myself, how I grew up without boys, with only my father as a role model...

I just heard that my friend is pregnant. This time she will carry the child, last time it was her girlfriend. Their first child sometimes plays with Mies. I can't pinpoint where it came from, but I got this emo mood. How can people receive/get a second child so quickly? It feels like shoving the first one aside. For me it is still so fresh, perhaps because we still have a bad sleeper ☹. Do you recognize this feeling? And I have another question for you. Do you feel guilty when you choose for yourself?

Hello sweet Ted,

You ask me whether I sometimes feel guilty when I choose for my own life and trust the care of my child to someone else. I don't quite know what to reply. My question to you is: how did you arrive at that question? What makes you feel guilty when sharing parenthood with your partner, day care, grandparents, ... Didn't you tell me that your mother chose to put aside her job to take care of the children? You also told me that you would love to live up to this expectation, but that being a stay-at-home mom is deeply pinching you. How do you define good motherhood? And how do your parents look at their parenthood?

It feels weird to write this down because you are one of the first people I entrust this to and certainly also because of how you ended your last letter... I feel I should tell you: I am pregnant again! Just when our life with Rosetta has settled somewhat, we have jumped in a new adventure...

You also share that you are having difficulties understanding people who start with a second child quickly. I found it important for Rosetta to have a brother or a sister. A bit odd perhaps, because I can't really describe my relationship with my brothers as friendship, but still, I love being family. The strange thing about a family bond is the blood bond that connects you, you cannot choose for this relationship. You simply need to deal with it... Could this be a first exercise in learning how to approach diversity?

I am also struggling to tell my mother I am pregnant. During my first pregnancy she was anxious, scared that Rosetta would have my brother's syndrome. Even before I was pregnant, my partner and I had our blood tested to check whether the syndrome had been passed on genetically. We received a negative answer. Lode's disability is an unexplainable little mistake of nature. An accidental mutation... Nowadays you get the NIPT-test offered in your first semester, the non-invasive prenatal test for the screening for Down syndrome.

We decided not to do the test, which was hard for my mother. I refused to go along with the fear that is strongly present in my family. Bringing a child to the world is exciting, with a bit of suspense. We've been 'lucky' with Rosetta. I find it wrong, though, to phrase it like this, as if you are unlucky when you suddenly find yourself with a baby with Down. I don't want to take on that perspective.

It's a peculiar experience, feeling how vulnerable you are as a parent. You are responsible for the well-being of a child whereas you can control so little... The thought that the child on its way is welcome reassures me. Isn't it comforting to feel that you can't control everything and that life is largely designing itself?

I do notice that the idea of taking control of 'the human' is strongly present from a scientific perspective. It inspired me to work with your mother's visitor-photograph in my graphic art classes. The pram transformed into a shopping cart during my first press... it reminds me of the expression 'buying a child'. The thought that you can simply go to the shop and choose which child you'd like to have. In comparison to our parents' life, we are presented with a whole range of prenatal tests and we need to decide whether or not we wish to 'buy' this child. A devastatingly difficult choice, if you ask me... Can you truly know what you are choosing from? And what you exactly want to choose? Can I risk having a child (of my own genetic material)? Did you know that a sibling of someone with ASS is seen as a person 'at risk' of 'producing' a child with ASS? I suddenly realize that I am such a person. 'And oh no, I have forgotten to take in my folic acid...' As future parent/sister/daughter you are in the storm of things...

You asked me once whether I was afraid that my child would be like my brother. Are you afraid that your son is like Pim?

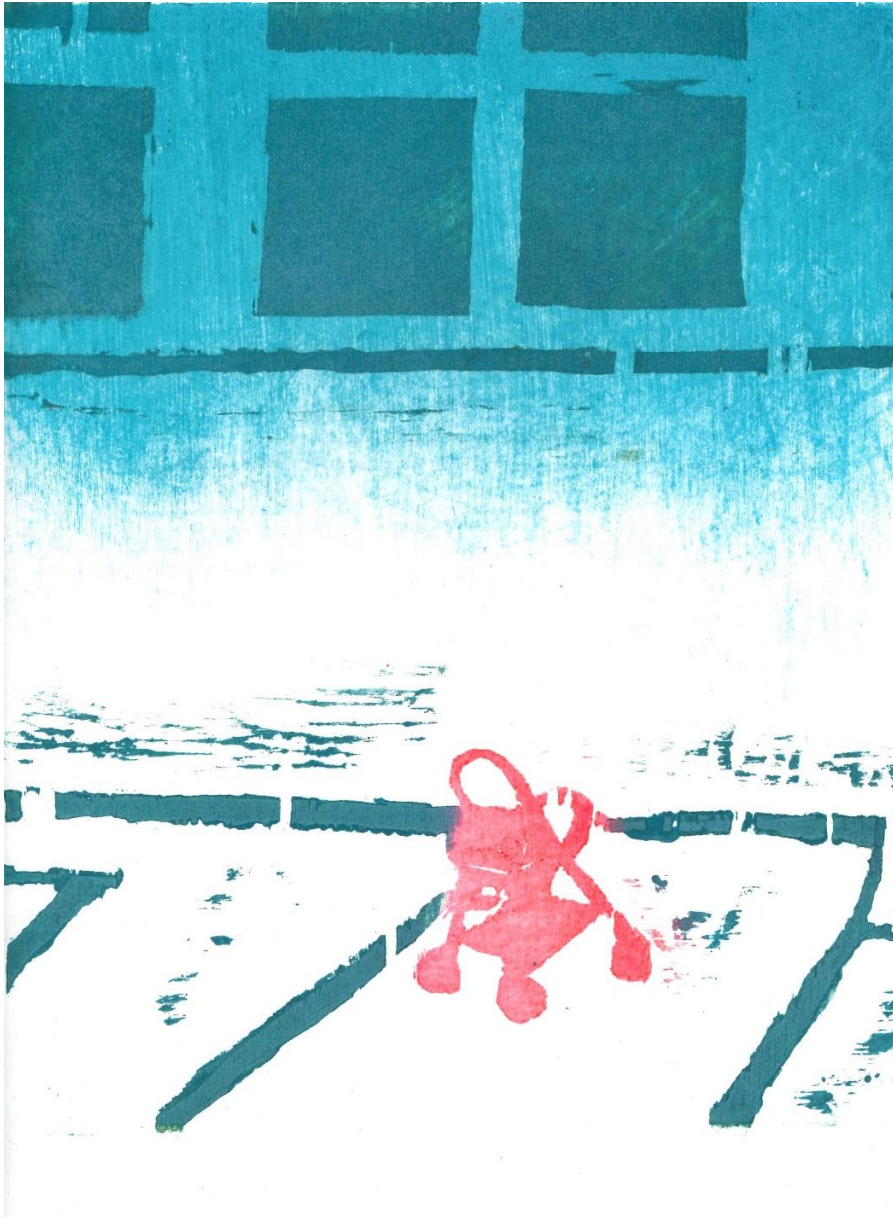


Figure 7. *Buying a baby* – Letter from Marieke to Ted (Japanese woodcut)

Dear Marieke,

I know that Mies is not like Pim... But I am not looking forward to the moment that I will realize that Mies will be able to do things that Pim will never accomplish. Like reading a book, independently getting on the train, and simply understanding a whole conversation. I notice that I struggle with the thought itself. Mies does not have Down indeed, but who knows what he does have? Something I can't see and don't know yet...

I am not an at-risk person for Down as Pim's sister, but I do remember the gynaecologist asking me explicitly whether I had a family member with disabilities. That NIPT-test in itself is okay, I only wonder how it will be embedded in society? If you choose to terminate, will you receive judgemental gazes, or if you choose to proceed, will this still be possible? An example to show how the NIPT-test is already shaping thoughts: my husband's colleague will be a father soon. They had done the NIPT-test and the doctor presented the results. Risk of deviation. The doctor told them literally that it was their moral duty to have it removed...

As a closure to this letter: what a difficult question you asked me... how my parents experienced their parenthood? ... I have never asked them how they received Pim. I do hear sometimes that Pim was demanding. And that my mother doesn't know herself how she kept going. That is why, I believe, I have never discussed her photographs of Pim with her. The fear for disconnected discussions is enormous, as well as the fear to get tangled up in them too much. What I do know is that for my parents the word 'family' gives them something very powerful to hold onto, and they would do anything to keep the family together. Because my father lost all his closest family members early on. I never got to know them; they were never talked about. He has hardly any childhood pictures. And my mother lost her sibling sister when she was 17. I think it was written in the stars that the two of them would go abroad to create a big family of their own...

Dear Ted,

A question that occupies me, and which I used as the ending of my shortfilm concerns the future. We may have already grown up, but there are so many questions left... What when one or both of my parents are gone, what will happen with my brother Lode? And what role can I or will I have to play?

I am sending you a photograph of Lode and Rosetta that makes me laugh because they are both wearing a red apron and they both are crazy about food, which makes them quite alike. The fact that Lode has become an uncle has also introduced an interesting shift. Lode used to be the one we intensely take care of, but the arrival of a baby has drawn care away from him. It seems to have given Lode fresh air, the opportunity for him to take care of someone himself... how much he enjoys being uncle Lode and how naturally he welcomed this new life... I notice that I attach quite some importance to Rosette getting to know her uncle, and to her uncle getting to know her. What if there were no 'Lode's' around anymore?



Figure 8. *The red aprons* - Letter from Marieke to Ted (photograph)

Hi Marieke,

Thank you for your beautiful questions. But are there any answers? Being a sister... is genuinely hating while deeply loving someone. I can't explain. It is something very natural. You can't renounce it. You can find it annoying, but you cannot leave it because there is a lasting bond. It is remarkable how every child in our family has removed herself physically from my parents. We all live far apart as if we were longing for a life of our own without any interference. I remember I couldn't wait to leave the house. Over time I have come to realize that interference can happen also on every non-physical level.

How I see Pim's future? It intrigues me to watch my sister become an adult woman, and I am curious about how she will grow. My photography is a way to watch her grow up and follow her. She is 25 now. In November she moved to a studio of her own. She now lives quite independently, in a house shared with other people. It is somehow a relief that my sister has found a place of her own.

I hope that she now will be allowed to make her own decisions and feel confident about her life because I suspect that my parents were sometimes living suffocatingly close to her skin... I also hope that my parents can finally feel 60+, separate from being carers, and that they can develop a relationship with Pim more as parents and less as carers/educators... I myself do sister-like things with Pim: going shopping together, going for a coffee, things I do with my other sisters too.

Interesting how you say that Lode has embraced Rosetta as if she has always been there. For Pim it was similar, the rest of the family is still adjusting to the changing structures. Mies and Pim get along well, and it is very important indeed that they don't fear each other because fear for what is different is the beginning of distance. Pim is a very sweet aunt, Mies always laughs when he sees her. Then she calls out 'hey little Mies!' Pim makes me integer. Integrity for me means that there is a certain simplicity, the ability to live in the moment, and that you can put yourself second, switch off your ego, and that you dare to admit that you might sometimes not know everything.





Figure 10. *Caress* – Letter from Ted to Marieke (photograph from Ted’s family project *This is not about you*)

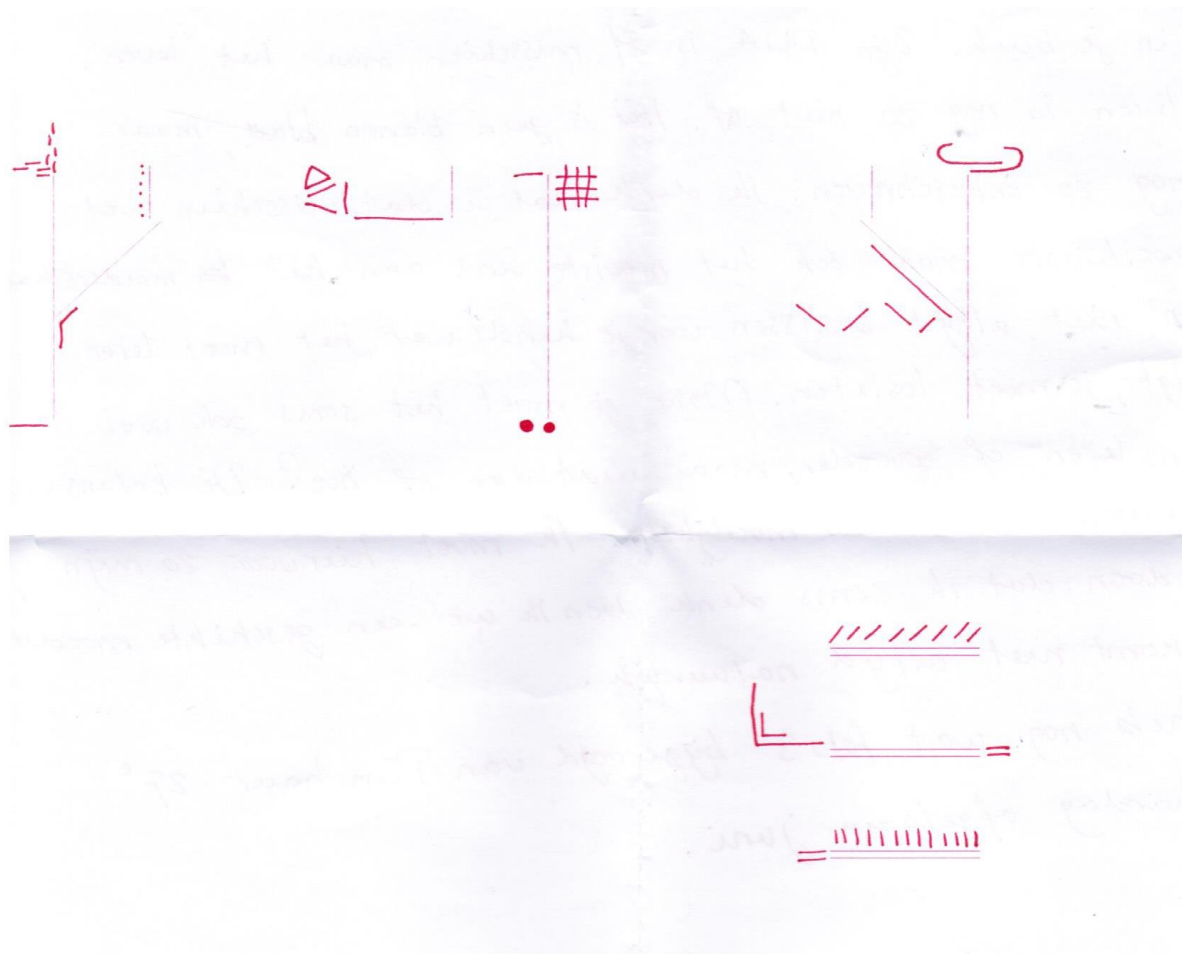


Figure 11. *Waste paper* – Letter from Ted to Marieke

The piece of paper above was waste paper, an abandoned misprint. I marvelled at the error of tiny pink lines. They resemble an incomplete DNA strand. I linked it to the child in your belly. His DNA is complete but life has yet to start. He is not a blank slate, yet not written upon. That might as well be the most difficult and the most beautiful aspect of motherhood. Sometimes you need to teach or 'raise' your child, but what or how? And sometimes you just need to follow and let go.....

Anyhow I hope that my family project will continue, it's not complete yet. The theme of abnormality versus normality is something that doesn't let go of me. In my photographic work I wish to question our ways of looking - our compulsive tendency to categorize and create standards - because aren't we all flawed with our obsession with control, wishing to normalize, and refusing to know our own abnormalities?

### **Concluding thoughts**

#### ***About entangled folds – non/normative families and creation***

You wrapped your letters, sometimes in dotted paper, sometimes in silk paper, always chosen carefully. You folded your letters, always in a different way. The ‘folds’ speak to me as a metaphor that links to Barad’s (2007) concept of entanglement. Families as folds, as entangled entities amidst past, present, future; environments/spaces/matter; different positions (sister/daughter/mother/...) that we embody to varying extents, and often simultaneously. One fold is co-constituted by another fold. A fold is not static, can always be re-folded, and is always covering something else. Something always remains ungraspable. When I was writing, I noticed that I was often putting on the brakes, encountering things I was unable to articulate... Every fold leaves a trace. You cannot iron them out; they form a path that you had not expected to walk. I will dwell on the early folds that shaped our trail of exploring non/normative family lives in our letter conversations.

The first fold returns me to the picture from your mother’s photo album. It brought us the concept of the visitor. Derrida writes about the visitor as a stranger, a person who somehow disrupts the natural order, values, and norms, and about hospitality as inviting and welcoming the stranger. Derrida points to the conditional nature of hospitality: there is always a certain distance, something alien between the host and the visitor. The host receives and sets the rules, the visitor is expected to behave respectfully. Derrida notes that this procedure can be suddenly disrupted, for instance by a visitor who is not meeting the host’s expectations. A visitor who is different raises the question whether the host is capable to acknowledge this stranger (O’ Gorman, 2006). Transferring this to our letter conversation, I notice that our labelled siblings thoroughly shook the folds that had already been created in our families, and how their arrival ripped open—initially harshly—the remnants of earlier, (too?) rigidly pressed folds of parenthood. We both felt that stiff folds continue to affect us especially when we refrain from touching them, and that these folds became more visible when we became mothers ourselves and were confronted with the being-different of our son or daughter.

The second fold brings us to the concept of care. As daughter/sister/mother we feel responsible to assume care, a sense of responsibility sometimes so compelling that it does not leave space for not caring for once. Our letters indicate the strongly *gendered* component of care found in the literature. It still proves hard for men to receive societal respect for their caretaking, which easily makes mothers feel obliged to take up more caretaking roles than their partner (McLaughlin, et al., 2008). An ethics of care perspective emphasizes to approach care not only as an individual affair but also within a moral framework that centralizes care interdependency and in which we are all interconnected subjects receiving and giving care (Kittay, 2002). Care is a nomadic concept that co-evolves with life. One moment it feels natural to play together on a blanket, the next moment you go for coffee together. Providing care can create meaning and direction, and it never comes about in isolation. Caregiving always exists in a reciprocal, interdependent relationship between care provider and care asker. As Skeggs (1997) summarizes, the ‘caring self is a dialogic production: a caring self cannot be produced without caring for others’ (p. 56). I see it in how you describe that you are not only taking care of your sister, but that she reciprocally bolsters your integrity, and draws your life to the here-and-now so you see yourself not as the central figure but as one tiny radar of a whole.

A third fold brings us to the neoliberal pressure that rules over our be(com)ing mother/daughter/sister-of and pushes us to deeply carve folding lines. We welcome clear instructions, but silently forget that this longed-for structure might block us from lingering in the non-normative unknown. Think of the increasing prenatal tests, or books overloading parents with prescribing tips to ensure the best upbringing for their children. Does this not feed the illusion that we, as mother/daughter/sister-of, are in complete control of the birth/growth/death of a child /parent/sibling? Erin Manning states that we are rarely aware of the neurotypical framework that resides in us (Manning, 2016). She has drawn the concept

of neurotypicality from the activist autism organisations that plead for a neurodiverse society. In a neurotypical/able-bodied framework, the neurotypical brain and the normatively able body are required for a satisfactory quality of life. People are only recognized as fully human, moreover, when they can choose and act autonomously; there is the assumption of ‘a self-sufficient body’ which is ‘regarded as a body that can consciously make decisions based on a strong sense of where the body ends and the world begins’ (Manning, 2016, p. 112). Manning strongly criticizes this ideology, questioning whether there is such a thing as full control over our actions and more broadly freedom of choice. What would happen if we saw our choices as moving learning experiments in which our bodies strongly relate to the world – making this relationship one of constant change? We think we can control our lives, and we experience the unexpected as abnormal... whereas it is exactly the unexpected, that which escapes our control, that might be the most normal aspect of life. Do we not become ill from the expectation of control? Your sister, my brother, they do not fit within society’s definition of a normal child (with the ability to read, write, and grow into an autonomous adult). Can the arrival of a strange visitor urge us to practice a release of control? Can we imagine not being the masters of our acts without falling prey to the idea that, if we are not master, someone or something else must be? Is it possible to create an account of immanent movement? (Manning, 2016, p. 120).

Here, we arrive at the final fold visible in our writings. What if we see the strange visitor not as a blockage but as an opening to re-direct folding lines, or to make previously covered folds visible? What can a visitor do with folds/norms that did not allow for difference and only enable one well-known crease? Can a visitor invite us to unfold new, unknown terrain where limits can become openings (Allan, 2008, p. 78)? The unfolding of folds ironed too rigidly requires time and necessary recovery breaks. Could this be the ‘parking’ you wrote about? Is it not up to us to have the courage to leave our parking spots and search for new routes/folding lines of movements? Can we, in the footsteps of Derrida’s concept of the visitor, approach ‘daughter-sister-motherhood’ as a voyage of discovery during which you can (re-)invent yourself as a parent, as a child, as a sibling? A voyage of exploration where we can welcome difference in our family, where we neither assume that our children’s desires mirror our own, nor that our own desires mirror our parents’ desires... in short, a voyage that embraces the possibility of different ways of caring.

What becomes possible when we engage with Barad’s (2007) entangled view in thinking about care? When care is relational and attention flows to every relationship that is present in every moment of unfolding~becoming, new ways of existence can be unfolded through creation over and over again. These new ways of existence impact established modes of existence politically; they enable that which was not possible before. For both of us, our art(s-based) practice empowers us to allow visitors to surprise us – however hesitant we are. Anna Hickey-Moody describes it as follows:

Making art is a tactile, sensory, and performative space to breathe and to be vulnerable. It lays me bare and opens up lines of flight into feelings that I could otherwise smother with words, often clichés. It is a material method that is spontaneous and vibrantly alive—an enchanting composition-in-the moment; a learning, thinking, and feeling through the body and its languages, and through the sentience and languages of the art materials. It is a Deleuzian becoming between human and nonhuman bodies that takes ‘place when a body connects to another body and in doing so, begins to perceive, move, think and feel in new ways’ (Hickey-Moody & Malins, 2007, p. 6).

The process of creation in the making of art can open spaces that were previously closely folded.

### Conflict of interest

The author declares no conflicts of interests.

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