

Is it time? Reflections on the experience of finding an ethical way to write a personal story for an audience.

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Volume 5

Issue 1

Autumn 2022

Keywords:

*embodied knowing,
dilemmas,
consent,
poetic reflexivity,
autoethnography,
writing as inquiry*

Citation Link

Abstract

How can I tell a personal story which finally feels ready to emerge and be written about? Can the composing of a reflexive, autoethnographic account help me to better understand my own experience? In this article I describe how I feel impelled to listen to my embodied feelings and to pause in my research writing to allow this need to be met. Responding to those urgings leads me to write a poem, *The Kite*, which becomes the reflexive core of my writing. Sharing the poem with my daughter results in challenging conversations which cause me to reflect on my motivation and to doubt whether I can consider writing this article. I explore my ethical position as a mother and a gran who needs to tell her story before continuing with her research study while remaining constantly aware of those things which are not mine to tell. I make use of reflexive, rhetorical questions to consider the dilemmas involved in obtaining consent and respecting the wishes of all those involved. I develop in the process a greater awareness of the ongoing effects of the serious illness of a child on a family, and I reflect on the many hidden voices of those undergoing the same experience. The creative telling of my story, incorporating both poetic writing and reconstructed dialogue, changes and deepens my understanding of what it means to write reflexively. And leads to an unexpected and deeply moving creative response.

“We are finite human beings who must learn to accept...that anything we write must always and inevitably leave silences, that to speak at all must always and inevitably be to speak for the someone else”

Smith & Deemer, 2000, p. 891

The Kite

*Is it time, the moment
to open, to reveal
to look at, to unseal
the folded paper kite
of memory and fear
and let the words fly free
I've held inside my body
and twisted round my mind
through scary days and weeks
and years of waiting....to
unwind the threads, let it
unspool and catch the wind
and find the air it seeks?*

*Is it time to tell the story now?
Whose story - what to tell?
And how? And why?
of being caught – suspended,
living phone in hand and
sleeping near the edge, just lying
waiting for the sudden ring,
the words: "we're on our way in"
hasty fumbling packing bag
the late-night drive across the moors
the quiet arrival, nodding heads,
asking the wrong question
saying the wrong thing
seeing old heads growing*

*on too young shoulders
checking the ones still sleeping
hearing daughter and grandchild leaving
always fearing, never knowing.*

*I think it's time - I start to write
it tumbles out -
a ragged, shapeless, unformed thing
a fragile pile, a fledgling. I begin
to smooth, unfold, unfurl
the crumpled kite between my palms
I cup it close - then lift it – feel
the air begin to shift it where
it wants to go up high.
I pause and pull its strings more
tightly round my hand
It's not ready yet to fly.*

July 2022

“Poetry is the way we help give name to the nameless so it can be thought”

Lorde, 2017, p. 8

I do not intend to write the first draft of the poem. I open my laptop with an entirely different plan for the day; but sometimes what we want to write and what we need to write are not the same thing. As a practitioner-researcher, buried deep in the writing of my thesis which inquires into ‘Keeping the Body in Mind’ in a systemic therapy practice, sometimes what rises to the top of my mind; what comes out from under my fingers is not what I had planned. In those moments of reflection when I have learned to sit quietly and breathe and think about how I am feeling in my body before I begin to work, sometimes the unexpected surfaces, a thought, a feeling, an image. I can, and often do, dismiss that *unexpected something* as a distraction; a way of my avoiding *getting on with it*, but this morning a more persistent bodily feeling is nudging me to put the plan to one side for a little while. I am conscious of a rising pressure inside, a need to yawn, to let something out, to *let it go* before I can concentrate again on my research. I am finding myself yawning again now; the writing of these words is continuing the bodily release that began as I drafted the poem.

That morning I became aware that I needed to write from that place in my gut which was telling me to write something different. A place where I have kept memories of sadness and difficulty and *not-knowing* for the last few years. Damasio tells us about “the strangely ordered emergence of mind, feeling, and consciousness, one that is subtle and easy to miss” (Damasio, 2018, p. 239). Those of us who practise as therapists are particularly aware that it is often our position of “Not-Knowing” (Anderson, 1992); an openness to the unconscious, intuitive promptings of our being, which leads to change. Constrained by the pressures of daily life, of *getting my study written up*, it’s a challenge for many of us to keep that openness to the other voices within us. But I did not want to miss whatever was trying to emerge at that moment; I have learnt since I began my research journey that time spent in unplanned writing is never wasted. *Writing from the gut* implies listening to the messages from our bodies. It’s a deeply reflexive process because we are paying attention to something which is *bubbling up* from somewhere inside our body and our mind and nudging us insistently to give those thoughts space to develop. As writers and researchers, we do not know immediately where the relationships will form between *gut writing* and traditional academic writing, but form, they will. It may be that taking time to allow new thoughts to surface will reignite our creativity; encourage us to write in freer and more innovative ways, remind us not to: “privilege rigour over imagination, intellect over feeling, theories over stories and abstract ideas over concrete events”. (Sparkes, 2003, p. 61). It may also be that allowing other voices to rise from within us will lead us to connect more fully with parts of ourselves which we are suppressing in our research writing. It may change the way we see our practice, our practice-research and our relationships with both clients and co-researchers. We may begin to listen differently and to hear other voices from them too.

Expressing bodily ways of knowing

Alan Jasanoff, a neurobiological engineer, writes compellingly about how the brain is in a constant relationship with our gut (Jasanoff, 2018). Common expressions such as having *a gut reaction* or *a gut instinct* both refer to a kind of deep bodily knowing, and in French, the other language in which I can write, *prendre aux tripes* means to feel overwhelmed, deeply moved by a gut feeling. So, for me, writing from the gut involves listening to the body as I begin; sitting and just allowing the words to emerge from the relationship between my body and my embodied mind. Not necessarily even sentences or phrases, perhaps just stray words which hold a memory, a mental image, the emotion of a moment, which capture in language an embodied sensation: poetic words.

Poetic writing as reflexive practice

“We can train ourselves to respect our feelings and to transpose them into a language so that they can be shared. And where that language does not yet exist, it is our poetry which helps to fashion it”

Lorde, 2017, p. 9

As I listen that day the words which float into my mind are:

waiting

suspended

sudden
phone ringing
on the edge
“we’re on our way in”
night
driving
young shoulders
fear
endless waiting

and I form the story around those fragments as they draw other memories up to the surface. I begin to write, thinking about assonance (the echoing of one word in another); the length of phrases; about alliteration and rhyme because words that resonate with each other create resonances in us too. Writing a poem opens a path for me into my reflexive being. They are imperfect, unfinished pieces always in progress or in process, which might make little sense if published separately from the writing which encloses them, but they crystallise an experience for me; they offer ways of knowing which might otherwise be lost. And all writing where the words encapsulate feelings and memories has poetic qualities. What is poetry after all? It’s any form of words that captures an emotion, that fixes a moment of meaning; that produces an emotional reaction in us; be it stopping us in our tracks, causing us to pause and reread the words, triggering a memory, a smell, a taste, a sound, a smile, an aching pain, wistfulness, temper; it’s any language that taps into our bodily feelings and emotions and helps us to understand ourselves and those with whom we are in relationship. And it’s a cyclical process because those words in their turn can give rise to feelings and new ways of knowing in the listener or reader too. Poetic writing does not always *look like poetry*. It can be written in sentences as if it were prose. And the line between poetry and prose is a blurred one. At times in this piece, I make use of italics to suggest the poetic narrative of my internal dialogue, at others I write in the historic present which gives a sense of embodied presence and immediacy to past events so that we can *feel* as if they are happening as we read. That *in the moment* energy can allow us as readers or listeners to experience language producing sensation and meaning in our bodies too.

As I re-read, reflect, rewrite, reshape the emerging words and phrases in the poem it is initially my own feelings about those tense and scary times that are “ragged, shapeless and unformed”. Watching the strength and resilience and *holding on tight* of daughter, son-in-law and small boy moving constantly between hospital and home, seeing them and their little girls living on a seesaw rising and falling without warning over days and weeks that turn into years, our role has been to support, to listen, to help when needed and to ‘back off’ at other times, while existing in a place of not knowing and not saying. Nobody ever said to us:

- It’s not about you!

But we knew it couldn’t be and didn’t want it to be. So, emotions were not expressed, were held in, pushed down, contained, in order to survive as a family, whatever might happen. Until the morning when my body no longer seems to want to contain the feelings, and sitting, jotting down random

words, my story of the experience begins to slip out. Those of us who work as therapists often see people keeping going, head down into the wind during the worst of times, but when the storm passes, there has to be a time to talk, to process what has happened. That time seems to have come for me.

What do I want to write and why?

I leave my poem half-written, returning to working on my research study, but as the days pass, I bring it up on my screen from time to time and gradually begin to reread it, to turn the words around in my head, to redraft, to reflect. And thoughts beyond the poem begin to swirl around at other moments during the day. What is it that I want to write? Is it something beyond the poem, a more detailed reflexive piece? And who do I want to write it for and why? Does “shapeless, fragile and fledgling” perhaps belong to my fears about writing for an audience beyond myself about my experience? Could those words relate equally to my not feeling capable of writing an academic paper, to the fear that I have nothing to say that anyone will want to read, to the fragility of my ethical position when writing about an experience which is so inextricably bound up in the lives of a whole family?

And will I not distort my experience in the writing of it? Will I not make it less ‘real’? The performance poet Kae Tempest says, “There is no way that a writer cannot injure that idea as they wrestle with it” but then adds: “You made a good go of it. The thing is out there, another step towards meaning.” (Tempest, 2020, p. 77). I think Kae is suggesting that although we will find anything we manage to write provisional and imperfect, it is the doing of it that matters. And the challenges involved in writing about personal experience are ones that those of us who are writing from a feminist standpoint are ready to face. “Feminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and object. It allows us to become answerable for what we learn how to see” (Haraway, 1988, p. 583). Haraway is suggesting that the truth of our text is tightly tied to our reflexive understanding of the context and the relationships about which we are writing. There is no universal truth about our family experience; those intimately involved: H, her husband, and children, are the closest to it and my account of it will, as Haraway also says, be partial and limited. But it will be a reflexive, embodied account which is searching through the writing for meaning and for purpose, and as it is a personal account of a lived experience, I cannot but be present in body and mind in the text in “my embodied standpoint” (Ellingson, 2017, p. 5).

Is this my story to tell?

But can I write about our family experience for an audience, or must it remain entirely private? I leave my computer and wander around my garden pulling stray weeds as I ponder. Those early words falling from my fingers are presenting me with challenges and uncertainties that I know it would be easier to swerve around than to find a way through. For the telling of a personal story that I have lived with since the very first weeks of beginning my doctoral studies, belongs to many people and to multiple voices. How much of it is mine to tell? How do I decide what it is ethical for me to reveal? Whom do I need to ask for their consent? When I share my writing, I may need to listen to thoughts which are not comfortable or easy to hear. Laurel Richardson says: “Each writing story offers its writer an opportunity for making a situated and pragmatic ethical decision about whether and where to publish the story.” And: “I feel constraint in publishing about my immediate family members. I check materials

with them” (Richardson & Adams St. Pierre, 2005, p. 966). So, if I ask family to read what I have written, will that fulfil my ethical responsibility? I think there is a little more to it than that.

But for now, I ditch my bucket of weeds and stride purposefully into the house and pick up my phone. Then I put it down again. H will just be picking the kids up from school...I'll WhatsApp her...

Clare: *H, I'm trying to write something personal, maybe a paper about what it's been like living through the last few years, but it's potentially got your family stuff in it, so I need your permission about what it's ok to write about and I won't submit anything you're not happy with. Could you let me have some thoughts? x*

H: *No problem, I'll get back to you when the kids are in bed x*

And a couple of hours later, she sends me the following email:

H: Mum, we need to ensure that in the present and the future our son is not exploited in anyway, either for story-telling or for the gain of others...or maybe to build a personal platform...Once information is released you lose control of the narrative...Our experience as a family feels very special and sacred...knowledge can only go as deep as your experience will let you, and most people lack the experience to understand the nuance and depth of our hurt, trauma, sadness and grief that live alongside our joy and euphoria...I never knew that it was possible to be breathless in grief whilst feeling equally liberated...

I feel as if I have been punched in the stomach when I read H's words. I feel shamed by the words "exploited", "gain", "personal platform". Is she referring to my writing when she uses those words? H later says she is not; that her words are prompted by the way people outside the family ask her for details in insensitive ways; but they are still for me a great big ethical thump in the chest. I am deeply moved by "special and sacred", "nuance and depth" and "breathless with grief"; I sense the intensity and rightness of her need to protect her child and for his story and their story to be no one else's to tell. I'm humbled by the dignity of her words. I know that she is coming to stay in a few days and that we can talk then, but I stop writing for now. I'm not sure that I will begin again.

A few days later I read a first draft of *The Kite* to H as she sits across the kitchen table from me and find myself breaking down and sobbing and apologising for my tears as I read the half-formed lines. I can feel the emotion rising again in my chest as I type this now. She begins to cry too. I am ashamed of my tears. I feel like I'm making it 'all about me', but at the same time I realise that not only have I never felt able to tell her how it has felt for me but that she has never ever told me how she felt either. I am her mother and yet I have feared to ask her, not read the clues, taken her way of being through it all at face value. And I am someone who works with those in distress in therapy. How much have I been taken in by a calm voice there too? How insensitive is it possible to be?

We go on talking:

H: *I had permanent toothache when he was in hospital and now realise I was grinding my teeth...I had cottonwool vision...I was in the supermarket the day before the transplant and I couldn't see and it was sheer terror....*

Clare: *I didn't have a clue...you held on so strongly, I didn't know how you were feeling...I'm ashamed...*

H: *I often didn't know how I was feeling...*

Clare: *But you do now, and we still haven't talked about it...I'm so bloody sorry...*

H: *It's okay, don't be. Now, even though he's well, I feel othered permanently by people... It's very isolating...they say "I don't know how you do it" ...instead of saying "How are you dealing with it?"...they put you in a box so they don't have to deal it...*

Clare: *Could you just say, "he's well, thanks"?*

H: *It's not that simple...they ask questions...they want me to talk about it, but once I share my narrative it doesn't belong to me anymore...it's like it's curated...it becomes a story they can pass on to other people...I think that with social media people are losing their ability to think things through...they publish without giving it a second thought...that's why I had that little special group on Facebook...it meant we could control what was being shared...*

Clare: *It took me a while to understand about that group because I'm not on Facebook, but you were so wise. It meant you were in control of that at least. I have learnt so much from how you handled it...*

We pause awhile, then:

H: *I feel comfortable about the experience of being with a very ill child and how to cope because we had to cope, and I know how others' behaviour makes it easier or harder...but I'm not comfortable to share details about the illness...people can be like vultures...We are outside of it and you're even another layer outside of it...it's like peeling onions...*

Clare: *Yes, we're yet another layer outside of it, and of course I won't write about details... I don't want to write anything that gives the impression that we went through what you did. We didn't, not in any way.*

We pause, drink cups of tea, check the children are still playing outside with their grandad. We talk about how my writing of the poem has led to our conversations today. I tentatively moot the idea of H becoming my co-researcher if I write an article for publication. Remembering Laurel Richardson's words, we talk about where, and why, it could be appropriate for a piece in which we have collaborated to be published:

Clare: *Do you think I could use your words if I go on writing, because they are such an insight into how it feels to be the parent of a seriously ill child? I would be writing an article for a professional audience in an online academic journal, many of whom work with people who have serious illness in their families and what you're saying about the long-term effects of the illness on you as the mum in your community even when the child gets better, or is cured, is something we don't think about enough...*

H: *Yes, of course you can, it might be useful to pass it on...*

I am scribbling down our conversation as fast as I can:

H: *That's the thing about grief...if you lose a child people expect you to grieve and get better, and because there's been a significant event you are given time and space to grieve and to recover...people help, they know how to behave, they allow you time, there's counselling,*

falling apart is expected, you are given time off work...but society is not built to support people with chronically ill children...or those who have been through it and what it leaves you with...There is no recognition of what happened...you can be left feeling that it's other people's responsibility to put you back together but ultimately it's not. There are points where you feel safe enough to mentally move on, but there's a large part where you have to learn to exist with the knowledge that you are never going to have a complete resolution or a line in the sand or whatever...and people find that hard because they expect you to have moved on and they want a clear answer...

Clare: *Yeah, suddenly people are sending you cards saying how wonderful it is that he's better...there's a complete lack of understanding of what you still have to deal with as a family... and that the future will always be uncertain...*

We pause, drink more tea. I'm unbelievably glad that we have had this time together.

Clare: *I was missing so much...thank you...I will go on writing my piece if that's okay with you? There may be bits which seem self-obsessed, and it will make me nervous about sending it to you...but maybe it's useful for people to know what it feels like to be an outer skin of the onion too...I will send you it all when I've finished writing it, and I'll only submit it if you are happy for me to do so...*

I begin to write again, holding in mind now that I am no longer just writing *my* story. Consent is never simple and is always wrapped up with power. My conversations with H have been deep and emotional, revealing feelings that had never been shared. How can I represent our talk in a safe and respectful way? "Because reflexive research is collaborative, dilemmas like this can be discussed with participants so that mutually agreed and morally satisfactory decisions might be reached." (Etherington, 2004, p. 82). I continue my conversations with H, open to further reflections on my writing and ready to make amendments or withdraw material at her request. I also read that "participatory approaches often blend with arts-based research practices" (Ellingson, 2017, p. 132) and lead to more effective sharing of power and control with participants. But I have no inkling that my sharing of *The Kite* with H will lead to such a powerful response.

Pausing the story to talk about positionality

I began this tale by writing about how I came to draft *The Kite*, and then moved on to talking about using poetic writing as a reflexive and ethical relational practice which finally led me to contact my daughter H and to our conversations which are at the heart of this piece. I am pausing the story here to talk about the theoretical frame and the thinking traditions within which I am writing. I have already said that my writing flows from a feminist, postmodern position, where "texts, any texts, are always partial and incomplete; socially, culturally, historically, racially and sexually located" (Lincoln, 1995, p. 275). I see a feminist standpoint as embracing both the embodied nature of all relationships; humans as laughing, crying, aching, struggling, enfolded beings, but also as embodied "material-discursive" matter (Barad, 2007), situated within a culture and a language through which we relate to the world. As a systemic practitioner for whom everything is always connected to everything else, reflexivity can never be disentangled from relationships and from ethics. We are always practising "continual relational reflexivity" (Simon, 2020, p. 153), which Gail Simon compares to a dance where we are

constantly moving between our cognitive and theoretical, emotional, and contextualised selves. As I write, I feel like I'm trying to dance on a narrow beam where I can easily wobble and fall off. How to maintain the balance between the emotion of telling my story and the acknowledging of my reflexive, situated, ethical position in this personal writing? I realise that it's being aware of the need to keep that balance which matters.

Personal writing: how to define my ethical position?

I have been struggling to put my ethical position into words other than *keeping on checking with H*: I have had several conversations with her about what I have written, and her responses after reading it form a significant part of the narrative. But that feels a very untheoretical way to describe my ethical process; how can I better define it? Carol Gilligan writes about "an ethics of care" (Gilligan, 1984). She describes it as being:

grounded in voice and relationships...An ethics of care directs our attention to the need for responsiveness in relationships (paying attention, listening, responding) and to the costs of losing connection with oneself or with others.

Gilligan, 2011

I hope that those who read my story will feel that it is "grounded in voice and relationships". And I have found that the process has strengthened my connections with family because it has led to conversations that have been unvoiced until now. Laurel Richardson says that when we write about ourselves and our families, we "bring the danger and poignancy of ethnographic representation "up close and personal"". (Richardson & Adams St. Pierre, 2005, p. 966). I have felt both the danger and the poignancy of representing my experience, entangled with that of my daughter, as I write. But we have talked to each other in safe spaces, at agreed times, with time to drink tea, to let our feelings settle, and the reading of what has been written has been given time for reflection and for responses both verbal and written.

What about the ethical connections with myself as mum, gran, practitioner, writer, and researcher in this story? One of the purposes of this writing is a wish to better understand myself as a relational being in the context of the experience I am describing. Karen Barad says we: "don't obtain knowledge by standing outside the world; we know because we are part of the world" (Barad, 2007, p. 185). Laura Ellingson describes the embodied, ethnographic researcher as: "Being "there" and writing about what one sees, hears, feels, smells, tastes, and otherwise senses" (Ellingson, 2017, p. 81). I am seeking, through my embodied writing, to pass on an understanding of my experience to the reader so that they may find their own ways to connect to *their* personal and professional stories.

Delving into autoethnography

I realise, almost as soon as I begin to compose *The Kite*, that my writing is too personal to be described as purely ethnographic:

"As an autoethnographer, I am both the author and focus of the story, the one who tells and the one who experiences, the observer and the observed, the creator and the

created. I am the person at the intersection of the personal and the cultural, thinking and observing as an ethnographer and writing and describing as a storyteller”

Ellis, 2009c, p. 12

I have always shied away from being at the centre of attention, but here I am clearly the observer and the observed, the author and the focus of the story. I delve further into Carolyn Ellis’s autoethnographic tales and I am in awe of the way in which she weaves personal experience and reflexivity together: “Through writing I discovered I only want to write stories that give meaning to my life and have the potential to offer meaning to and evoke meaning in others.” (Ellis, 2009c, p. 118). I find the honesty and vulnerability she offers the reader courageous, and her witnessing to the life-changing events of her brother’s death, her partner’s terminal illness and her changing relationship with her geriatric mother incredibly generous. But at the same time, the deeply personal nature of her stories and the way in which she writes about her relationships with family sensitises me to the delicate ethical positions implicit in autoethnographic writing. I wonder about how her mother, brother and partner might feel about so deep an exposure of their most intimate moments; (Ellis, 2009a, 2009b, 2009d).

Ellis opens my eyes to the power of writing to reconcile us to events, and I much appreciate her candour as she questions her earlier ethical choices as she writes her “Meta-autoethnography”. But I also find myself thinking about at what point we as readers become voyeurs rather than witnesses as we read those very personal and usually private details. I have cared for my own elderly mother in similar circumstances; I know how intensely she guarded her bodily dignity, and so find myself struggling at times to read Ellis’s dissection-like prose.

At the same time my understanding benefits from the deeply reflexive way in which Ellis presents the ethical dilemmas inherent in her writing. She questions relentlessly her own leaving in, or taking out, of personal details within the text. And as a result of reading her stories, I become aware of how sensitive and comprehensive I want to be in obtaining consent for how I represent others in my text. Am I listening carefully enough to the voices of those who are part of my story? And am I respecting their wishes as fully as I can? You may have noticed that I scarcely mention my husband, who I refer to only as “we” and as “grandad” in the text. Although we have been together throughout this experience, he is, at his request, absent from my tale. He allows me to say that he wept as he read this piece, but he says that how we have dealt with the experience as a couple is a “whole other story”. And H lets me know when I first ask if I can write about my own experiences, that her family’s story is to be reflected through her words to me; she is telling only the part of the story she wants to tell here. And she becomes my co-researcher in the process. We are bound together in the writing by our personal relationship of respect for each other as mother and daughter, and in our ethical relationship as researcher-writer and co-researcher.

Inviting in the unheard voices

“postmodernism invites other, often tentative, marginalized voices to be heard alongside those of the dominant western discourses that value certainty, action and decisiveness”

Etherington, 2004, p. 21

I write another poem; it is impressionistic and without personal details, but I shake my head and delete

it, although the words continue to turn around in my mind. So many voices and faces of unseen and unheard parents of children and teenagers with life-threatening illnesses. So many stories that are not mine to tell. But I hope that those voices echo through these words in some small way. The months and years of loss of income and security at work which endless hospitalisation of a young one entails; the waiting, the not-knowing; the constant living on the edge, the hope and the fear. I read and re-read this piece of writing. I write an abstract which I hope gives a summary of the content, though it doesn't express the feelings of thankfulness, and renewed confidence which the telling of this story are engendering in me. I remember Carol Gilligan's words about the dangers of *losing connection with oneself* in the research. I realise that the opposite seems to be happening; I am finding a voice that is "giving me desire, strength, and enough self-knowledge to narratize other memories and experiences, to give myself agency, and to construct myself anew for better or for worse" (Richardson & Adams St. Pierre, 2005, p. 966).

Final thoughts

Writing *The Kite* and talking to H about it, began a dialogue in which she allowed me to feel in very few words the depth of what she and her family have been through, and how that experience reverberates through all their lives and will continue to do so. *Listening to my gut* encouraged me to dare to write a piece which felt selfish and *me* orientated, but led to new talk and understanding, and to a sharing of feelings that have become part of my lived experience as a writer, a researcher, a practitioner, a mum and grandmother. I hesitate to use the words *a blessing* to describe the experience of writing this piece, but that is how it feels.

But although I have *dared* to write within an autoethnographic frame, I am aware, even more strongly than before I began, that it is a methodology to be handled with extreme care. And that sometimes the person whose well-being is deepest in your heart and who has been at the centre of everybody's thoughts for so long cannot be in the piece because it's not your story to tell. And he may one day want to write his own story - he can read and write now- but he is currently far more interested in the 'Beast Quest' fantasy stories and in getting on with his life in his characteristic thoughtful and decisive way.

I have said that because H didn't tell me how she was feeling during those long months and years; because she held on so tight to her emotions around us, her parents, there will have been times when I was insensitive and probing when I could have been so much more aware. So many of the people I meet in therapy; particularly those who have partners with long term illness spend so much time "holding on tight"; saying "I'm fine..." when they are far from okay. And sometimes that question which I have forgotten, or hesitated, to ask, *the question about how they are feeling in their bodies*, as well as in their minds, can open the possibility of talking about emotions when they are not sure if this is the right place to share. I need to permission those I meet in therapy to express their bodily feelings too.

And I will continue to ask myself the questions: why do I want to write? And whom am I writing for? The fact that I can write something that tugs at the heart strings and creates a lasting memory, that is aesthetically pleasing, has symmetry, resonance, lived experience and is appropriately referenced, does not make it okay to write it. This foray into an autoethnographic way of writing has brought me closer to the ethical dilemmas involved in all participatory research. When I wrote the ethics

application for my doctoral study it was in no way an embodied experience. I didn't think with my heart or my gut as I filled in the forms for approval or as I asked my co-researchers for their consent. H is my daughter and would make no bones about saying 'no' to my request. But the power relationship is quite different between therapist and clients. I hope that I have been sufficiently sensitive and careful in asking people to participate in my research study. I have a heightened awareness of how I will ask for consent in the future.

By the time I have finished revising my poem *The Kite*, it has begun to morph into a metaphor for the process of writing this piece. It is becoming a material expression of the ethics involved in writing for an audience about a personal experience, the fragility and slow shaping of the writing, the power of memory to move us emotionally and to change us. And I watch as the story moves from my body and mind into the body and mind of my daughter and then evolves between us in our conversations. I hope that my story may change the reader a little as it goes out into the world, into what Bateson calls "the external mind" of which we are all a part. For the emotion generated by story has the power to create understanding in ways which *cold reason* cannot.

Epilogue

I phone H, hesitantly; I know it's the first day of the summer holidays and she may be up to her neck in work and childcare at the same time:

Clare: *Hi darling, it's me have you got a minute?*

H: *I have, the kids have got friends for the day and they're all getting on at the moment...What's up?*

Clare: *I've finished writing the piece I talked with you about and I wanted you to read it and comment before I submit it...*

H: *No problem, that's fine, happy to do that.*

Clare: *I'm a bit nervous about sending you it...the first bit may seem self-obsessed...*

H: *Why do you think that?*

Clare: *Because it's about how it felt for me...*

H laughs: *Mum, it's okay, you've already explained to me what you're doing and why and anyway, why shouldn't it be about you too?*

I send all that I have written to H and I am overwhelmed by her unexpected response. Her poem is mostly written as if she is speaking to her children, and that is too personal to share, but with her permission I include the last stanza that she has written to me:

I see you...

I see you Mum.

I see the quietness and kindness. I see the things you said that I didn't need you to say...

But that's ok. We've made a safe space to say.

I see the constant arriving, bags in hand, cancelling work. Wanting to ask, not wanting to ask. I see a need for privacy but your need to release what can't be kept in.

Kites fly but they come back down. We release but the thing still exists. It will never go.

If we roll the Kite away carefully, we can get it out, on a windy day and let it fly, safely, away from crowds, on the top of a hill, on a beach...

People will see our Kite and wonder at its flight. How did we catch the wind so well? What pretty colours, what tassels. Look how they share it...

One runs with it and releases whilst the other holds the strings. We have all held the strings. It's all the same Kite.

H. August 2022

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Citation

Wenham, Clare (2022). Is it time? Reflections on the experience of finding an ethical way to write a personal story for an audience. *Murmurations: Journal of Transformative Systemic Practice*, 5(1), 13-27.

<https://doi.org/10.28963/5.1.3>