

## Views about access to psychological support Comments in response to survey questions April 13 – 19<sup>th</sup> 2018

### 1. Have you ever felt the need for emotional / psychological support in relation to managing the impact of your child / young person's SMA?

As my son has gotten older he has a wider gap between him and his peers - he sinks low as his social group has dissipated. They attend parties, hang out, go into town and they don't invite him as he needs a carer to assist. He has also become ashamed of his body and dislikes any attention when out and about. We have all the troubles of a teenager times 100 and we don't have the tools or vocabulary to help and we struggle too. **Parent of young person age 15 – 17 years with SMA Type 2**

I need extra support usually around assessments/reviews and especially if they all happen close together. Trying to get the PHB up and running has taken nearly 3 years. **Parent of young person age 15 – 17 years with SMA Type 2**

When I first received the diagnosis, it was very hard mentally to accept that my child had this condition. I remember walking out the doctor's office in huge tears and my daughter asking me what was wrong. I couldn't even reply to her due to the huge shock of being told your child will never walk and will slowly get weaker as time goes on. It was extremely hard. **Parent of child age 3 – 4 years with SMA Type 2**

In preparation for my spinal surgery. **Young person age < 17 years with SMA Type 3**

I have depression and can get suicidal. **Adult age 26 – 35 years with SMA Type 1 / 2**

When you get older and friends start having families and being less available it can impact you if you are struggling to achieve the same. When social services and access to work play silly games with cutting benefits it can drain you, worry you - the fear of building up a life for a social worker to destroy it in seconds is frustrating. **Adult age 36 – 45 years with SMA Type 2**

I went to a mainstream school, which gave me a great education, but I was the most severely disabled person at the school, and did not have any peers who could understand my situation. I had lots of friends, but felt very isolated. Especially as a teenager, I had a difficult time coping with my able-bodied peers, and feeling that I was not on the same life journey... i.e. learning to drive, having a girlfriend, becoming more independent from parents, etc. I coped, and went to university, but I struggled emotionally. As a young adult, I did not even see myself as a disabled person, and I did not know how long I would live. Finding the Jennifer Trust (*now SMA Support UK*) at about age 20, was really important for me, and I made friendships with other disabled people. From 21-25 I went through various sessions of counselling, and even hypnotherapy, which definitely helped. I then trained in counselling at my local college, and obtained a certificate in counselling. **Adult age 46 – 55 years with SMA Type 2 / 3**

Yes, I have recently experienced post-traumatic stress following a hospital admission. **Adult age 18 – 25 years with SMA Type 2**

I am getting older and weaker now. I am constantly worried about my deterioration. **Adult age 18 – 25 years with SMA Type 2**

I've had anxiety and depression for 5 years now. **Adult age 18 – 25 years with SMA Type 2**

Have had to access counselling to cope with stress of recruiting and managing carers and dealing with funding worries. **Adult age 26 – 35 years with SMA Type 2 / 3**

I received much counselling support as child which ended when I became an adult however I have little need for it now. **Adult age 18 – 25 years with SMA Type 2**

Diagnosis time was devastating and so little known of the condition from the local children's hospital that only negative prognosis given. My marriage of 25 years ended 8 years ago and I now find myself caring for my son pretty much full time because the quality of male care workers is not very good and not many people apply for the job when advertised. I could do with support from someone who understands what it is like caring for someone 24/7 who is intellectually very able but cannot find a job in his chosen field. **Parent of adult with SMA Type 2**

One of the things that is most frustrating is the lack of support from social services following the impact of reduction of services. Living with this condition is exhausting both mentally and physically. As a parent you have to keep yourself together. **Parent of adult with SMA Type 2**

Talking to someone who doesn't understand the everyday life of living with a neuromuscular condition is difficult. They don't understand. It makes looking for help difficult. What's the point they have no idea what it like, always referring to the 'normal' 'we don't live a normal life! Not worth it just keep going!! **Parent of adult with SMA Type 2**

The time of diagnosis to bereavement was very short so there was no time to contemplate emotional support in relation to managing the impact of SMA. **Parent of child with SMA Type 1 Bereaved (2010-2014)**

## 2. How did you find the counselling or psychological support you accessed?

My GP was very sympathetic and referred me locally. This meant having an assessment on the phone by someone from local services. However, as soon as I was not deemed to be in any way 'high risk' or severely depressed, I was not able to access any one to one support at all. I was told to attend a local group for 'anxiety' but this was not remotely appealing or what I needed. My apparently healthy 14-month-old child had just been diagnosed with a life limiting condition which meant he would never walk and would face physical challenges and vulnerabilities for the rest of his life. This meant I needed very specific support with these issues, and getting my head around what this might entail for all the part of our lives which would be affected. A general group discussing anxiety was never going to fit the bill for something so personal and so specific, and so I didn't get any help on the NHS. Fortunately, I was able to afford to go privately and therefore I sought out my own counsellor (at

London prices), but I am very aware this is not something everyone in our position would be able to do. **Parent of child age 9 - 10 years with SMA Type 2**

Great Ormond Street Hospital sent me the first time. The second time, it was via health services in the local hospital. **Young person < age 17 years with SMA Type 3**

My most successful sessions were through hypnotherapy which I discovered through an advert in the local newspaper. I did also access counselling services as a post-graduate studying teacher training, and also again (I think) through social services I accessed one session of counselling, but it wasn't very useful. **Adult age 46 – 55 years with SMA Type 2 / 3**

I got seen really quickly by the counsellor in my GP practice. But his knowledge of SMA was non-existent. This made my treatment really challenging. I had to explain 25 years of SMA as well as my current issues. **Adult age 18 – 25 years with SMA Type 2**

Through work and also through private health insurance. **Parent of adult with SMA Type 2**

Had to go privately. **Parent of adult with SMA Type 2**

Was difficult enough to ask for help but was so frustrating. The friend of a friend was better help she had a disabled sister. **Parent of adult with SMA Type 2**

### **3. What in particular made you access counselling or psychological support?**

Around times of surgery, illness and management meeting/issues of either health, social or education - usually trying to fight for services or equipment, sometimes all at the same time. **Parent of young person age 15 – 17 years with SMA Type 2**

I don't feel that I ever came to terms with my child's diagnosis. **Parent of child age 9 - 10 years with SMA Type 3**

I think the 12 months after our son's diagnosis was the hardest time we have had. This is because our whole lives were tipped upside down and everything was in question - where we would live, whether we could continue to work, how we would manage financially if we couldn't, whether we could have another child (this is a genetic condition with a one in four chance of any subsequent children being affected), families who were very upset and so on. We were also very afraid that something would happen to our son and alongside the practical questions, there were also a lot of emotional hurdles - finding out your child is very vulnerable, and being powerless to change this, strikes at the very core of your being. You have to find a way of managing the fears you have about your child's health and 'manning up' (for want of a better phrase) for the journey ahead so you can give them the best possible life experiences. This is also the time when suddenly you have to get used to lots of different agencies becoming involved in your lives. This loss of privacy can feel very intrusive, and the

bureaucracy and level of competence of some of the individuals involved can add stress to what is already a very difficult time. **Parent of child age 9 – 10 years with SMA Type 2**

I've been diagnosed with stress and anxiety, currently on antidepressants. **Parent of child age 9 – 10 years with SMA Type 1 / 2**

I had a lot of psychological support around the time of my spinal fusion surgery at GOSH. **Young person < age 17 years with SMA Type 3**

I was and can still get suicidal **Adult age 26 – 35 years with SMA Type 1 / 2**

I felt like I was fed up of being alive. **Adult age 36 – 45 years with SMA Type 2**

Above everything else, I wanted to be loved, so first I had to start to love myself... **Adult age 46 – 55 years with SMA Type 2 / 3**

A serious lapse in mental health. **Adult age 18 – 25 years with SMA Type 2**

For me, the amount of mental strength I need to be able to deal with your own condition and other personal matters is hard but I can do it. But then needing people to help me in every way for everything I need & want, the way I want things done is mentally exhausting and frustrating. My brain is just exploding with what I need to do, what I need somebody to do for me, when I need that done, how I need it doing, and it goes on. I have no mental down time apart from sleep. **Adult age 46 – 55 years with SMA Type 2**

After separating from my child's father, it all got too much. Second time after my father (my rock) died. Felt totally alone. **Parent of adult with SMA Type 2**

**4. What in particular made your child / young person with SMA access counselling or psychological support?**

Anxiety. **Parent of child age 9 - 10 years with SMA Type 1 / 2**

Low in mood, then when an operation is imminent. **Parent of young person age 15 – 17 years with SMA Type 2**

She was very angry and needed some support. School recognised this when I spoke to them. **Parent of child age 9 - 10 years with SMA Type 3**

Panic attacks, taking over responsibility for own care and health. **Parent of young person age 15 – 17 years with SMA Type 2**

## 5. How easy was it to for you to access the counselling / psychological support?

Not a long wait. However, the first person I saw was not very helpful and I needed to access someone with more experience, which I eventually did. **Parent of young person age 15 – 17 years with SMA Type 2**

My son was referred to CAMS when he became very depressed about his SMA a few years ago but the waiting list was so long he didn't want it when it became available. **Parent of young person age 13 - 14 years with SMA Type 1 / 2**

I had to wait a few months for a telephone assessment. When I had this she then referred me to face to face counselling which I am on the waiting list for. Unsure how long the waiting list is. **Parent of young person age 9 - 10 years with SMA Type 3**

I was not able to find help without sorting it out myself and paying for it. **Parent of child age 9 - 10 years with SMA Type 2**

I was referred for CBT by GP half a year ago, still waiting for an appointment. **Parent of child age 9 – 10 years with SMA Type 2**

GP waited months Friend of a friend was via church but she had limited time. **Parent of adult with SMA Type 2**

Recently, when going through the local hospital, the doctor who was supposed to refer me, forgot to put me on the waiting list. Two months later we queried why there had been no response, and from that point it was quite fast progressing. **Young person < age 17 years with SMA Type 3**

My GP said there was a 16 week wait so I had to find an alternative. **Adult age 26 – 35 years with SMA Type 2**

It was easy as a postgraduate student, but not so easy as a young adult. **Adult age 46 – 55 years with SMA Type 2**

It's difficult to find somewhere with an accessible practice. **Adult age 18 – 25 years with SMA Type 2**

I asked the hospice for counselling during my baby's illness but they said it wasn't available till post bereavement. Then when I met her after my child's death I knew she wasn't the right person for me. I then paid for a private therapist. I also saw someone privately briefly during his life to try and just process what was happening. **Parent of infant with SMA Type 1 bereaved (2015 -18)**

**6. How easy has it been for your child / young person with SMA to access counselling / psychological support?**

It was over a few months but it has now stopped. Which she is very disappointed about as she enjoyed her sessions. **Parent of child age 9 - 10 years with SMA Type 3**

**7. Can you tell us more about who has provided your counselling / psychological support?**

Key Lead Professional has been critical in progressing all round support for the family. Psychologist - as and when I feel low, I can contact her via email and make an appointment. **Parent of young person age 15 – 17 years with SMA Type 2**

Access to the building in which the counselling took place was impossible. I had to travel 1hr 30mins to get to my appointment in an accessible office. **Adult age 18 – 25 years with SMA Type 2 / 3**

**8. Can you tell us more about who has provided your counselling / psychological support?**

Hypnotherapist. College counsellor, Social worker (who wasn't very good) **Adult age 46 – 55 years with SMA Type 2 / 3**

It was a lady counsellor for disabled people in general from our local hospital. This service is not available any more. **Adult age 46 – 55 years with SMA Type 2**

I received psychological support from carers at the hospice I went to as a child. **Adult age 18 – 25 years with SMA Type 2 / 3**

Local children's hospice have been the primary source of support, along with SMA support UK. **Parent of infant with SMA Type 1 bereaved (2010-14)**

Counsellor at hospice and CBT counsellor via GP. **Parent of infant with SMA Type 1 bereaved (2010-14)**

I saw a general counsellor for a couple of sessions during my babies illness then a specialist bereavement counsellor after he died then a psychotherapist when he retired. **Parent of infant with SMA Type 1 bereaved (2015-18)**

**9. In your view, have your counsellor(s) or psychologist(s) been sufficiently knowledgeable about the impact of long - term progressive conditions like SMA?**

My counsellor was not particularly knowledgeable about SMA but this didn't matter. She did understand how stressful it was to try and renegotiate your whole life in the midst of a trauma, and the fact I saw someone qualified meant she was able to make a real difference with strategies and

CBT techniques I have used ever since. I only saw her for a year but it really helped to have someone to speak to who did not have any agenda or view. **Parent of child age 9 - 10 years with SMA Type 2**

Hospice had counsellor knowledgeable with impact of life limiting condition, but the service was stopped due to lack of funds. **Parent of child age 9 - 10 years with SMA Type 1 / 2**

I've had 3 different ones some were better than others. **Adult age 18 – 25 years with SMA Type 2**

It took so long to explain about how the condition affected my child. Then how it affects us as a family. **Parent of adult with SMA Type 2**

**10. How helpful has your counselling / psychological support been?**

The hypnotherapy was extremely useful to me. The counselling less so - but it could have been more useful if I had seen someone with more experience pertaining to disability. **Adult age 46 – 55 years with SMA Type 2 / 3**

Thinking about my past experiences. The thought of going to look for help is too exhausting. I think I would just try to battle on. But I only know that this only works for a limited time. **Parent of adult with SMA Type 2**

I saw a counsellor approximately 15 years ago but I don't think it really helped. I might as well be chatting to a friend who would probably give me more advice. **Adult age 46 – 55 years with SMA Type 2**

A 15-minute phone call and then referred to a website about CBT, no follow up at all to test whether it had been effective, and very little discussion with psychologist to understand the underlying problem, nor a discussion whether the challenge of a disability had played any part in the need for a referral. **Adult age 46 – 55 years with SMA Type 3**

**8. What, if any, other sources of emotional and psychological support have you accessed?**

We have asked for help, we are on a waiting list apparently but as he hasn't tried to take his own life we aren't a priority nor can we afford private counselling on a regular long-term basis. He has accessed counselling in school but it's just somewhere to talk with NO advice on how to deal with his

emotions. I sought counselling, which we paid for, 2 years after he was diagnosed and was sinking which helped as it gave me tools to understand what I was feeling and how to get on top - this isn't available for my son. **Parent of young person age 15 – 17 years with SMA Type 2**

Occupational therapist. **Adult age 56 – 65 years with SMA Type 3**

I try to keep any emotional issues to myself and not involve others. **Adult age 56 – 65 years with SMA Type 3**

I once went to the Samaritans. **Adult age 46 – 55 years with SMA Type 2 / 3**

Social media groups. **Adult age 46 – 55 years with SMA Type 3**

I do not want to burden my family with the distress caused by SMA, and as the person affected sometimes it feels like the emotional needs of your family and caregivers is more important. Your mood affects your interaction with those around you, and so care relationships can become strained if you share thoughts and feelings. Professionals are ALWAYS focused on the medical and physical implications of the condition not the emotional impact. SMA friends can be helpful, but sometimes you just get to a point where you're both just wallowing in the bad stuff. **Adult age 18 – 25 years with SMA Type 2**

Local children's hospice has provided family counselling. **Parent of adult with SMA Type 2**

Family and friends has been my main support in later years via friends made through MDUK and SMA UK but this has been through Facebook etc Group support which became a stage for 'know it all types' often very scary advice being given. I had to withdraw from it all. So, I could keep myself strong. **Parent of adult with SMA Type 2**

**11. Looking back at how you have managed the impact of your SMA, would you have wanted better access to counselling and psychological support?**

It might have helped but I've got a feeling they would have made me a weaker minded person and reliant on others for emotional support. **Adult age 26 – 35 years with SMA Type 3**

It would be amazing if people working in mental health had some basic understanding of SMA. It would increase the understanding of the common challenges as well as influence treatment decisions. Both talking therapy and medication. **Adult age 18 – 25 years with SMA Type 2**

Yes, I/we need someone who knows about our disability and can support us throughout our lives. **Adult age 46 – 55 years with SMA Type 2**

I've been through some really frustrating and upsetting situations with care agencies and councils. Nothing has come easy and everything always comes back to "if I didn't have SMA..." or "if I was stronger...". I have tried reaching out to family but this is a very personal dilemma and it can upset

them too. Therefore, an external professional would be great. **Adult age 18 – 25 years with SMA Type 2**

Counselling with specific knowledge of the condition would have been helpful. **Parent of infant with SMA Type 1 bereaved (2010 – 14)**

**12. Looking forward at how you will continue to manage the impact of your SMA, would you have want access to counselling and psychological support?**

If I considered putting yes, that would probably mean I needed it now. It's impossible to know what's going to happen to me in relation to my condition so I can't put 'no'. **Adult age 26 – 35 years with SMA Type 3**

Absolutely - the SMA as a progressive and limiting condition alongside working presents multiple challenges and there is no support to help people mentally deal with the change and ever-increasing limitations that come with a progressive condition. **Adult age 46 – 55 years with SMA Type 2**

A lot of my past dramas have left me feeling very unsure about my independence in the future - both in terms of where I can live, where I can work, who will be assisting me and if I will get physically weaker. All of these things need addressing as they arise. **Adult age 18 – 25 years with SMA Type 2**

**13. Is there anything else you would like to say about the need for or access to counselling or psychological support in relation to SMA?**

Currently both my husband and I are on anti-depressants to deal with SMA and the impact to our son, our family our lives, on top of the usual dramas of life - mortgages, jobs, ill health - we have SMA and we worry about his health, if he is alone in the school day, what he will do after A levels, next hospital appointment, next health meeting, next adaption, planning a holiday what will we need is the insurance adequate will he enjoy it .. what will he enjoy what can we all do together as a family .... but ultimately is he ok. **Parent of young person age 15 – 17 years with SMA Type 2**

I am uncertain of the access to this support after my son turns 19. **Parent of young person age 15 – 17 years with SMA Type 2**

What I am finding out the diagnosis was hard - but it is an ongoing hardship as the disease progress and the emotional impact on the parents is huge. Would very much appreciate to have support from a counsellor that understand the nature of SMA because - SMA has a huge impact on my emotional side of life at time takes us to a very low level. Specially when you see your child deteriorating and succumbing to the disease without no treatment at present. **Parent of child age 5 - 6 years with SMA Type 2**

I think around particular ages. Secondary school, college, Uni, Transitions and events like illness. **Parent of young person age 15 – 17 years with SMA Type 2**

We have received some support from a local charity but it would be good to have more specialist support from people that know about muscle wasting conditions. Especially with SMA as they are usually such happy and social people and come across as very able when in their power chairs when in reality it is very tough and they tend to hide their worries well. **Parent of child age 7 - 8 years with SMA Type 2**

It becomes more difficult to cope emotionally with SMA as you become older and less able to do things physically and therefore rely more on help from others. **Adult age 56 – 65 years with SMA Type 3**

I think the hardest part, is the transition from child to adult. Any support given has got to be handled in a delicate way. You do not want to stigmatise the young person. At that age I was very sensitive to being different from my peers, and I would have struggled to ask for the help I needed, or even accept that I needed any help. **Adult age 46 – 55 years with SMA Type 2 / 3**

The support I've been offered in the past has been from professionals who had little experience in long term, life limiting conditions in general. It often feels like counselling is offered to people to work through particular situations or feelings in a short amount of time. I was given 6 sessions to discuss and manage a lifetime of self-harm, depressed thoughts, denial and fear for the future. Towards the end of the sessions, I began lying about my emotions and just 'making do' which is a common theme in people living with SMA. I believe that we need specialised support without a limit on how many times we're able to access it. Our problems aren't going to go away and we need support that isn't just created to fix problems but manage them. **Adult age 18 – 25 years with SMA Type 2 / 3**

Our current therapists do not have the expertise and understanding of what it is like to live with SMA. Although they contend with depression, anxiety and PTSD the involvement of our condition makes everything much more complex and harder to process. **Adult age 18 – 25 years with SMA Type 2**

Cannot underestimate the added stress and anxiety that comes with employing carers, working while continuing to juggle all normal aspects of life. People without a disability get tired and stressed by life! **Adult age 26 – 35 years Type 2 / 3**

More awareness on how it is necessary and ok to ask for that help **Adult age 18 – 25 years with SMA Type 2 / 3**

The process of getting counselling should be easy to access and from someone who has some understanding of disability and the impact on family life, not someone who is wanting to do tick exercises and gather statistical evidence that you have benefitted from the course. **Parent of adult with SMA Type 2**

Parents ease of access to trained psychological therapy is critical to keep families together and ensure the optimisation of children and young adults suffering with sma. **Parent of adult with SMA Type 2**

There is a real need for support because it is a continual battle to access funding for support with every day things such as personal care and continually having to justify everything is emotionally draining. My daughter's agency left her with minimal care because they couldn't replace the carer who left. She was crying to me on the phone because the social worker said to her "can't you just go home"! Instead of helping she didn't want to know. She didn't care that my daughter was left vulnerable and not knowing when she could go to the toilet. This would have been a great time for access to emotional support to help her through it. **Parent of adult with SMA Type 2**

Some kind of information has to be ready for counsellors etc so they have a better understanding. **Parent of adult with SMA Type 2**

Counselling with someone who has knowledge of the condition would be helpful. I often came out feeling they didn't truly understand what I meant or how I was feeling. **Parent of infant with SMA Type 1 bereaved (2010 – 14)**

If I hadn't have been able to afford to pay privately I would not have been able to find a long-term support I was happy with. I think more support should be offered during illness. Our community nurses were amazing though as we're SMA Support UK. **Parent of infant with SMA Type 1 bereaved (2015 – 18)**