

Using therapeutic documents: A story of creativity tricks and living after childhood cancer

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In this article, we discuss the aims and intentions of using creative documents within a paediatric setting. We have been fortunate to write this article with a young woman who accessed the service and has given her consent to share her story.

WORKING within a medical field, we often see young people positioned as passive recipients of care. Letters frequently use jargon, are written in the third person, such as ‘diabetic’ or ‘brain injured’, and outline plans that don’t directly involve the young person. One alternative is to create therapeutic documents written directly to a young person, in order to re-position them and empower them in feeling it is possible to manage the impact of a health condition.

Written communication

Research into the benefits of written communication has shown that it can have a significant influence on clinical work. For example, maintaining a connection, overcoming distance when young people or therapist cannot be physically present, providing a sense of immediacy, extending the conversation and ultimately reducing suffering (Epston, 1994; Wojcik & Everson, 1989; Wood & Uhl, 1988; Moules, 2009). Therapeutic documents have been equated to 3–10 sessions’ worth of therapy time (Freedman & Combs, 1996; White, 1995; Wright, Watson & Bell, 1996).

With advances in technology, Moules (2009) noted with curiosity that written documents still continue to hold importance, perhaps due to the significance of a tangible object. Fox (2003) highlighted the therapist’s privilege in

‘owning’ the case notes, and suggests clients having their own records of sessions can allow them to reconnect with the work, see markers of change, record progress, as well as ideas and conversations. Attention has been drawn to the importance of documents being written with or by clients to capture their own discoveries and progress. Thinking with clients about timing and content are important, so that letters are not premature or overly positive (Payne, 2006), which can leave people feeling unacknowledged or disconnected.

Documents and their intentions

Fox (2003) reviewed and identified four main types of therapeutic documents:

- 1. Documents recording a session:** help the client to keep track and provide a bridge between sessions.
- 2. Documents of knowledge and affirmation:** support the client to hold onto preferred stories that are beginning to thicken through therapy and give others in the system an opportunity to hear alternative stories.
- 3. Documents of circulation:** include documents to celebrate or appreciate the client’s knowledge, or how they have responded to challenges.
- 4. Documents of rites of passage:** often signify endings and can be celebratory in nature.

Using letters and documents at University College London Hospital (UCLH)

Within a paediatric setting, we hold the intentions of therapeutic documents in mind and drawing on ideas from Vermeire (2017), use creative and playful ways to help engage children and capture this in our documents.

Examples of documents

There are five main types of documents used by our service. An *initial consultation letter* is a record of the initial assessment which includes problem free talk, the problem using the family's language and the agreed plan. An *after-session document* can be used to record discoveries, progress and ideas from sessions in a meaningful way for the young person. An example of this has been creating a flashcard with 'words of encouragement' or a certificate celebrating progress.

A *review letter* is written after a colleague is invited to review the work completed so far and is an opportunity to document progress, acknowledge challenges, preferred responses, affirm and thicken preferred stories and spread news within a young person's system. One example is creating a 'Recaptured Speech Poem' (Speedy, 2008) using only the words spoken by the person, their family and professionals in the room, to capture the journey travelled.

Another document is a *cognitive assessment report*, in addition to the report itself; we incorporate the ideas of Griffin and Christie (2008), making results accessible by utilising the interests of the young person. In the case of a young person who is interested in football, we would design a document using headings such as 'Things you are great at', 'Things that need practice' and 'Ideas to use in training.' Finally, an *ending document* is created after a final session, similar to Fox's 'rites of passage' and is often of a graduation style.

Denisa's story

Denisa has given her permission for her story to be told and her documents to be shared alongside her reflections.

Denisa was referred to the UCLH Psychology Service in her late teens, for a cognitive assessment following concerns around memory.

Denisa had been known to the late effects and psycho-oncology service after being diagnosed with cancer and receiving extensive treatment of chemotherapy, radiotherapy and surgery. At the end of her medical treatment, Denisa felt low in mood, isolated and had disengaged from education. As part of our initial consultation, we started with problem free talk. Denisa initially found it difficult to connect with things that were important to her, but we did hear that she fundraised and loved dogs. For Denisa, the biggest challenges were feeling really low and poor memory. She used words like 'disabled' and 'brain injury' to describe herself and felt like her life had been stuck for some time wondering, 'why did I get saved from cancer?'

Denisa's words

'When I was 12, I was diagnosed with a stage 4 brain tumour. I underwent two 5-hour brain surgeries', 6 weeks of radiotherapy and 8 cycles of chemotherapy. From the age of 13, things got really bad for me. I felt like I had a bad angel on my shoulder with bad thoughts, they were really dominant. It made me really tired and didn't let me go out of the house.'

I (first author, Rachel), completed a cognitive assessment which identified no significant memory impairment. We wrote a formal cognitive assessment report which was sent as a draft to Denisa before the feedback appointment. At this appointment, we heard that Denisa had not been able to make sense of the results. Denisa and I thought about different ways of presenting the results. Denisa decided on a dog themed poster highlighting strengths, learning about challenges and collaborating with solutions. The difference in using this document was that Denisa reflected, 'oh so my memory is OK then?' See Document 1.

Following the success of using co-constructed and creative approaches to the cognitive assessment, Denisa was keen to continue using documents (which she called 'creativity tricks') in our sessions. We began with developing charts and stars as rewards for achieving daily activities she had set (Jacobson, 2001).

'We started off with sticker charts and trying to achieve twenty stars a week. At first, I was very low, so I needed fantasy or something childish, because I had lost my childhood at a very young age. [The stars] were for basic things like getting up, washing your face. Every week I would come back and get all the stars. After time it got too easy, so then we went on to higher stars; looking for jobs and different ways to exercise. After achieving stars, I got a certificate; one of my ideas was a unicorn certificate because unicorns give you good luck. The bad angel had been around for such a long time, but I had ideas about how to make the good angel and the good thoughts more. When my brain started to get rid of the bad angel and bad thoughts, I knew I could stand it myself. The good angel started taking over telling me "you can do it on your own ... you don't need the star chart anymore". I was then actually ready to start thinking about the future.'

We had wondered whether the dominant story (White, 1995) of being someone who was 'brain injured' or 'disabled' had contributed to feeling low. Continuing the creative work, we captured different parts of Denisa's identity using the tree of life, a therapeutic approach which helps people share stories about their life

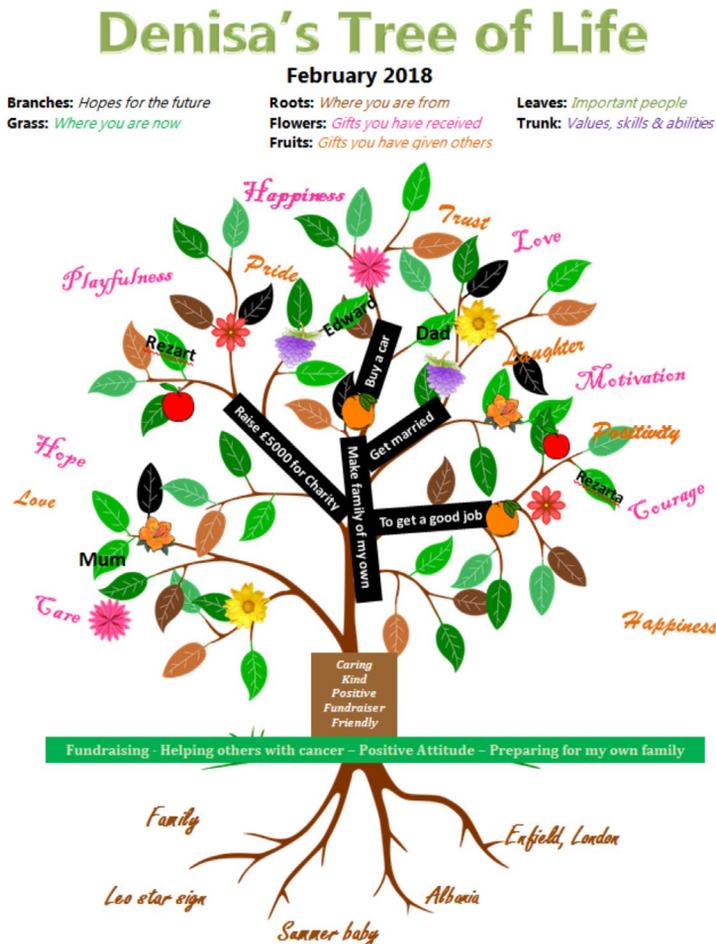
in ways that make them stronger (Ncube, 2006; Denborough, 2008; Portnoy, 2016). This reconnected Denisa with her culture, skills, dreams and important people. Noticeably, she reconnected with her beliefs and started to tell her story differently, 'I was meant to survive cancer; God had a plan for me'. See Document 2.

'Rachel brought in this big sheet and we ended up sitting on the floor drawing my tree - another creativity trick! We started with the roots; the roots are where I came from. Grass is where I am now. Trunk is all my skills, my values and my abilities. Leaves were important people. Flowers were the gifts I received. Fruits were the gifts that others got from me. Branches were hopes for the future. This helped me gather up my brain together in a playful way. If you explained this by just talking or asking about these in a boring way, people struggling with stress aren't going to be interested. You need to interest them by doing something they love, and Rachel knew that I loved arts and crafts. To be honest, the tree was my favourite part because we do arts and crafts, but we are also working our brains. It makes you know where you stand and how you can move forward. This helped me get rid of the bad angel completely and I found ways to control myself to not think about anything bad anymore.'

Document 1: Denisa's dog themed cognitive report



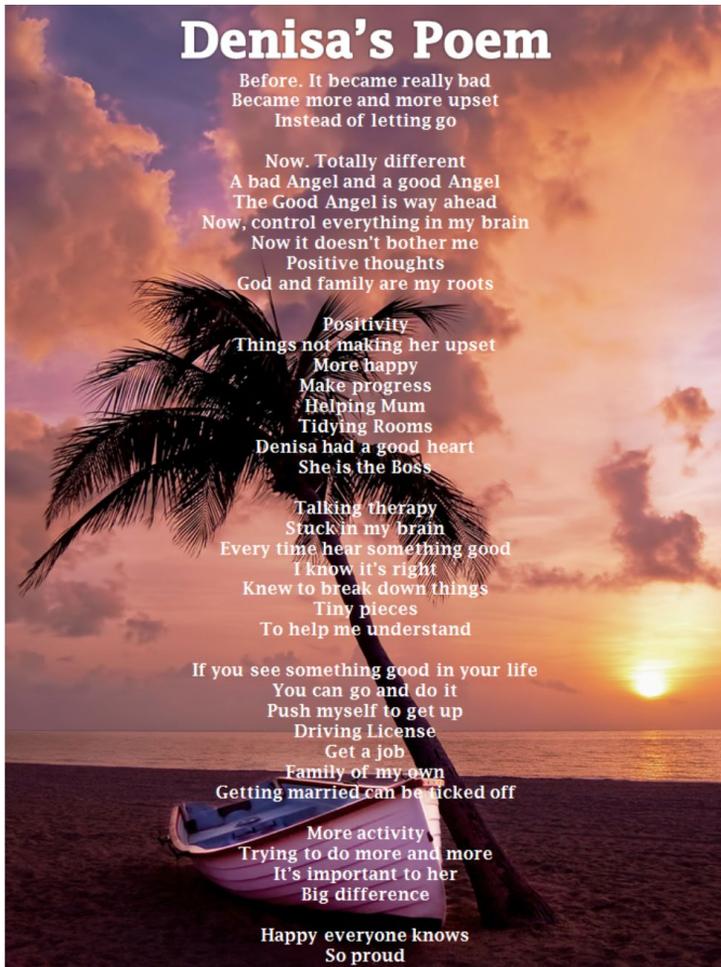
Document 2: Denisa's Tree of Life



During each session, I wrote down Denisa's words and we used them to write letters to capture new stories and preferred identities that were growing. Initially, these letters were just to Denisa, but she was keen to share these with others. We organised a review, and Denisa invited her parents and fiancé. The review, led by a colleague, focused on the work, developments that everyone had noticed and a plan going forward. Another colleague joined to capture the words from the session and retold them as a Recaptured Speech Poem (Speedy, 2008). At the end, Denisa reflected that she no longer felt she needed psychology and so this was our final session. See Document 3.

'My poem was written during my last appointment led by another psychologist. It used the words of my husband, my Dad, my Mum, me and Rachel. When I saw it in a poem, it made me more proud of everything. You realise the words even more when it is out there. Rachel always wrote down the words I used in sessions. I saw them on her page; words like brave and positivity. Looking at those again and again made me proud and [think] "yeah I have done it!" I had bad experiences when I was in hospital as a child. The chemo was getting to me; I had stress and got angry. They would write down everything that I would say. I didn't know why they were writing everything down; I thought it was so they would call someone about me. With Rachel I could say anything, I felt like a normal person.'

Document 3: Denisa's recaptured speech poem



Why should documents be used?

'If [psychologists] are looking for achievement then they should use playful techniques or what I've called 'creativity tricks.' All people are different, but these helped me go from [the floor] to [the sky]. You need to do practical things with a person that has got stress. So they forget about their stress, they're thinking about what sort of things they want to go on their certificate or their letter, and they're going to be thinking about how they're going to achieve the stars! Now, [the documents] are all in my brain. When I need them, they are there just like a clipboard.'

Final reflections

Since ending, Denisa helps the psycho-oncology team facilitate groups, has fundraised over £2000 for charity and is training to become a brain tumour ambassador. Denisa has gone on to present her poem, tree and certificates at charity events for other survivors, highlighting the power of therapeutic documents. Using documents in this way can enable people to hold on to preferred identities, have an active stance in their care and bring 'creativity tricks' into sessions.

Final words

'From the age of 13, things got really bad for me. Now, my story is different, totally different. The Good Angel is way ahead. I still have some physical problems, but now I know that I am someone, and my husband and family remind me of this every day. I think about my experience a little differently. I believe that it was written for me to have cancer, and for me to survive cancer. I wouldn't be who I am and where I am today without these things happening to me. I now feel pretty fearless, because what can be scarier than cancer? At the age of 22, I am now happily married, and I regularly fundraise to raise money for cancer to give back.'

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