

Couple relationships when parenting a child with SWAN (a syndrome without a name)

Exploring the impact of couples counselling

About Genetic Alliance UK



Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 200 patient organisations.



Rare Disease UK is a multi – stakeholder campaign run by Genetic Alliance UK, working with the rare disease community and the UK’s health departments to effectively implement the UK Strategy for Rare Diseases



SWAN UK (syndromes without a name) is a patient and family support service run by Genetic Alliance UK. SWAN UK offers support and information to families of children with undiagnosed genetic conditions.

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Executive summary

Invaluable – comforting – heard

Dignified – fair – professional

Parents of children with SWAN, when asked to describe the counselling in 3 words

Genetic Alliance UK and Rareminds work to improve the lives of people living with rare and genetic conditions, whether they have a diagnosis or not. The couples counselling provided through their partnership has to date supported 19 couples who have a child with a rare, undiagnosed condition or ‘syndrome without a name’ (SWAN). The counselling service was created specifically for those with a child whose condition remains undiagnosed, because these couples also live with huge uncertainty in the absence of a diagnosis as well as navigating often intense medical and behavioural needs at home.

The headline findings presented in this report are the result of research with couples and the therapists delivering counselling, to explore the experience of parenting or caring for a child with SWAN, and the impact of the couples counselling service.

The research highlights the stark reality of how individuals and families can be affected, and the strain which that can place on couple relationships. Futures must be reimaged and professional support for children fought for. Day-to-day life is turned upside down and quality time with loved ones is squeezed out. The couple bond is placed under intense pressure.

Peer support has its limits and the health and social care system in place to support children does not offer parents professional psychological intervention despite their own wellbeing being critical to that of their children. We found that the couples counselling had a positive impact on parents as individuals, on their communication as a couple, and on other dynamics in the family.

Couples indicated that the fact therapists understood their challenges helped promote confidence and facilitated service uptake.

Therapists reflected on the distinct nature of this client group and the challenges in drawing out the painful but important issues facing the couples. They concluded that part of the value of targeted counselling specifically for this population was in ensuring that couples feel heard, understood and respected. Reflecting on their relationship with the help of a neutral third party allowed couples to develop new ways of thinking about difficult couple dynamics and potential coping strategies. They were helped to mitigate the ongoing impact of uncertainty and trauma, and to grieve for the child (or life) that had previously been imagined.

The situation these parents live with is complex, unique and often extreme in terms of the stress being endured. The Rareminds therapists are building up valuable and specific expertise in order to deliver an effective intervention. Their understanding of how SWAN and rare genetic conditions affect parents is crucial to building a strong working alliance with the couples. The administration of the service – including its online delivery - has developed to offer the substantial flexibility required to fit into the complexity of these couples’ lives. The intervention is however limited by capacity and slots are oversubscribed within hours of being publicised.

We would like to work in partnership with the NHS to explore the potential for offering systematic provision of couples counselling to parent carers of SWAN children as an intensive family therapy with the potential to significantly improve the lives of children with SWAN and their families.

Background

As genomic technology improves and is established within the NHS,¹ more people with rare, genetic conditions are receiving a diagnosis. However, many children with complex syndromic conditions (affecting more than one part of the body, and often including 'global developmental delay' which involves intellectual as well as physical disability) remain undiagnosed. This has become known as SWAN or syndrome without a name. The number of children with SWAN born each year is unclear but is thought to number in the thousands. Genetic Alliance UK runs SWAN UK, the only dedicated support network in the UK for families affected by a syndrome without a name, which currently has 4,000 families registered with it.

The complexity and severity of undiagnosed children's medical needs can place huge stress on their parents and carers.^{2,3} Living without a diagnosis means uncertainty - around, for example, how likely children are to meet developmental milestones such as in speech and mobility, or whether their condition will deteriorate or be life-shortening. Many children with SWAN die in childhood. Being undiagnosed also means a risk of isolation because there is no diagnostic label that parents can use as a foundation to communicate with family, friends and professionals about their child or about their experiences as parents.²

There is a growing body of evidence about the psychological impact of parenting a disabled child, and a smaller evidence base relating to parenting children specifically with rare conditions.⁴⁻⁸ Beyond this, there is little data available about how parenting a child with SWAN can specifically affect the relationship between co-parents or co-carers, but what exists demonstrates the strain of the situation.⁹ We have identified only one study that has evaluated an intensive family intervention,¹⁰ and to our knowledge there are no studies exploring relationship therapy for couples with a child with a rare or undiagnosed condition.

There is ample demand for psychological support. Genetic Alliance UK has worked in partnership with the community interest company Rareminds since September 2021 to provide couples counselling, free of charge, and demand always far outstrips supply. Initially, couples were offered 6 sessions, but it became clear that this is insufficient for this group. Couples now have an average of more than 9 sessions in total.

Aim of the research

The current project aimed to investigate both the perceived impact of parenting a child with SWAN on couples' relationships, and to evaluate the couples counselling, through interviews with parents/carers and with the therapists providing the service.

Findings

1. What do parents say about their experiences with their children?

Parenting a child with special needs

Parents have to re-arrange their lives and re-imagine their futures. They must learn how to navigate 'the system' (health, education and social care) and can find themselves battling to get their child's needs recognised and to secure necessary support. The administrative and caring responsibilities placed on the parents can be huge. It can be an extremely isolating and stressful experience that impacts parents, their relationship with each other and the life of the wider family.

'It's also you have dreams, aspirations before your child's born, that was radically changed'. Parent

'Her [mother's] career trajectory changed slightly...Well it just ended'. Parent

'I felt like very much back then that I was simultaneously the least important but most important person in the house – but it's a really weird space to occupy'. Parent

'I had these red flags but then people were telling me "He's a baby. Babies can be a bit slow in reaching their milestones" so I did feel like I wasn't really listened to, and I felt quite lonely in those moments'. Parent

'You end up fighting battles that I didn't even know... existed, you know, like, I had no idea, just no idea. And so that just brings an enormous amount of strain and stress, you know, onto a [couple's] dynamic that wouldn't have had that strain and stress'. Parent

'We've had our differences before we've had our son, and now that we've had our son, perhaps it's even more highlighting our differences and they are becoming more of an issue'. Parent

'Even in a thing as simple as feeding and just getting up and his emotional dysregulation; everything just takes so much time. So we hardly have any time for, as a family, let alone each other'. Parent

'Her behaviour is extremely difficult a lot of the time. And that has an impact on everyone, you know, our son as well as us, that affects the quality of time that we spend together'. Parent

Caring for the carers

Despite the absolute dependence of children with SWAN on their parents/carers for their care needs, there is no systematic provision of support for the parents/carers. The Rareminds counselling offer is perceived as a validation of their need for support and provides a space to focus on the couple – to allow the relationship to continue as an emotional resource for the child and the parents themselves.

'That's the point that I tried to make to social care as well, I said "but hold on a minute, why can we not talk about the impact on us and our needs because if we're not meeting her needs then nobody is"'. Parent

'When you apply for a social care assessment – and we only got something out of social care on the fourth attempt – they absolutely tell you that none of [the parents'] needs [can be met] – that you can't talk about your own needs or the impact of caring for a disabled child on you at all'. Parent

'...even just the fact that ... [the counselling service is] offered is a validation that actually somebody's listening, somebody is heard and somebody cares'. Parent

2. What do parents say about sources of support, and specifically about their Rareminds couples' counselling experience?

Sources of support

Peer support only goes so far for parents in this situation, and finding appropriate, affordable private therapy is extremely hard.

'There was a specialist playgroup...you learn from other people, but it's not always that supportive, because everybody's got their own battles and everyone's got their own difficulties that they're facing'. Parent

'There's not really that many other people that we can really have these open conversations with. Either they don't understand [or they] may not have the capacity to hear us out on such a sort of deep level, on such a regular basis, or if we do have special needs friends, they also have their own burden as well'. Parent

'Before this was offered to us, I was looking at private options. But it's very difficult to find private options that are specifically for special needs families and for couples'. Parent

'We're already spending most of our, you know a lot of our money on private therapies for [our child]. And so spending money on ourselves [for therapy] seems to be not the priority'. Parent

Benefits of counselling

Couples reported positive impacts of the counselling on themselves as individuals, on their relationship, and the wider family.

'It's definitely helped monumentally'. Parent

'The counsellor has helped me sort of put into words feelings and my emotions that I haven't been able to say myself'. Parent

'[The therapist] very quickly kind of understood our relationship and the dynamics...I think [they] quite quickly got me'. Parent

'I think that's what the couples counselling was useful for, was just recognising and naming and identifying those fundamental differences between us [as parents] and therefore where they were coming out and, yeah, the impact that they were having'. Parent

'I think if we hadn't done it I think we would have had less ability to find a way to be at one, be together and be on the same team'. Parent

'So you always end up in the same stalemate and [arguments] would always be the same kind of thing and we haven't had those in absolutely ages'. Parent

'I think there's definitely been a shift in our dynamic for the better, which I think positively impacts everybody in the family'. Parent

Concerns and limitations

Some of the parents expressed nervousness ahead of the counselling, but quickly settled in. The service has limited capacity which means a cap on the number of free sessions per couple and, for some, a long wait.

'I think I was a little bit nervous, I didn't know, you know, sometimes I think my worry was is it going to rock the boat?' Parent

'It would have been useful to have more. I think if we could have afforded it we would have carried on and done more...- because 6 sessions is actually not very much'. Parent

'I think because we had to wait a year, there was probably a year of where there were more arguments where we weren't able to understand each other'. Parent

3. What do the therapists say about providing the Rareminds couples' counselling?

'SWAN life' is a new landscape for therapists

Despite extensive experience, working with this particular client group was a new landscape for therapists. The depth and intensity of the painful issues in the parents' lives are varied and quite extreme.

'Clients always bring something that you've never heard of before, you know, but yes, it was an unfamiliar space and that's why you need special training I think'. Therapist

'There's that kind of unknown with this group of what's it like to receive a diagnosis and what is it like not to receive a diagnosis. So although they get quite a lot of comfort within the SWAN family [that is, peer support], all the children are potentially very different and that's what's different to working with them compared with other genetic conditions that Rareminds work with, because they're not neatly pigeon holed ... it's the fact that they have hope, they don't have hope, will they get a diagnosis, won't they get a diagnosis, there's so much more unknown within that group'. Therapist

'The first session, when you meet people for the first time...particularly where there isn't a diagnosis - [it can feel] intrusive in asking about the child what is appropriate to ask, what do the couple want to divulge... there is a level of anxiety, their anxiety, my anxiety, because none of us know what we're going to meet'. Therapist

The painful spot – getting to what is uncomfortable for parents to talk about

The therapists' role is to draw out the things the couple do not want to talk about, the 'painful spot', to get them to look together at the unthinkable, without judgement. There is a balance between getting to this in a short space of time, given the constraints of the service, and not pushing too fast or too far.

'The difficult bit was realising or...finding the painful spot for the clients, for the couple, finding the painful spot that was not being spoken about, but got in the way of the couple communicating with each other, the communication tended to be "we don't talk about that"'. Therapist

'With these parents, I found myself homing in on the things that were familiar like ... sexual, marital problems. ... I could see them straightaway and the parents wanted to talk about them. ... I realised I'd actually not asked about their child, about ... symptoms, about anything about the child.... So I had to turn myself around, if you like, and say "OK, now tell me about the bits you don't want to talk about"'. Therapist

'And that complex, sort of a very powerful, ambivalence which they had around their children that it was not the child they 'wanted' but it is the child they have and that brought some of the parents to their knees in terms of the conflict that that evoked'. Therapist

Power of therapy to help

The therapists have a strong sense of the value to parents of being heard and validated, and this results in very engaged and constructive sessions.

'It's been very effective in enabling people to feel back to that word 'heard', heard, understood, respected and responded to and enabling them to feel that they've been known and that they can talk about the most terrible thoughts and feelings'. Therapist

'They're often very, very engaged – they want to work and ... they get a lot from it, because they're not having to fight for it, unlike everything else in their lives. And I suppose it's also about somebody acknowledging the position that they're in and hearing them without fighting them'. Therapist

'They said 'they're terrible things and we say how can we keep on living like this, how do we do this' and I say 'it's very hard, very hard to feel that you're living in a situation which is so unremitting'. But they were able to admit that they were at their rock bottom at the time'. Therapist

Conclusions

Looking after a child with SWAN who is utterly dependent on their parents/carers is an isolating and stressful experience that affects parents, their relationship with each other, and the life of the wider family. There is no systematic provision of counselling or support for parents/carers to help their relationship continue as a practical and emotional resource for their SWAN child, siblings and the parents themselves, and it is hard to find appropriate and affordable private therapy. Couples who were able to access couples' therapy through this project reported positive impacts on themselves as individuals, on their relationships, and on their wider family. The current project has limited capacity and we are keen to secure funding to provide further couples counselling. Ultimately, we would like to work in partnership with the NHS to explore the potential for offering systematic provision of couples counselling to parent carers of SWAN children as an intensive family therapy with the potential to significantly improve the lives of children with SWAN and their families.

Methods

Ethical approval for the study was granted by Manchester Metropolitan University research ethics committee (Ethos ID 50777). Semi-structured interviews were carried out online with a) 3 couples who had completed a course of at least 6 SWAN couples counselling sessions delivered by Rareminds (each couple attended a single interview together), and b) 3 therapists who had each provided at least 4 full courses of the SWAN couples counselling. For this report a thematic analysis approach was taken to assess the views of the parents/carers and therapists about the experience and value of the service. Potential participants were identified and emailed by the Clinical Director of Rareminds from their records. Only invitees who accepted the invitation and then shared their own contact details with the research team at Genetic Alliance UK were eligible to take part. Genetic Alliance UK carried out all the interviews and the analysis for this report. Evening interviews were offered to increase accessibility for parents and therapists outside of normal work and school hours.

The participant information sheet included signposting to Rareminds, Samaritans, Mind and SWAN UK.

Participants provided verbal (recorded) consent prior to participating in the interview, including specific consent to the use of anonymised quotes. Participants were free to withdraw at any point up to 2 weeks post-interview. Interviews were audio-recorded, and anonymised, and verbatim transcripts were prepared from the recordings.

All information and data collected during this project is strictly confidential and will only be used for the purpose of this study.

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