Exploring narrative therapy and therapeutic letter writing in a genetic counselling context

by Stephanie Badman

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Abstract

This paper explores using narrative therapy in a genetic counselling context to support people having predictive genetic testing for neurogenetic conditions. Using case examples, I describe my use of narrative therapy practices in this setting, with a particular focus on therapeutic letter writing. I set out the ideas from narrative therapy that I considered in the development of my letter-writing practice.

Key words: genetic counselling; genetic counseling; genetic; medical; neurodegenerative; neurogenetic; letter writing; narrative therapy; narrative practice

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Genetic counselling

I work as a genetic counsellor in a public hospital clinical genetic service. Genetic counselling has been described as "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" (Resta et al., 2006, p. 77). My work involves meeting with people who are seeking information, support or genetic testing in a variety of contexts across prenatal, paediatric and adult medicine. I work in a team with other genetic counsellors, clinical geneticists (medical specialists) and administrative staff. Genetic counselling usually occurs over one to three sessions, although this is flexible depending on individual needs.

Predictive genetic testing for neurogenetic conditions

This paper describes meetings with people who are considering predictive genetic testing for neurogenetic conditions.

Neurogenetic is an umbrella term used to broadly describe genetic conditions that affect the nervous system. These conditions affect the central nervous system (brain and spinal cord) and/or the peripheral nervous system (all the nerves that connect the central nervous system to other body parts). Neurogenetic conditions affect the ways people move, think, behave, communicate and relate to others. Many neurogenetic conditions are progressive, meaning they become worse with time and result in early death. Other neurogenetic conditions progress slowly or are more stable over a person's lifetime. There are very few treatments or preventative measures for neurogenetic conditions. Some examples are Huntington disease, motor neurone disease, frontotemporal dementia, spinocerebellar ataxias, neuropathies, myotonic dystrophy and the muscular dystrophies[1] (Crook et al., 2022; Goldman, 2014).

Neurogenetic conditions have profound effects on families because they can be inherited and passed from one generation to the next. A feature of some neurogenetic conditions is that they can cause more significant symptoms and have an earlier age of onset in subsequent generations of a family. For example, myotonic dystrophy can cause symptoms later in life (after the age of 50) for some people. The specific gene fault can then "expand", causing subsequent generations to develop symptoms in early adulthood, childhood or from birth (congenital myotonic dystrophy) (Goldman, 2014).

Predictive genetic testing is for people who are at risk of developing a genetic condition but currently have no symptoms (Crook et al., 2022).[2] For example, a person may have a parent with Huntington disease and want to know if they have inherited the condition. If they have inherited the condition, they will very likely develop symptoms in their lifetime. People seek testing for varied reasons and at different life stages. Predictive testing can help people plan how to have children of their own, particularly if they want to avoid passing the condition on to future generations. Testing can also help people make plans for their life, such as buying an accessible house or deciding on a career that could accommodate early symptoms of the condition. Genetic testing is undertaken in a genetics laboratory using a blood sample.

Genetic counselling involves consideration of the genetic, medical, social, reproductive and financial implications of predictive testing (Crook et al., 2022; MacLeod et al., 2013). It includes counselling to support decision-making about whether to have testing, and consideration of the ways people hope to be supported through the process. If a person decides to proceed with testing, they need to formally consent to the test.

Operations of power

Genetic counselling is a mandatory requirement of predictive genetic testing, with established protocols and guidelines that support this process (Crook et al., 2022; MacLeod et al., 2013). The aims of genetic counselling are to enable informed consent and to support psychological wellbeing and safety. Although these aims are important, people seeking genetic testing sometimes question the value and purpose of genetic counselling. Narrative practice has led me to explore these concerns with the people I am meeting with, and to reflect on the operations of power that support my position as a health care professional in this process:

- Some people find the process of genetic counselling frustrating or unhelpful. They have said things like, "I've already made my decision. Why can't I just have the test?" or "This counselling isn't helpful for me; it makes things more difficult than just dealing with the result". These statements are commonly made

by people caring for a family member affected by the condition, or by those who have already been considering their decision about genetic testing for months or years.

- It takes several months to obtain a referral, wait for appointments and receive a genetic test result. People tell me this waiting time is difficult, and they feel a lack of control over the process.
- The requirement to undertake genetic counselling places me in a "gatekeeper" role within the system. It also invites ideas about approval or assessment: people can feel they need to demonstrate their suitability to undertake predictive testing. This can lead them to wonder if they are being observed and evaluated, and to adjust their behaviour accordingly (White, 2016).
- The medical setting is one that privileges professional knowledge over local non-expert knowledge. As a holder of professional knowledge in this system, I carry the power that comes with this expert position. The significant local knowledges of the people I am meeting with can be devalued in this context.

I have found the postmodern approach and values of narrative practice to be supportive in guiding my responses to the operations of power in this setting by:

- drawing attention to systemic harms and injustice
- working in ways that promote justice
- attending to the effects of power and privilege
- respecting and valuing people's own local knowledge and skills.

Introducing narrative therapy to genetic counselling

As I have learnt more about narrative therapy, I have adjusted the way I approach genetic counselling for people considering predictive genetic testing.

Key methods and practices I have been using include:

- externalising conversations (White, 2007) to explore the impacts of genetic conditions on people's lives and families, and the impacts of the predictive testing process
- re-authoring conversations (Carey & Russell, 2003; White, 2007) to explore people's choices about testing, and the hopes, values and commitments that inform these choices
- re-membering conversations (Hedtke, 2014; Russell & Carey, 2002) to explore significant support figures and relationships in people's lives
- ideas about folk psychology and the value of local non-expert knowledge (Freedman & Combs, 1996; White, 2004) to explore people's skills and knowhow for getting through the testing process and coping with test results.

I noticed this approach was helpful in supporting people to create a "riverbank position" from which to embark on genetic testing. The riverbank metaphor was coined by Caleb Wakhungu to describe the use of narrative techniques to create a "different territory of identity", built upon preferred storylines, to support children who have experienced trauma. The riverbank is "a safe place to stand" without being "swept along by the current" (White, 2006, p. 89). I have been using narrative therapy to help people create a riverbank position that is supportive throughout the process of genetic testing. These conversations are underpinned by an assumption that lives are multi-storied, and a commitment to linking current choices about genetic testing to broader hopes, values and commitments which have a history in people's lives. My use of narrative practices in a genetic counselling context has been significantly influenced by the work of MacLeod et al. (2021), Stopford et al. (2020) and Ferrer-Duch (2025), who have introduced narrative practice to genetic counselling and reflective supervision for genetic counsellors.

Narrative conversations facilitate a "thickening" of the plot of preferred storylines (Carey & Russell, 2003), which I feel increases resilience as people move through a predictive genetic testing process. With this new approach, I noticed counselling conversations became more grounded in the specific details of people's day-to-day lives. I also noticed that people described their reasons for testing and their knowhow for getting through the process in ways that became more diverse and distinctive, rather than broadly similar. However, when I shared test results with people, it was often hard for them to remain in touch with their preferred storylines. This was especially noticeable if the genetic testing results returned unwanted news (often showing a person had inherited the condition in their family). In this situation, the shock of results can be destabilising. It is hard to remain in touch with hopes, values and knowhow, and local knowledges are easily displaced.

It was in this context that I began to think about the possibilities of therapeutic letter writing to record and make more secure people's preferred storylines: their hopes and reasons for testing, the values that support these hopes, their skills and knowhow, and the support figures in their lives.

Therapeutic documentation in narrative practice

There is a rich history of therapeutic documentation in narrative therapy, including various kinds of letters, poems, certificates and drawings that act as records of preferred identities and storylines that emerge in therapy (Madigan, 2011; Nylund & Thomas, 1994; White & Epston, 1990). More than recordkeeping, therapeutic documents create possibilities for the witnessing and re-witnessing of preferred identities (Carlson, 2020; Myerhoff, 1986). The letters I started writing were:

- material evidence of my act of witnessing and authenticating the preferred identities of people I was meeting with
- a document through which people could witness themselves as they made decisions to undertake or decline genetic testing
- an opportunity for reflexive re-witnessing (and potentially revising) of preferred identities after genetic test results are known.

The letters allowed people to be actors and audiences (Myerhoff, 1986) or "insiders" and "outsiders" (Carlson, 2020) to their own emerging stories and preferred identities.

In constructing the letters, I tried to capture the essence of our conversations and what was important to people as they undertook genetic testing. I also thought about the act of "rescuing" aspects of the conversations which might be easily forgotten (Newman, 2008). This has a particular relevance to genetic counselling where psychosocial counselling is interwoven with an exchange of medical and genetic information. In this context it is easy for descriptions of hopes, values, acts of support, skills and commitments to be lost in a sea of professionalised "expert" knowledge, combined with grief and worry about genetic test results. Letter writing is part of my commitment to secure these non-expert local knowledges, and to witness and authenticate people's preferred identity claims as they undertake genetic counselling and testing.

I will share some stories of practice through themes that emerged from my work with three people who decided to proceed with genetic counselling.[3]

Hopes and values

I have found narrative practice particularly helpful to support people in exploring their reasons for having genetic testing and their hopes for how the genetic test result could support their preferred ways of living. The re-authoring conversations maps (Carey & Russell, 2003; White, 2007) were integral to these conversations. I learnt to ask scaffolding questions that help people link their decisions about testing (landscape of action) to their hopes and values for living (landscape of identity), and consider what actions they could take in response to different genetic test results (landscape of action). I have noticed these conversations lead to richer understandings of people's reasons for choosing to have testing, and this is supportive of them when they receive test results. If the result returns difficult news, reflection on people's reasons for testing, and the values that underpin these reasons, can be grounding. I have outlined my approach to re-authoring conversations in Figure 1.

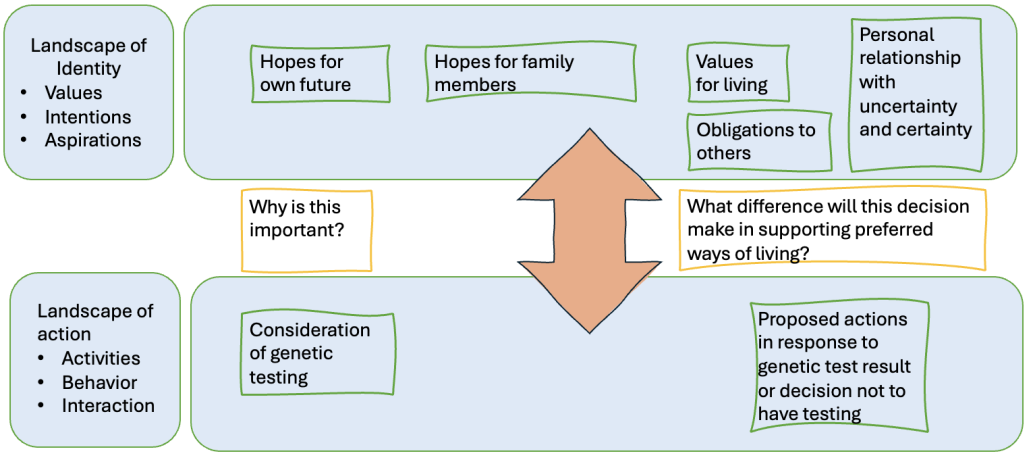

Figure 1: Re-authoring conversations map to explore reasons for undertaking predictive genetic testing.

Nathan

I met with Nathan and his partner, Kate. One of Nathan's parents had recently been diagnosed with a neurogenetic condition, and Nathan had a 50% chance of inheriting the condition from them. Nathan and Kate had a young child who was born before they had knowledge of the neurogenetic condition in his family. Nathan's reason for testing was directly linked to his hope for another baby, and a value about not passing on a serious genetic condition to the next generation. If Nathan's test result was positive, he and Kate planned to use IVF to conceive a second pregnancy that would not inherit the condition.

Some of the questions I asked Nathan were:

- Why is it important for you to know this information before you have another baby? Is this linked to something you value?
- Who are you thinking of in your decision to have this test?
- What do you want to remember about what's important when your genetic test results come back?
- What might be your next step if your genetic test result is positive [or negative]?

Excerpt from Nathan's letter

> You told me one of your main reasons to have genetic testing was related to you and Kate wanting to have another baby. Now that you know [neurogenetic condition] is in your family, you said, "I don't want to keep it passing down the family line … we should try and stop it now when we can".
>
> …
>
> You said that you wanted to take this one step at a time. The most immediate thing in front of you and Kate is your hope to have another baby, and a desire not to pass [neurodegenerative condition] on to them. You told me, "For now, I'm just thinking of the next generations".
>
> …
>
> I asked you if there's anything you'd like to remember for yourself when the results come back. You told me: "I'd be pretty upset to think that [our child] could have [the condition]. But there are ways to help situations … it's not like it's the end of the world. We need to look at it in a positive way, as much as we can. There's treatments and IVF. Nothing's going to stop life. Moving forward is important for us. I don't want to stop that; it's just the ways that we'll do it, I guess".

Lou

I met with Lou, an Aboriginal woman aged in her 30s who had young children. Lou was seeking predictive genetic testing for the neurogenetic condition in her family. Her decision to have genetic testing was related to "healing" and "learning to face up to difficult things". Lou described a multigenerational history of hardship in her family, some of which was related to colonial violence and the trauma that resulted from this. Lou was advocating for her kids to have more opportunities and support than she did when she was at school.

Excerpt from Lou's letter

> You told me having testing would be part of healing, of learning to face up to feelings and difficult things. You told me you wanted to stop blocking things out.
>
> You also told me how you are learning to stop pretending things are okay. You said [your son] always knows if you are upset or struggling with something, and he asks if you are okay. Sometimes you shut these enquiries down, and other times you're able to tell him something is wrong. I wonder what it means to you that he notices you and is curious about how you are going. How do you think he learnt these skills? You told me you want to be a good example and help your boys learn to talk and share their feelings. You told me you want to break the cycle of difficult communication in your family, and you think this could have a big impact for your boys.

Skills and knowhow

An important part of pre-test genetic counselling is exploring the resources and support people have for

coping with the genetic testing process and results. This part of my genetic counselling practice has developed significantly with narrative therapy ideas. Previously I would have asked in general terms about a person's close family and friends, professional psychological supports, and ways of coping. With narrative practice I have begun to ask questions that invite people to describe their own skills and knowhow in rich and particular ways. The re-authoring conversations maps (Carey & Russell, 2003; White, 2007) have guided me during these conversations, leading me to enquire about the values, significance and histories of people's skills and knowhow. I have noticed the conversations are increasingly centred in the lives and knowledge of the people I am meeting with.

Some of the questions I have asked are:

- Have you experienced any hard times in the past?
- What kinds of things did you find yourself doing that helped?
- When did you first start doing these things? How did you learn these skills? Were they introduced to you by someone?
- Why is it important to you to maintain these routines/skills/activities?

Excerpt from Nathan's letter

> We talked about some of the things you do when things get tough, and which could be useful to remember after your result comes through.
>
> You told me how you like to go fishing, and that this is a good way to spend quiet time with yourself. You said that this is not about "running away from problems" but more about "taking time to be positive" and think things through. You told me it's sometimes hard to find the time for this when life is busy, but you thought it would be something to focus on if you need to. You said you don't need to go far to fish, even just a spot at the lake close to home can be nice.
>
> You also told me how you like to be around other people, and this helps to switch off from stressful things. You use this as a way to "leave work stress at work and not take anything home".
>
> You said you have a couple of [sport] trips booked in with your friends. You also said you and your friends like helping each other with work on your houses. There is someone in every trade, so you can join together and get things done.
>
> You said it's a balance, spending time by yourself and also keeping busy and being around other people.

This excerpt from Nathan's letter demonstrates how I was able to scaffold a conversation around his love of fishing. Nathan described this as important because it allowed him to "take time to be positive". The letter also makes visible some of the barriers for Nathan in being able to fish, and his strategies for overcoming these barriers.

Acts of support

Another important aspect of genetic counselling for predictive testing is exploring the social, family and/or professional support people have in their lives. In the past I have found it easy for conversations to become focused on "psychological safety" and making sure the people I am working with have access to appropriate professional support. While this is important, narrative practice has given me tools to explore the support people have in ways that are more embedded in their day-to-day life. I am increasingly on the lookout for less visible connections or acts of support, rather than psychological or social "problems".

I have drawn heavily on the narrative practice of re-membering for these conversations about supportive figures and actions of support people are receiving as they undertake genetic testing (Hedtke, 2014; Russell & Carey, 2002). Re-membering was described by Myerhoff (1982, p. 111) as a "special type of recollection" that allows people to purposefully reorganise the membership of their support system. Re-membering conversations provide possibilities for thinking of support more broadly and placing that support within a historical and social context that is supportive of people's preferred identities.

Some questions I have asked are:

- Is there someone in your life who would be supportive of you having this testing [even if they don't know you are here]?

- Is there something they do [or say] that lets you know they are/would support you?
- What impact do these words [or actions] have on you?
- Why do you think it would be important to them to offer this support?
- What do you think it would mean to them, to know that you are leaning on them for support?

Excerpt from Nathan's letter

> You told me about how Kate and your family are wonderful supports. I could see how Kate supported you when she came to the first genetics appointment with you. I remember her saying that it was your choice whether to have testing, and that she would support you either way. What difference does it make to you that she is supporting you in this way? You also said it's made a difference that you've been able to talk with Kate about IVF, and how you might work together towards having another baby. You said these conversations have made you feel like "it will be okay".
>
> You told me about how your friends have been checking in and making sure you're okay as you move through this genetic testing process. You told me it's been good to share a little bit about [neurogenetic condition] and the testing with them. They let you know they support you by saying things like "I hope everything's going to be okay" or by asking about when your appointments are or how they went.

This excerpt from Nathan's letter documents the support his friends provide by checking in with him. Nathan wasn't forthcoming with details about his friends or other supports, but by "rescuing" the few things he did say about this, I was able to capture these ideas and fix them in text. I hoped this would be a reminder to Nathan, capturing something brief that might be otherwise forgotten among the other things we discussed. It also created a stepping stone – a base of understanding that we could return to in a future session if we needed to.

In Nathan's letter I also included some of my own reflections about Kate's support. I did this because Nathan and I didn't have an opportunity to explore Kate's support in detail together. I wanted to keep the letter as close to Nathan's own words and responses as possible, and clearly state the difference between my observations and his words. I hoped this distinction would make it easier for Nathan to disregard my interpretation of Kate's support if it didn't resonate with him.

Lou

In conversation with Lou, I drew on the re-membering conversations map (White, 2007) to connect her ways of coping in hard times with the significant people in her life. This led to some beautiful and unexpected reflections on Lou's relationship with each of her parents. Lou shared that going and having a cup of tea with her mum would be comforting. When I enquired about this further, Lou told me their relationship had been difficult in the years previously, but they had done a lot of work together to improve the relationship. I enquired about the impact of Lou reaching out to her mum for support.

Steph: What do you think it would mean to your mum if you went to her for support?

Lou: I think it would make her feel valued as a mum.

In Lou's case, both her parents were supportive, but in different and incomplete ways. I chose to document the specific ways her parents were helpful in their own ways. My hope was that this might capture the variety of support Lou was receiving from different family members; perhaps this could be considered "multi-storied" support.

Excerpt from Lou's letter

> You also told me about some of the ways you could support yourself after you get your genetic test result. I wonder if some of these ideas could also help while you wait for the testing to be done. Some of the things you mentioned were:
>
> - Hugging your boys.
> - Jumping on the trampoline with your boys.
> - Ringing your mum. Asking her to have a cuppa or to come over to your place. You told me how your relationship with your mum has improved in the last few years. You said it means a lot to you that she's there to support you, and you think it would make her feel valued as a mum if you reached out to her for support.

- Going to [café] with [your partner] for coffee. You told me this was one of the first cafés you found together when you moved to the area. You enjoy the coffee there, and the staff have got to know you both over time. It's a familiar place.
- Calling your dad for a chat. You told me there are some things that he's really good to talk to about. For some of these things, you said he's less judgemental than other people. You also told me he's good at practical support – like coming for a sleepover with your boys so you and [your partner] can have a night out together. You told me your dad often says how proud he is of you. You think this is because you're being proactive about doing things in your life to support your family.

Responses to genetic test results

It is not unusual for people who receive a negative genetic test result (meaning they have not inherited the condition) to experience some distress, despite receiving the result they were hoping for (MacLeod et al., 2018). This can be related to shock or disbelief, changes in self-perception, reactions from family members, or a feeling of guilt at being dealt "a good hand" when others in the family had been less lucky.

Dan

Dan's response to his "good news" genetic test result was quite profound, and this led me to write him a letter that "rescued" what I could of his response to the result. This was a particularly tender appointment, and I didn't feel it was respectful to record or take too many notes as we were talking. For this reason, the letter contains fewer direct quotes, instead focusing on my attempt to capture the meaning of Dan's story. Dan told me he was so shocked by the genetic test result that he couldn't imagine what was next for him in life; he'd had a rough and traumatic past, and this result felt like one of the only times something had gone well. In our conversation, I focused on asking questions that allowed Dan to connect actions and commitments from his earlier life to his hopes for the future. Re-membering practices allowed Dan to reconnect himself to his sister and nephew, his hopes for their future, and the part he could play in this.

Excerpt from Dan's letter

You said you didn't allow yourself to think the result could be negative for [neurogenetic condition]. You said it's one of the first times in life when something important hasn't gone badly for you; it was actually a really big shock to receive the result.

You told me how much Harry [nephew] means to you, and how he has brought you closer to Louise [sister]. You talked about being a good uncle for Harry, and how this result means you'll be able to support Louise when she develops [neurogenetic condition].

You told me all about your interest in astronomy, and how you're clever at maths. You told me how you like to learn about space and stars and other astronomy things using YouTube. Even though it's difficult to do a lot of things because of your back injury, you're still able to keep learning. You said this is because of your curiosity about the universe and how it works. I'm wondering if one day you might get the chance to share some of this knowledge with Harry.

You also said you wanted to learn to fly a helicopter, and talked about the simulated training centre in [suburb]. You said this is something on your bucket list, and something that might be possible now you know you won't develop [neurogenetic condition]. Maybe some other things will be possible too?

Negotiating letters

An aspect of letter writing I am still working on is having careful and thorough discussions with people about whether they would like to receive a letter, and what would be most relevant to include in the letter.

The times when I have asked people what they would like me to include in a letter have been quite revealing. When I asked Nathan if there was anything he would like me to write down for him to remember when the results come back, he said,

> I'd be pretty upset to think that [my son] could have something. But there are ways to help situations … it's not like it's the end of the world. We need to look at it in a positive way, as much

as we can. There's treatments and IVF. Nothing's going to stop life …. moving forward is important for us. I don't want to stop that; it's just the ways that we'll do it, I guess.

To me, this seemed like Nathan had crystallised what was most important in the testing.

There have also been many times when my attempts at negotiating letters led to indifferent responses, with people saying things like "Sure, that's okay", or "Yeah, you can do that". As I move forward with this work, it may help to share an example of a therapeutic letter with people, so they can have a sense of what I am thinking about and whether this is of interest to them.

It may also be that some more interesting questions are needed to get a real sense of what would be useful for people:

- Is there anything you would not want me to include in the letter?
- If you were writing a letter to yourself to capture what was important, what would you want to include?
- When do you think the letter would be most useful to receive?
- Do you think it would be useful to share this kind of letter with anyone?

Sharing letters

Some of my biggest learnings have come from sharing letters with people. I have shared several therapeutic letters with people during their results appointment and found they were not able to fully engage with the letters in that moment. My observation has been that the impact of the result is significant, and people haven't had capacity to engage with anything additional.

As an alternative, I sent Lou's letter to her by email in the period between having DNA samples collected for the test and receiving the result (this is usually about two months). During Lou's results appointment, we reread the letter together, and Lou told me she had been drawing on some of the skills and support actions mentioned in the letter during the weeks she was waiting for her result. Ideas in the letter, such as Lou's larger project of "healing" and "learning to face up to difficult things", then became themes in future sessions we had together as her child subsequently had genetic testing. From my position, this project of *healing*, which was made "more solid" in the therapeutic letter, gave us a broader purpose for future genetic counselling with her child. There was a shift from focusing on the result as a binary (positive or negative for the condition), to focusing on *healing* regardless of the result. In this sense, either result was manageable for Lou, because both could be supportive of healing and caring for her children.

These observations have led me to believe it is better to share supportive letters with people in the time after their DNA samples are collected, and before the results are available. This gives people a chance to read and engage with the letter on their own terms, so it might be drawn on as a familiar and supportive resource after they receive their test result.

Notes

[1] Some of these conditions also have non-genetic causes.

[2] This is distinct from diagnostic testing, which is genetic testing for a person who has clinical symptoms of a suspected genetic condition.

[3] All participants have expressed willingness and provided consent for our work together to be included in this paper. I have used pseudonyms and removed identifying details. I would like to share my gratitude for the participants in this work for their openness and willingness to explore the possibilities of narrative therapy with me.

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