# Clinical record-keeping, narrative documents and chronic illness:

## When "fat files" tell thin stories about experiences in healthcare

### by Rewa Murphy

*Ko Ingarangi me Aerana te whakapaparanga mai. Ko Tāmaki Makaurau te whenua tupu. Ko te Whanganui a Tara te kāinga. Ko Rewa Murphy toku ingoa, he kaimātai hinengaro ahau. Kia ora, my name is Rewa Murphy and I'm a consultant clinical psychologist working with young people and their families in an outpatient mental health setting near Te Awakairangi, in Aotearoa (working for Te Whatu Ora in Wellington's Hutt Valley, New Zealand). I recently completed Dulwich Centre's one-year course in narrative therapy. Relevant to this article, I live with Type 1 diabetes.*
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## Abstract

The extensive medical records of young people living with chronic illnesses can tell a thin story about the experiences and humanity of the person they supposedly represent. Through the story of a narrative document developed with a client, and the responses of others I shared it with, this article explores the skills and knowledges of young people navigating mental health systems while also dealing with chronic illness. From a poststructuralist perspective, the paper considers the effects of what one young person called "fat files" on how clients are "known" in clinical spaces, with implications for how professionals engage in notetaking.

***Key words: chronic illness; hospital; youth; medical records; clinical files; therapeutic documents; narrative practice***

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In this article, I share a practice story about collective therapeutic documents. I've been learning recently about the opportunities that can come from inviting therapy clients to record some of their skills and hard-won knowledge in writing so they can be shared with others. This might start, for example, with "rescuing the said from the saying of it" (Newman, 2008), which I've found useful in helping clients underline things that matter to them. I was surprised to learn in Michael White's (1995) writing about how much his clients valued a good therapeutic document – sometimes seeing it as many times more valuable than a therapy session itself (see also Nylund & Thomas, 1994). I've been fascinated by the opportunity documentation presents to share knowledge and ideas among clients indirectly, particularly in settings where institutional privacy or social stigma might make practices like in-person outsider witnessing feel confrontational or risky.

My main work as a therapist is with children, young people and their families in an outpatient mental health service in a hospital. As a person living with a chronic illness, I had noticed that a number of the clients who came through our doors also lived with ongoing physical health concerns. These could have a huge impact on their wellbeing and on the risks and resiliences they might bring when facing the "mental health" distress they were referred for. Because of the separated approaches in our healthcare systems to physical and mental health, I don't think the interactions between them are always well understood by people who work in these spaces.[1] This seemed to me like an excellent opening to acknowledge some of the expertise of my clients in this area, and perhaps to share some of that with colleagues.

Another thing that motivated me to consider sharing documents was how often clients tell me they feel alone – like being the only person at their school who has to go to the office each lunchtime for their injections; being the only young person in a hospital waiting room surrounded by elderly adults; feeling like the experiences of watching their peers grow up around them was a particular kind of developmental loss that health professionals just weren't tuned into. I had read about how collective documents shared between clients could leave people feeling less alone (e.g. Handsaker, 2012), and I hoped documents might offer a new avenue of conversation with some of the young people I'd been working with.

## About Wednesday

I decided to invite one of my clients to experiment with me. Wednesday was 17 years old and had been referred to our service because of "social anxiety". She kindly agreed for me to share this story with you. Wednesday had already done substantial work with another therapist when we met – she had managed to get back to school and had made new friends. However, her therapist was concerned about discharging Wednesday from our service. She also was born with a problem in her kidneys and had been told that she needed to self-catheterise regularly to prevent their decline. Wednesday did not want to talk about this at all. However, according to her medical team, Wednesday was fast heading towards needing a kidney transplant, which she was unlikely to be eligible for given her "refusal" to engage in specified treatments and her "noncompliance" with interventions designed to reduce her medical "avoidance". Her clinician wrote to us sharing her worry that if things didn't change, Wednesday's life expectancy would be very short. There's so much I'd like to tell you about the hard work Wednesday did over the next little while alongside myself and my intern. That's a different story, but at the end of my time with her I was left with an incredible and humbling respect for someone saving their own life. Wednesday still lives with (in her words) "chronically sad kidneys" and all the challenges that come with that, but she is so much more in charge of what medically needs to happen to stay on top of this.

I was delighted when Wednesday agreed to explore the following questions with me:

- What's it like to live with chronically sad kidneys?
- What are some of the things that people who live with this have to face in life?
- What impact has this had on your life? On the life of your family?
- What gets you through these tough times?
- What do you think other people who aren't going through this need to know?
- How can the people who love you help when things are tough?
- What strengths, skills or knowledge have you developed that you might not otherwise have had if you hadn't gone through this?
- What have you learnt to value or hold on to because of your experiences?

- If you met someone going through something similar, what would you say to them?
- If they asked for your best advice, what would it be?

From a narrative therapy perspective, I wanted to keep things broad. I included questions comprising elements of externalising (asking about the experience and the impact of a problem) and re-authoring (asking about knowledge and skills and offering the opportunity to frame these as advice to others), asking about unique understandings based on those experiences, asking about what is valued, and exploring the landscapes of identity and action (what is important to you and what you do) (Carey & Russell, 2002, 2003).

When Wednesday began responding to these questions, the first thing I noticed was how much she had to say. I had heard from her doctors that she rarely spoke in their meetings, and even in my own sessions with her I had noticed that Wednesday often would say "I don't know" or tell me she wanted to answer my questions but wasn't sure how she could put things. However, in contrast to that, Wednesday was incredibly articulate while working on the document.

She spoke fluently about the hours and hours of her life spent in hospital waiting rooms – so many hours that she had developed special tactics and even an activity bag of items to help pass these chunks of her life. These strategies of survival were distinct but similar to those she used during the days and weeks when she was an inpatient. She talked about how much she would have preferred to be at school. Her classmates told her she was "lucky" to get out of lessons and eat McDonald's for dinner, whereas in reality, the price of this was being "poked by a thousand needles" and having to tolerate invasive medical procedures and violations of her physical privacy. (If you ask anyone who has spent a lot of time in emergency departments, I imagine they'd recognise that these takeaway dinners were not just about trying to reward Wednesday's cooperation but also about the practicality and cost of finding food on the way home after a long day.)

Wednesday spoke about her mother being alongside her, bearing much of the emotional weight of the illness as well as the organisational and occupational challenges of having her child in hospital. Wednesday described her appreciation of the times when her mother had helped her hide from the hospital mascot and the demi-celebrity children's ward visitors, because, she said, "Why would they make sick children do that?"

So much of this stood out to me that I could not write fast enough. But it was Wednesday's decisive answer to my next question that particularly stayed with me.

Rewa: What are some things that kids living with chronically sad kidneys have to deal with that other people might not understand?

Wednesday: Fat files.

Wednesday explained. A "fat file" is the sigh of the health professional when they are given your notes and they can see by the sheer size of them that you are not "straightforward". It's an unspoken but silent judgement before they've even read your name. They've probably just read one or two recent letters about you, and from that have made up their minds. Further, Wednesday said that health professionals look at "fat files" with the same kind of prejudice associated with "fat" bodies[2], where fat somehow says something about the kind of person you are – you get spoken to differently and you can feel it in the air of every medical conversation.

In that moment I realised that I too had looked at files and made meaning of their size. I remembered when part of my job was triaging new referrals into the service. On electronic health records, referrals have a number beside them indicating the number of documents attached. If I saw a number one, showing it was the first time a child had been referred to a hospital service, I would be intrigued about why they might be here. If the existing notes and letters numbered in the hundreds, this would be the very next thing I knew about a person after their name and hospital number: and I would know that I'd never have time to read everything. When I saw a large number, I would tell myself that this was another reason to accept a referral if I had been unsure. I intended this approach to be benevolent, but Wednesday now had me wondering if I had inadvertently contributed to more waiting-room hours and a proliferation of file pages that might never be read again.

I also wondered, how fat are my files?

I asked Wednesday if she would be willing to share the document we had written together with some of my other clients living with chronic health conditions. She agreed. In fact, this is where her pseudonym in this article comes from: it was gifted by another client, January, who also generously agreed that I could share her responses with you.

## About January

I first met January when she was an inpatient at the hospital. She was 14 years old and had been admitted because she was struggling to eat and had lost weight to the point where her heart was unwell. January had been born with her oesophagus disconnected and had survived a series of surgeries to correct this. I had been asked to see her because the medical staff felt they had exhausted all physical interventions and she should now be able to eat. January, her doctors and her family had started to wonder whether her struggles were now a "mental health" problem. Although January was polite each time we met, I noticed she would answer my questions briefly. A couple of times she mentioned concern that whatever she told me might be shared with her parents, or that information might be recorded in her notes for "anyone" (hospital staff) to read. We started to meet more regularly following her discharge, but it felt difficult to build a connection with January. My questions about her interests and her life outside of her health challenges elicited limited responses, and she seemed even less interested in talking about her experiences in hospital or with managing her eating plan. Our interactions had little emotion, and I rarely saw her smile.

As another avenue of enquiry, I asked January if she would be interested in reading Wednesday's letter with me. I suspect she said yes as an opportunity to get out of conversations that were more directly about her.

When I read Wednesday's words about "fat files", I thought I heard January laugh (which seemed impossible). I looked up and there she was, trying not to smile – I hadn't imagined anything. I had to ask. "It's true", she said. She went on to explain that she had been laughing at a memory. During her recent stay in a hospital where the inpatient wards still used paper files, a medical professional had requested "all her notes" from the records department, not realising quite what this would entail. When January transferred from one ward to another, her files had to go with her, but there were so many of them that a second wheelchair was used to carry them. January discovered that her files weighed more than she did. She explained that as she was wheeled through the hospital, employees and visitors all looked at the wheelchair of notes, and then at her – not knowing what she had been through, not knowing her efforts to survive, but knowing about the size of her files and from that developing an impression of her condition. And even though the files being wheeled along in a bizarre parade behind her were supposedly all about her, none of these files was available to her. If she ever wanted to read them, she would need to make a formal request. Despite their comprehensiveness, these files were really not about January at all; they were about one piece of her life, and a piece she would really rather avoid thinking about if she could.

Wednesday and January had touched on something that sits at the core of narrative practice: these very "fat" files presented a very thin story.

The thin stories contained in these extensive files presented a limited and self-reproducing view of these young people. Aside from all they left out, the information they included often lacked important context. The files certainly did not contain the whole story of how Wednesday or January might want to describe themselves! And when files are reproduced starting with the most recent letter, this iterative process becomes increasingly narrow over time.

Alice Morgan (2000) described the stories we tell about problems as "thin" when they are missing broader context and descriptions of exceptional events (e.g. parts of people's lives that aren't dominated by medical concerns [see Mann, 2002]), values and skills, or other ways of talking about the character and humanity of the people they refer to. Thin stories, like those contained in hospital files, can also have limited authorship, readership and availability for editing. Medical files in particular often contain abbreviations and acronyms that truncate their descriptions even further. (I remember a woman who had "G15 P1" written in her birth record, and talked to me about what it was like to see this reproduced across her notes.)

There was also something about the physical size of the files that struck both Wednesday and January. Their files held representational weight without even being read, and they felt this had an impact on the kinds of conversations that were possible between themselves and their health providers.

## More stories about large files

The insights of these young people about their files were profound to me. And I enjoyed the humour with which Wednesday and January had told these stories: the dramatised sigh of the health professional, the files riding in their very own wheelchair, the outrageousness that the never-to-be-read-again volumes were larger than the client herself and yet said nothing much at all about her. I couldn't wait to tell my family therapy team about what Wednesday and January had shared. However, after I told their story, no one else laughed. The feeling in the room was grim. I think hearing about young people with very large medical files felt hard and serious. People weren't drawn to make light of the "fat files" and the system that produces them. Humour had felt like just the right thing in one moment but definitely not in the next. But I couldn't stop thinking about "fat files"

I remembered a young person I worked with in my second year of practice. It was still the days of paper files, and he presented to our service "in crisis" 51 times in the course of a year. Each of these visits required extensive administrative notes. Trying to find ways to support him, I felt out of my depth and so wrote even more to make sure at least I was documenting the efforts I had made to assist him. I had also been taught that thorough notetaking would protect me in the event of a client not surviving. After a few months, a visiting administrator to our service informed me that there was a health and safety requirement that files not be wider than a particular size to reduce risk of a hospital employee developing a repetitive strain injury picking them up by the spine. By the end of the year and the transfer of his care to adult services, my client had seven volumes of files, as well as volumes from his psychiatric inpatient stays and medical ward stays. I put them all in a box, and it felt like grief to say goodbye to them. I remember thinking that unwritten in these files was the weight of so many feelings I had towards this young person and his family. Struggling to lift the box felt like a metaphor for these struggles and intentions.

I also thought about a file request I'd received a few months before. When clients ask for their notes, they're reviewed by the hospital for third-party information before they are released. Sometimes when files are too large and the department is short of time, clinicians are asked to support this process. I'd finished work with this young person some years ago and had not heard from her since. I wondered about what her life might be like now. Reading the (handwritten) file felt like reading a platonic love letter – how much I had wanted to know about her! How much I had wanted to help her make things right! How many hours I had spent recording the hours of our conversations! And how difficult it was remembering how hard things had been for her.

When clients request their notes, it's been my experience (both as the note writer and the person requesting) that there's a question they are hoping to answer; a piece of the story they're hoping to make sense of. When I requested my notes from a recent hospital visit, I had wanted to make sense of why I had waited alone in the emergency department for so long between my test results coming back and being informed of their outcome – I had overheard discussions about who would be responsible for telling me and how. Although it felt like the most important thing to me, and although my notes were comprehensive, there was no reference to anything even remotely related to the time I spent alone or why this had happened. I wondered what question was on the mind of the client above when she requested her notes. Did my very big file represent what was most important to her in our meetings? Would my intentions be apparent enough in my notes that she might experience feeling cared for in reading them? Or at the very least, would she feel cared for when she saw how extensive they were? I was grateful for the opportunity to re-read the story of her therapy (when files are closed, they are sent away for storage and therapists don't see them again).

In all this, I kept coming back to the idea that there was something deeply ironic about the kinds of biographies created in medical files – stories written about people which those people mostly aren't allowed to read, that their loved ones might never appear in, written by someone else who decides what the most important events might have been. These files are typically written "about me but without me", in the third person (if there is any acknowledgment of the protagonist–writer relationship at all), and by a professional who was probably under huge time pressure. They're also multifunctional as records of decisions with perhaps the hope of protecting the health professional against medico-legal consequences in a worst-case scenario, but at the same time deeply personal to the client represented by a code number on the cover.

## Linking this to some theoretical literature

Writing about the education system, Valerie Walkerdine (1990) drew on the work of Michel Foucault to examine how schools produce records and "knowledge" about their pupils based on assessments and evaluations.

In this process, the particular kinds of information that get recorded becomes a powerful way of knowing people – constructing the story of who they are. Educators collect this information as an act of "love" with good intentions to care for the students they are working with. They also do so as part of institutions that impose systemic requirements about the ways in which records are to be produced (Walkerdine, 1990). As a health professional, I think a similar intention of compassion is present in the work I'm doing and the notes I'm keeping. I'm also sure that institution of psychology and its ideas about "best practice" are present too.

Thinking about metaphors reminded me about other feminist authors who have written about the pejorative meanings of fatness that Wednesday referred to. Her interpretation was that health professionals can look at a "fat file" like they might look at a "fat" body and make all kinds of (individualistic) assumptions about how things came to be that way. Annemarie Jutel (2001) wrote about these moral judgements about "fat" bodies, arguing that they simultaneously confirm the authority of the medical establishment in evaluating people's character and lead to stressful and dehumanising experiences on the part of clients. This reminded me of Wednesday's comments about how the size of your file seems to say something about who you are as a person and can change how people talk to (and about) you. In 2006, Susie Orbach wrote about "fat" as a public health crisis – specifically, the crisis for her was not directly the size of people's bodies but the meaning made of "fat" by medical and commercial institutions in ways which promoted their own profits and interests. Linking these two metaphors of "fat files" and "fat" bodies together, it got me wondering: who stands to gain in cases where people's medical files get really, really "fat"? And, like with physical size, are there gendered, socioeconomic or racist biases that colour the way that a large medical file is represented in the minds of health professionals or influence how big it might get?

## What should we do about this?

Wednesday's comments stayed with me as a challenge. How should I feel about my contributions to files and file size? What obligations do I have as a health professional working in a system that requires me to keep notes? These questions continue to feel bigger than I know how to address. However, I've been testing out some of the following things.

### *Notes as a record of a meeting*

I try to keep in mind that notes are a record of a meeting with someone, rather than a story about their life; for example, this might look like me encouraging interns to record what people say, rather than making statements about how things are.

### *Holding a client in mind*

I try to write in ways that I hope clients will feel okay about reading if they ever request to; this includes thinking carefully about the use of clinical language or evaluative statements

### *Collaborative note-writing*

I've been experimenting with collaborative note-writing; clients haven't always been interested in doing this with me, and writing notes with or to every family after every session is not made easy by the structure of our clinic, electronic health records and workloads.

In her writing about collaborative documentation, Sue Mann (2002) talked about how, for her, writing collaborative notes had been an antidote to the risks of judgement in the "hospital story" when notes are kept separate from the people they are written about. I have noticed that the more opportunities I've taken to try collaborative notetaking, the easier it has become. And it changes my other note-writing practices for the better, too, because I'm encouraged to think harder about what clients might want recorded and about documenting their skills and intentions. I can't do this perfectly, but making an effort is better than the status quo.

### *Sharing notes directly with clients*

Where collaborative notes are not possible, my colleague and I have been experimenting with a clinic where we have "no more secret notes" – instead writing letters as our documentation of a meeting. This isn't always possible or practical, but the more I do it, the more I think about what notes should be.

### *Using "I" in my notetaking*

I am also using "I" in my notetaking because I am a person in these meetings, too, rather than an omnipresent writer. This might include references in my notetaking about what I chose to ask or to be curious about, rather than just the information I received.

### *Asking about the most important thing*

I try to ask clients towards the end of meetings what felt like the most important thing to them in the meeting, and I make sure that this is part of what's recorded, rather than making my own assumptions about what that thing might have been. This also has given me good feedback about what clients might be interested in talking about in the future.

### *Reflecting on assumptions*

Finally, I'm continuing to reflect on what assumptions I'm making in my practice: what "good" notetaking looks like, who says so, who is it for and why. This also might look like taking the opportunity to have conversations with my colleagues about these ideas to help me deconstruct what I was taught about this and to think about what I might want to keep or to change. I talk about it with clients, too, when time allows.

Thinking about what the alternative story to a "fat file" might be led me back to Wednesday. It had been a while since we caught up last, and I was delighted to have the opportunity to be back in touch with her. I had more questions!

- Are there specific skills or strategies you've developed in order to face health professionals when you feel like your file has already spoken for you? How did you come to learn these?
- Have there been experiences that have felt different from the "fat file sigh"? What happened?
- What do you want health professionals to know about what it's like to have a "fat file"?
- What do you think health professionals should do about "fat files"?

Wednesday had so many ideas to share. First, in relation to the skills she had developed in the face of a "fat file" moment, she spoke about how her disengagement (the very reason she had been first referred to me) had been an act of self-preservation: "I'm not enjoying how you're talking to me so I'm not going to engage with you." She also talked about trusting her mum with the big words, and how her mum knew it was so important to create experiences in their lives that were not about Wednesday's health status: making the most of moments in between the hospital stays, eating all the good food. She spoke about her mum's good humour and its ability to cut through moments that were frightening.

Wednesday also spoke about exceptional experiences of talking to health professionals. She said that when she was smaller, paediatric doctors often took the time to make sure she understood what was happening – she thought maybe this was a time when no one yet knew what her diagnosis or condition was, so health professionals were perhaps more willing to join her family in not knowing: "Once they thought they figured it all out, they stopped listening." She said doctors asking "How are you feeling?" was also helpful. This was a question that only could be answered by her, not her parents and not her file. (I enjoyed the simplicity of this! Aside from being something I hope health professionals would do anyway, it seems like something that could be universally possible to do.) Finally, she gave an example of a recent emergency department visit, during which a doctor said to her, "I'm sorry I have to ask you this list of questions" and "What tells you that something is wrong right now?" She said these questions respected the idea that she might know her own body, and acknowledged that she would have already heard the list of questions many times before. For Wednesday, everything that her health professionals need to know about her is a question she can answer, but she said it's rare that they ask in a way that acknowledges this: "I probably know their list of checking questions better than they do by now, and additionally I know what my answers to them are."

One thing that Wednesday thought would help improve things is if clients had better access to their own notes. If her notes were readily available to her, she could make sure that health professionals had access to the information they actually needed within them, rather than it getting lost.

Finally, specifically about the large size of her files, Wednesday said that when she looks at her notes, there is something about her that feels proud. She said rather than a sigh, she sees her health journey as a huge part of "my character development – it's not the whole story, but it's how all the little things have come together into bigger chunks of who I am". She said that when she looks at her file, she thinks "Wow, that's a lot of paper" and "Wow, a lot has really happened to me". It's an acknowledgment of the size of something that she's endured. She said, if health professionals could look at the size of files in this way too, it might make a really big difference.

## One more question

Since meeting with Wednesday and asking her to respond to the questions above, I've had the chance to ask several young people living with chronic health conditions about their experiences. I was so inspired by Wednesday's commentary that I could not wait to share her letter, and then to ask the next young person for their answers, which I then wanted to share too. There's one more question I want to share, perhaps because the answer has been so ubiquitous:

| | |
|---|---|
| Rewa: | What's one thing about living with chronic illness that health professionals don't understand enough about? |
| Wednesday: | How they make you feel. |

This spoke to my own experiences of what it's like to live with chronic illness, and many others have offered the same response. The repetition of this answer reinforces for me that we need to keep asking our clients about their experiences of consulting with us, and to keep thinking about the power imbued in health professional roles and the responsibilities we have to people who will have long-term relationships with healthcare. I am grateful to Wednesday for participating in this experiment with me! I hope others will enjoy reading about where these ideas took each of us.

## Acknowledgments

Thank you to Wednesday and January for the time we spent working together. I'm so glad we got to meet and wish you all the best on your next adventures. Thanks also to the other clients who read this document with me and offered their perspectives on what it contained. Thanks to Marnie Sather and her colleagues at Dulwich Centre for their kind guidance through the one-year narrative therapy course, to the peer-reviewers, and to my colleagues at ICAFS for your supportive responses to my enthusiasm for narrative approaches.

## Notes

[1] In some areas of New Zealand (and also internationally), paediatric teams might include a psychologist or other allied health specialist whose job it is to try to bridge this divide; equally, mental health teams might include medical practitioners whose job it is to consider the physical wellbeing of clients. However, service provision for "paediatric health" and "mental health" is often still managed by separated teams for pragmatic reasons; hence my interest in the expertise of clients who live with both about what it's like.

[2] It has been important to me in writing this paper not to contribute to cultural ideas that vilify "fat". It was also important to me to use Wednesday's insightful words as these reflect her experience and the meaning she is making of events in her life. Wednesday's use of the word "fat" was provocative. Her term, "fat files", deliberately brings to mind judgement-laden, moralistic stories of fat shaming and what it's been like for her to be on the receiving end of her healthcare experiences – she is critical of these meanings of "fat" too. Narrative practice is interested in nuanced explorations of meaning, and in this article I wanted to engage with the politics that her words are situated in. However, I encourage others to take care if introducing the term "fat files" to other clients for whom using "fat" in a negative way might thicken problem stories. I was particularly mindful of this with January, whose story is shared later in the paper, as her physical size was part of what she had been struggling with.

[3] Including as a prerequisite to large files, do people even feel able to access or have access to health services at all?

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