

Executive Research Summary for The Childhood Tumour Trust

The Experiences of Living With Neurofibromatosis Type 1 (NF1) and Of Attending a Therapeutic Camp.

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About me: My name is Aysha Yousuf and I am a Health Psychology Masters student at Manchester Metropolitan University. In November 2019, I started working with two of my University Lecturers (Dr Keenan and Dr Pilkington) in partnership with the Childhood Tumour Trust (CTT) to carry out a research study to explore the lived experience of NF1.

Our Study's Aim: After doing some reading, I realised that very few studies have investigated young adults experiences of living with NF1. I also found that no study to date has explored young adults experiences of attending the CTT camp and if camp helps individuals to manage their condition. Therefore, after considering this information, I decided to focus my study on investigating young adult's lived experiences of NF1 and of attending the CTT camp.

Research Method: During April 2020, I conducted telephone interviews with 9 young adult volunteers over the age of 18, who had received an NF1 diagnosis and had attended the CTT camp. Each young adult was asked about their personal experiences of living with NF1, their experiences of attending the CTT camp and their experiences of accessing other forms of NF1 support.

Our Findings: I analysed the data from each young adult's interview and summarised them into three themes. These are the following:

- 1. Self-reflections of living with NF1:** From the 9 young adults interviewed, 6 reported negative experiences in relation to their NF1. These included peer bullying, coping with symptoms (e.g. pain) and feeling isolated from others due to appearing visibly different. Many young adults also reported living with other conditions (as well as their NF1) such as ADHD and Autism. These additional conditions made it challenging for the young adults when trying to socialise or form friendships. However, 7 young adults recalled times where they felt their NF1 did not severely affect their lifestyle and noted some positives

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of living with their condition. These included supportive friendship groups, being able to access trained NF1 specialists and being able to attend the CTT camp.

- 2. Lack of NF1 Education Provision:** Many young adults felt that their academic Teachers and Doctors did not understand their condition and had (in some cases) never heard of NF1 before. This lack of knowledge often caused young adults difficulties when trying to access appropriate medical advice or extra academic support. Furthermore, young adults also reported being teased by school peers about their visible symptoms (e.g. café au laits, plexiform neurofibromas) as well as the difficulties their parents had when trying to access NF1 support information during their NF1 diagnosis.

- 3. Accessibility of NF1 support:** All 9 young adults talked of their positive CTT camp experiences. These included being able to relate to and offer support to peers at camp, feeling socially included by others, forming long-term friendships and perceiving camp to be a non-judgemental socialising environment. 4 young adults provided suggestions for how camp could be further strengthened which involved running additional camps in various UK locations to increase accessibility. Also, 2 young adults recommended the need for mental health support at camp.

Our Recommendations for the Childhood Tumour Trust:

After considering these findings, I have suggested ways in which the CTT could tackle the issues highlighted above to improve the experiences for these young adults living with NF1 moving forward. They are the following:

- **Create an NF1 information handbook for teachers** - I believe the CTT's medical board, Special Education Needs (SEN) nurses and teachers could collaborate to form an NF1 information handbook for teachers. This handbook would provide teachers with an overview of NF1 as well as young adult's (typically required) medical and SEN support needs, so they can arrange support for their students accordingly. The handbook could also contain tips for teachers to detect peer bullying behaviour as well as examples of communication strategies to use when discussing these young adults career goals to ensure they feel supported.

- **Collaborate with the General Medical Council (GMC) to create a mandatory NF1 training programme for medical students and existent Doctors** - The aim is that after they have completed the training, all aspiring and existent

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Doctors will be well equipped to aid young adult NF1 patients with their medical support needs.

- **Formulate an intervention to combat NF1 peer stigmatisation** – To combat peer bullying, the CTT could collaborate with Health Psychologists, Teachers and young adults living with NF1 to form a behaviour-change intervention that aims to alleviate NF1 peer stigmatisation in Schools and higher education institutions.
- **Add a 'Parents' NF1 information section to the CTT website** – The main aim of this website section is to provide an overview of NF1 so that any parent who suspects their child has the condition will be able to get the reliable information they require online (E.g. key diagnostic symptoms, signs of more serious symptoms). The CTT could also partner with trained NF1 medical professionals to create an anonymous (and monitored) public forum on the CTT website for parents to ask any specific (non-emergency) medical NF1 questions. Furthermore, a partnership with a mental health organisation (such as 'YoungMinds' or 'Kooth') could also be beneficial when creating a separate advice tab for parents on how to support their young adult's mental wellbeing. Then, a second parental public forum could also be added here for parents to query specific (non-emergency) mental health questions to be answered by trained advisors from the organisation.
- **Have ambassadors from a mental health organisation attend camp (E.g. YoungMinds)** – Ambassadors could provide a public talk for young adults on effective ways to manage their mental wellbeing and hand out their organisation's (existent) leaflets/booklets. Additionally, qualified counsellors from the organisation could also attend camp to offer 1-to-1 drop-in sessions so those young adults or children with (more personal) mental health matters can get the support that they require.
- **Run more therapeutic camps in different UK geographical locations** – This will increase camp accessibility for those NF1 young adults who struggle to travel to the original campsite.
- **Work with the Children's Tumour Foundation (CTF) and Psychology researchers to create more tailored NF1 support-mechanisms for young adults** – Researchers could interview young adults that attend the CTF and CTT camps by querying what other forms of NF1 support they would like to access (as well as camp). The researchers could then summarise these suggestions into a report and hand the document to the CTT and CTF. Both organisations could then collate their funding and make the most reasonable suggestions a reality.