

Appendix 5.

Surveys January – February 2018

SMA Type 2/3 and 3 ages 18+

Biggest Challenges

Type 3 age 18 – 25 years young adult (one of three siblings with Type 3)

As an individual with almost no upper body strength and being wheelchair bound, I am completely reliant on my mother's support/ care during the day and my father's assistance at night. I suffer constant chest pains and muscular pain and this pain impacts my day to day living. I struggle to find work suitable for my needs. As a result of the all day and night care, my parents have no time to connect socially or manage their own wellbeing. Their full day is dedicated to caring for me and my other two siblings with SMA type 3 and I can see their strength and stamina is gradually reducing as they age. The treatment would help us and also as a result help my parents.

Type 3 age 18 – 25 years mother (of three siblings with Type 3)

Both my health and my partner's is deteriorating, I struggle to manage on a day to day basis and I don't have any help from the NHS and social services to meet my needs. I am expected to provide care for 3 adults (my sons and daughter) for the remaining 22 hours in the day. The fact that I care for 3 adults is overlooked and at times I struggle to get through the day. As their condition deteriorates, the support and assistance they require increases. My youngest has lost all of his independence and it is crippling his self-confidence and emotional stability. My other children are following closely behind. All 3 of them are bright individuals unable to reach their potential or fulfil their ambitions as they are held back by a condition that deteriorates over the time. The hardest thing for all 3 of them is that as children they could walk, the youngest couldn't only walk aided, but my eldest daughter walked independently until 19. It's hard for them to accept their present condition and it's hard for us to see.

Type 3 age 18-25 years father

He is not using a wheelchair. He struggles with his balance and has difficulty walking any distance above 20m due to muscle fatigue. Steps and uneven surfaces present significant challenges. This affects where he goes and how he gets there. Often, he would not be able to make journeys alone. He has significant hand tremors which presents issues when preparing food from scratch. This includes chopping food and using hot pans. Due to mobility issues mentioned above, once a meal has been prepared he must eat it where he's prepared it unless help is available to carry the meal to another room. Getting out and about generally presents problems. The mobility issues mentioned above make it impossible for him to use public transport safely. He often declines invitations to activities/functions/holidays if he is unsure whether he has easy access. He has been subjected to instances of verbal abuse because of his standing position and walking gait. Notwithstanding present legislation, He is prevented from considering many job opportunities because of his physical

restrictions. For example, a recent work placement was severely compromised by the lack of lifts/ramps available at the venue.

Type 3 age 18 – 25 years young adult (one of three siblings with Type 3)

... I am completely reliant on my mother's support/ care during the day and my father's assistance at night. If either one isn't around I panic and get anxious and distressed.... We struggle to overcome each day and dread small changes which can potentially have a large impact on our day to day.

Type 3 age 26-25 years adult

I am dependant and reliant completely on my mother and as her health is deteriorating I find myself not being able to do what I hope to for fear of impacting her health. I struggle to do everyday tasks independently.

Type 3 age 26-35 years adult

The biggest thing is independence, with SMA I have slowly lost more and more independence. I am now struggling to get out of bed myself and can no longer dress the bottom part of myself. I need someone with me to leave my flat as I can't push my manual wheelchair outside, this has affected my social life. I am becoming more and more reliant on my mother but she is also ageing and has had health troubles.

Type 3 age 36-45 years mother

Staying positive while fighting physical and emotional tiredness.

Type 2 /3 36 - 45 years Partner

It's challenging watching my wife not being able to do things for herself or be able to do more for herself. For example, the fact that her hands aren't as strong since it was sore a while back and she had to wait for surgery and then she had lost strength in her hand altogether- she needs her hands for everything so it's hard to see it deteriorate.....

Type 2 / 3 age 46-55 years adult

Physically, I am unable to do anything for myself as all my muscles are that weak now; I cannot walk, stand, transfer, change position independently, hold a pen to write, cannot move or turn over a piece of paper, send a text, use a cash point, clean my teeth, blow my nose, brush my hair, shake your hand, put make up on, scratch an itch, wipe my bottom, feed myself, hold a cup (drink through a straw), cuddle my son (unpaid carer), stroke our pets, draw with a pencil, turn pages of a magazine, sew, etc. I own a personalized signature stamp for signing official documents but require my teenage son, friend or a personal care assistant to actually physically stamp it for me, as I do not have the strength. Emotionally, my severe physical disability continues to have an enormous impact on my life. On occasions my son has been late for School because he has had to stay at home with me until the arrival of a personal care assistant. He has had sleepless nights worrying about me, particularly

when I have been coughing continuously night after night. My son deserves to have a life free from worrying about my physical challenges. My worries and anxieties in relation to my lung function, chest infections, cramps, swallowing and many other body functions and abilities which decrease rapidly with age. It is quite demoralizing, frustrating and degrading to be fed by someone else. Dignity and privacy no longer play much of a role in my life. I am reliant on 24/7 plus care assistance and support...

Type 3 age 46-55 years adult

As the SMA deteriorates it becomes more expensive to buy the equipment that makes living with the condition easier. I have had to take ill health retirement a couple of years ago which has resulted in a significant reduction in income. I have been using my savings to install a stair lift, to adapt a motability vehicle, buy a rolator and to pay for some physiotherapy. There will come a point when these savings will run out. I feel that my life is slowly shutting down as the level of pain increases and what I can do decreases.

Type 3 age 46-55 years adult

Wheelchair dual controlled, Cough assist, Stretches, Driving an adapted vehicle, Assisting me in my vehicle, Assisting me shopping, bank, visiting family/friends, events, campaigns, concerts, physiotherapist sessions, Assisting during the night, Cream application, Bathing, Hair washing, Make up application, Hair styling, Brushing teeth, Showering, Stamping my signature on my authorized documents, Using cash machines

Type 3 age 46-55 years partner

Holding down a job while caring for SMA sufferer. Lack of help with things like equipment because you work and try to be self-sufficient. Because the condition changes you adapt your home and think you've thought of everything however something will happen the condition worsens then your back to square one and this often has massive financial implications. Lack of knowledge of medical professionals other than the specialist makes every medical visit so frustrating for carer and sufferer.

Type 3 age 46-55 years adult

Most days I have some form of pain in my joints (mainly my legs) No longer have the confidence to go out alone

Type 3 age 56-65 years adult

Feel liked loosing independence as the condition is progressing. Need more assistance from my husband for everyday tasks. Frightened of falling as cannot get up unaided. It is becoming increasingly difficult to do tasks that I once took for granted. Leaving the house unaided, I am now finding it impossible to go out alone. My husband assists with getting my wheelchair in and out of the car.

Type 3 age 56 – 65 years adult

I am always uncomfortable and exhausted so am finding it increasingly difficult to participate in daily activities. I used to be able to do everything without help and enjoyed dog walking with a mobility scooter, driving, swimming, gardening and part time work. However, my condition has recently deteriorated rapidly so I am no longer able to do any of these things without help. I also now need help with personal care which I find embarrassing and upsetting. I am fearful of the future and depressed about my situation most of the time.

Type 3 age 56-65 years partner

Having to maintain constant attendance 24/7 to support all their needs can be very wearing and physically demanding....It can also be emotionally draining when you feel the pressure of caring is all on yourself.

Type 3 age 56-65 years adult

I cannot leave the house unaided, this restricts my partner to what he may like to do or has to do, and it restricts me from having free choice of what, where and when I do things that I would like to do. I have totally lost any independence that I once had and I have to rely on my partner for everything. This obviously causes a strain on our marriage, as I have lost abilities gradually over a number of years I have found it very difficult to accept, and it has caused me anxiety, panic & depression...

Type 3 age 66+ partner

For me - Showering; washing clothes; all the car driving; seeing my husband steadily worsen is preying on my mind.