

Over 16s Survey - The Results

The survey was completed by 165 people ranging in age from 16 to 69 years old and nearly 2000 comments were recorded. A full report of the results can be downloaded from our website, but here is a brief summary. The majority of people surveyed had congenital hemiplegia (86%) but many people commented that their parents had never been sure whether they'd had hemiplegia from birth, as it was not diagnosed until later in their life. More than half (56%) of those surveyed had associated conditions in addition to hemiplegia, including learning difficulties (35%), epilepsy (30%), visual impairment (30%), speech impairments (8%) and Autistic Spectrum Disorders (4%).

Treatment

Over 59% of Over 16's surveyed said that they were not receiving treatment or therapy for their hemiplegia. Of those that did, 39% were receiving physiotherapy, 21% occupational therapy and 8% speech and language therapy. Typical comments were that people had these as a child but 'not anymore'. Access to different services varied dramatically and physiotherapy treatment often seemed to end or fade away at times of transition, such as moving schools. Despite this, 64% of people said that were happy with the service that they receive and the frequency of therapies.

Benefits

Over 65% of people surveyed were in receipt of the Disability Living Allowance or other benefits and most (76%) did not receive any other financial help. Of those that did, half were on incapacity benefit and others were in receipt of tax credits, income support, student disability allowance and severe disability allowance. Over half (52%) of those surveyed had a driving licence, but most of those that didn't said that this was not through personal choice.

Employment

35% of those surveyed were in higher or further education, 43% had left education and were working and 23% had left education and were unemployed. People had studied a wide range of subjects and a there were a variety of jobs listed, including factory work, administration, accounting, computing, teaching, catering, banking, nursery, occupational therapy, project management and public relations.

Education

Over three quarters (75%) of people surveyed had attended a mainstream school and 61% said that they enjoyed school. However, 67% said that they did experience difficulties at school and 63% were bullied. Over half (55%) reported problems with academic work, concentration and anxiety. A lack of understanding from teachers and peers is cited in many comments, such as 'some of my teachers clearly didn't know what hemiplegia is and how it affected me'. Just under a fifth (18%) of people said that they had behavioural difficulties but some felt that this was sometimes interpreted as bad behaviour; e.g. 'I was generally a well behaved student but sometimes I got in trouble in relation to my disability e.g. involuntary laughing, making mistakes because of visual perception difficulties etc'. Bullying and exclusion come through as clear themes. One person commented 'I was just different and kids pick on that...I was run away from, chosen last for sport, whispered about and excluded from social events, which damaged my confidence and self-esteem well into adulthood'.

Transition

Half of the people surveyed said that they encountered difficulties connected with their hemiplegia during the transition to adult life. The fall off in services and support after the age of 16 was commented on and people felt that they had to fight for benefits, support services and NHS treatment as well. Some people also reported workplace bullying and a lack of understanding about the condition amongst employers, making it harder to get and keep a job. A whole range of suggestions were made for making this transition easier including advocacy, information, knowing other teenagers with hemiplegia and 'the support of older people with hemiplegia who'd been there and done that'.

Relationships

The majority of people who filled in the survey (67%) were single, 16% were cohabiting or in a relationship, 16% were married or in a civil partnership and 12% had children. We asked people what they liked to do in their spare time and a diverse range of activities were mentioned. Amongst the positive comments, there were also a significant number of people who found meeting people, socialising and taking part in activities difficult. Most people (73%) said that the activities they did were all in mainstream settings.

Family

Over half of respondents (57%) lived in their parents' homes, 11% in a shared flat or house and 33% in their own home. We asked how Hemiplegia had affected family relationships, and responses ranged widely from 'in a positive way... my family take more care of me and are more protective over me' to 'very negatively, family take more care of me and are more protective over me' to 'very negatively, as I was an extremely temperamental and sometimes violent child and demanded a great deal of attention from my parents'. Many people felt that having hemiplegia had 'put a strain on relationships' but most echoed the person who said 'I am very grateful for the amount of love and care they all give me'.

Impact of Hemiplegia and disability

Many people said that they have not let having Hemiplegia hold them back; 'I regard myself as normal and do everything I want to', 'I overcome problems and ask for help when needed'. However, many did feel that Hemiplegia affected their life in a negative way; physically ('I become more aware of the limitations it imposes, and I experience tiredness more') socially ('I feel sometimes people see me as a disability first and a person second') and emotionally ('has affected my self-confidence and made me insecure'). A majority (62%) of those surveyed consider themselves to be disabled, but some people struggled with this definition. One person wrote 'I find it hard to answer this question as most of the time I would say no, but occasionally I come up against limits that remind me that as much as I'd like to ignore my Hemiplegia, it is part of who I am. I just don't like using the term because I don't want my hemiplegia to define me'.

HemiHelp

Most people (58%) felt that they did not receive enough help and support in general. However, 86% thought that HemiHelp had helped them, often 'just by being there'. One person wrote that HemiHelp had 'helped me come to terms with having hemiplegia', and another said 'it helped me when the going got tough!' Despite this, people did feel that there was more HemiHelp could be doing to help adults with Hemiplegia. Many people felt that it had been more of a support for their parents and nearly a third of those surveyed said that they were over the age of 20 when they first knew about HemiHelp. One person noted that 'The articles you have for adults [in the Magazine] are good but more is needed. General disability info tends too often to stop at the paediatric level'. People felt that leaflets on adult and teenage subjects, conferences, workshops and social events and adult pages on the website would all be beneficial. We were delighted that 64 people said they would be interested in helping us develop HemiHelp services for young people and adults by joining an Over 16's Panel/Committee and hope to be able to contact everyone who offered their help in this way at some point next year.

As part of the survey, we asked people what advice they would give to children and young people who have hemiplegia, and their parents. Here is a small selection of the responses:

For children:

- Aim high and do not let your disability get in the way of your dreams. Selfconsciousness limits you.
- Be yourself and try your hardest. Real friends will always help you. Don't ever doubt yourself just because other people may doubt your abilities.
- Persevere. I know it can be frustrating sometimes coming to terms with your disability, but just don't give up and always try your best. Keep exercising!
- Sometimes it's hard having hemi and it feels unfair, but you must keep faith that you're brilliant. You'll do just fine wherever you choose to go and whatever you choose to do.
- Having hemiplegia should not prevent you from leading a happy and satisfied life - and it'll probably make you quite wise!
- You are not alone. Stay positive and be proud of yourself!

For parents:

- Love and encourage your child - be their best friend but challenge them to try things and be honest with them.
- Seek all the support and information you can. Give your child support and build their confidence. Be happy and your child will be happy.
- Be patient with your child and with yourselves. Do not be angry when your child cannot do things but above all do not give up on them. They can do things but perhaps slower or in a different way.
- Everyone is entitled to grieve over their child's diagnosis but the best gift you can give yourselves and your child is...to accept the disability and love your child for who they are.
- Be positive and do the physio - it pays off. Kids with hemiplegia can be independent, confident and successful.
- It's not your fault.
- Hemi is not the end of the world!!! Be a positive role model, don't wrap your child in cotton wool. Make them "get on with it" - they'll thank you for it later in life.