



# The impact of RARE disease on sibling experience

Impact report



**ALEXION**<sup>®</sup>  
AstraZeneca Rare Disease

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## Special thanks

This report has been created thanks to 52 incredible young siblings, aged 8 to 25, from families affected by rare disease, without whom this work would have been impossible.

We would like to thank each participant for their courage and candour in sharing their most personal insights and experiences. Their willingness to broach difficult conversations and share often unsettling aspects of their lives provided us with a rich, first-hand perspective into the unique challenges they face. We feel immense pride in the way these remarkable young people conducted themselves and supported each other during this study by validating their peers' experiences as they found and shared common ground.

We hope the insights within this report will be a launch pad for greater conversation and action around supporting young siblings and carers, and we feel sure that the legacy of their contribution will shape the landscape for future generations of rare siblings.

# Introduction

**RARE** [adjective] **Sibling** [noun]

reər /'sɪb.lɪŋ/

[1] loyal protector

[2] steadfast advocate

[3] devoted ally

[4] young carer



Life with a rare disease can undoubtedly be challenging, beginning with the road to diagnosis, which is typically long, confusing and exhausting. Worries about health, treatments, finances and the future can dominate. Many rare conditions are life-limiting with complex and degenerative symptoms, and the majority have no effective treatment or cure. Most rare diseases are diagnosed in childhood, and many are genetic. A rare disease diagnosis affects not just the individual but the whole family. It inevitably alters family dynamics and can completely change the life path a family had planned and set out on. The impact and burden are felt by all.

While the effects on the individual and the parents are perhaps more apparent, siblings also carry the weight of rare disease on their shoulders, and their lives are impacted in many ways by the challenges of living in a rare family. They regularly have plans changed, miss out on opportunities and have to respond to a barrage of questions and often unkind comments from their peers, all while accepting the responsibility of caring for, and worrying about, a sibling.

This project, supported by Alexion, AstraZeneca Rare Disease, aims to give a voice to RARE siblings. To find out what impacts them most, understand their individual and collective experiences and determine their unmet needs. These are personal insights from young people living each and every day with RARE embedded into the fabric of their family life, who want—and deserve—to be recognised, supported and heard.

Often overshadowed, RARE siblings have to quietly persevere amid the many challenges RARE families face. Yet this group are the fiercest protectors and most loyal defenders of their siblings. They love and care for them, champion and advocate for them.

**They just want to be seen and heard.**

**This study comprises insights from 52 RARE siblings split into two age categories: 23, aged 8–16 and 29, aged 17–25, alongside facilitating carers. Insights were captured in June and July of 2022. The participants are from the UK and USA and represent over 35 different rare conditions.**

# Executive summary

RARE siblings are unique individuals with extra challenges, responsibilities and limitations in their lives. The demands and burdens of a rare disease can unfortunately mean this group is often overlooked. At times it can seem like everything is about their sibling with a rare condition, affecting every family decision made and everyday living. RARE siblings often can't do things that other families or their peers do. The needs of their affected sibling may mean socialising and having friends over to visit is difficult. They can regularly miss out on 'the ordinary', and simply making plans for tomorrow is challenging.

Parents are generally stretched to their limits caring for a child with a rare condition. Understandably, this can mean RARE siblings yearn for more attention and some one-on-one time with their parents.

While RARE siblings are generally not the primary carer, some responsibility for care and support still features in their young lives to varying degrees, which only increases with age and maturity. They may be required to supervise their sibling, help them eat and dress or take them to appointments. Some can experience physical harm from their sibling, or they may be kept awake at night, which then affects their ability to concentrate at school or work the next day. It may prove difficult to secure full-time employment with the demands of caring for a sibling with a rare disease.

The effect on the mental health of RARE siblings can be profound. They worry about their sibling, parents or themselves getting ill

or dying. It can be heart-breaking to watch a sibling in pain or deteriorating. They inevitably have questions and fears about the future, about their sibling's prognosis and about the responsibility for care once their parents are no longer around. While fears about health and the future can affect everyone, with RARE conditions, these concerns often seem more pressing.

It can be emotionally draining for a RARE sibling to constantly field intrusive questions and endure harsh comments and bullying aimed at the person they feel most protective of. A lack of awareness and tolerance can greatly impact RARE siblings.

While the younger group of RARE siblings certainly find aspects of living in a RARE family challenging, they have a propensity to celebrate the positives. As RARE siblings get older and the responsibilities increase, the burdens of RARE have a greater impact on their mental health and on their expectations for the future.

Accessing vital support to deal with the emotional effects of having a sibling with a rare disease can be difficult, with little available by way of a structured pathway for support. But it is clear that more is needed to protect and sustain this group of young people. They demonstrate such tolerance and empathy through their experiences with RARE. They love their siblings and are staunch advocates. They just need to be seen, valued and supported. And just sometimes, ***it needs to be about them.***



# Meet George

George, who is 27 years old, is the primary carer for his 13-year-old sister who has complex health needs, including autism and diabetes. The family receives no external in-home care provision, meeting all of her needs as a family. Although George is the primary carer, he's supported by other family members when needed; his parents must leave the home daily for work.

"Everybody has to contribute to the work of taking care of our sister, but it is my main job and responsibility. My relatives call me occasionally to advise or help me if I am in serious need. However, it was decided that I should stop going to college, where I was studying a degree in engineering, to take on her care so that my parents could continue to work."



**"My sister needs me, and she is more important to me than my education."**

"Being a carer for his younger sister means meeting all her daily needs, including feeding and bathing, which can be challenging. "At times when she is in pain she can react badly and take it out on me verbally and physically (often with choice language). This can be tough, but I know it's because of the pain. I have learnt to forget it and go on with my duties."

Spending time with friends is hard, and George takes the opportunity to sneak out of the house when his older siblings or relatives are visiting, giving him some respite. "This is easier to do when she is asleep, otherwise she will want to know where I'm going, and why I'm leaving her. Often, I will come back early because I know she prefers it when I am there. My friends know my situation and they check on me and bring me goodies. On the weekends when my mum is home, she'll give me some money and encourage me to go out with my friends to chill."

As George watches his peers move on with independent lives, he remains committed to his care role. "I believe you are successful with your family by your side. And my sister's health is more important to me than anything. People need to understand that young caregivers who help someone in this critical condition are—well, for me, at least—experiencing one of the best parts of the human experience. If only everyone understood how it is to take care of someone in this condition. Care and time is the only thing you can afford to give them: giving them money, giving them anything material will not solve the problem. But showing them love and care will help them a lot. This brings you a level of closeness you cannot otherwise experience."

**"There are times that my sister won't eat if I'm not around. My care and attention help her considerably but that does impact on what I can do outside the home. I would love to travel abroad, but even going to a football match can be impossible because of my sister's health, so I have accepted that for now this isn't going to happen."**

Meeting a life partner can be difficult for young people with such significant care responsibilities, but George is clear on how this fits into his life. "Let me be honest. Right now, I think of having my entire life caring for my sister. I don't go to work—this is my role. If a partner really loves me, they must show that care for my sister too."

When asked what he would like others to know about being a young carer, George said he hopes that studies such as this will help raise awareness to allow others to see how difficult caring can be, but also how rewarding. "It is all about patience—nothing good in life comes easy. So, taking care of your family is part of your experience that you will never forget. And also, for me, because I'm a Christian, I think of my sister as a blessing to me."

# Recommendations

Through the invaluable insights provided by these RARE siblings, these are our recommendations for supporting and nurturing this unique group of young people:



1.

## Facing the future

Training and education for parents and siblings on how to open up and facilitate conversations around the future and what will happen when the parents are no longer around or able to assume primary care responsibilities.



2.

## It's all about them

Tangible ways to make it just about the RARE sibling. Protected one-on-one time with their parents in the form of redeemable vouchers which children can exchange for quality time with parents—helping initiate conversations and create time and space for connection.



3.

## Improved school support systems

Improved support pathways at school in the form of a counsellor or designated member of staff to talk to. Increased understanding that RARE siblings may be tired because their sibling kept them awake or was hospitalised. Sensitivity to worries RARE siblings may be experiencing and a safe and calm space for them to go to decompress.



4.

## Time with 'those who know'

More opportunities to spend time with other RARE siblings in fun settings, such as on camps and days out, can help to share and ease the burden, and help RARE siblings to not feel so alone. It can be invaluable to be surrounded and supported by other people who experience and understand the same challenges, fears and uncertainties. They may also get to experience an activity or day out they otherwise wouldn't get to do because of their sibling.



5.

## Awareness

Helping to raise awareness of the challenges and issues that affect RARE siblings. A conference poster and shareable materials would aid in educating advocates and charities. Collaboration with existing programmes to help increase visibility and reach would also be beneficial.



6.

## Clinical trial education

Educating RARE siblings on what to expect when their brother or sister takes part in a clinical trial with simulated experience. Managing their expectations around possible outcomes and the obligations trials place on parents, which will affect their availability.



7.

## Mindfulness programme

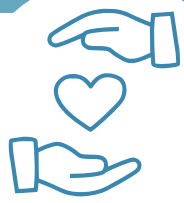
Many RARE siblings may have home lives that are hectic or at times chaotic, and they may be very uncertain and fearful about the future. Providing safe spaces and resources to help them regroup and relax can help with promoting positive mental health. Resources such as mindful colouring-in, journaling, yoga and art therapy would provide mental respite.

# RARE siblings: ages 8–16

While having a sibling with a rare disease brings its own unique set of challenges and burdens, it shouldn't be forgotten that this is just one part of who a RARE sibling is. Ultimately, they are still someone's brother or sister, with whom they argue, laugh, play and spend time.

Many RARE siblings find being in a RARE family rewarding and they have an increased sense of empathy, tolerance and acceptance of other people. When RARE siblings were asked to use five words to describe having a sibling with a rare disease, the most common word was **fun**. While the challenges are unique, so too is the bond between these siblings. Like life itself, there are ups and downs, good days and bad, and living with RARE certainly embodies life's rollercoaster of experiences.





## Young caregivers – a role of responsibility

Having RARE in the family does present family members with additional challenges, concerns and burdens, and this is especially true for RARE siblings.

While not the primary caregiver, these RARE siblings, consciously or not, assume the role of caregiver in some form, be it entertaining and caring for their sibling, helping with their medication or calming them down after a seizure. These young people take on a role of significant responsibility and many parents rely on them to do so.



75%

of RARE siblings help with the care of their sibling

50%

of RARE siblings consider themselves to be carers

“I remind my brother to be safe and tell him to stop doing something that might hurt him. I help him do things he can't do.”

“Sometimes I'm asked to look after my brother if my parents need to do something else. And I'll help by fetching things that are needed for him. I help him walk or push the wheelchair when we're out.”

**“It makes me tired because sometimes I have to shout quite a lot in one day, because when my sister's really wobbly, she has quite a lot of seizures, and if mum and dad aren't in the room, I have to shout for them. And sometimes they don't hear the alarm at night.”**

“I help with eating, entertaining and supervising.”

“I get my brother's medications and water bottle. I sometimes help feed him and make sure he doesn't walk outside. I let him pin me (he likes to sit next to me and put his legs on mine).”

“I help with getting my brother pillows when he has a seizure and I also watch him.”





Despite their young age, the responsibility of these RARE siblings doesn't end at giving practical help but extends to worrying about their brother or sister's health and well-being and protecting them. Such considerable worry on such small shoulders can affect the mental health and well-being of RARE siblings.



50%

of RARE siblings said having a sibling with a rare condition affected their mental health

“

“It is hard work keeping my sister safe and well. It's stressful going to hospital with her. I worry about her a lot.”

“I have to make sure he is safe and I don't knock his hat off or accidentally open a door or window when I shouldn't.”

**“It is difficult to provide unconditional support from a young age. Spending extra time and care, answering questions, et cetera, can be tiring.”**

“It's most challenging protecting them.”

“The most challenging thing is trying to stay calm when they hurt you. Worrying about them when they are poorly or having seizures or get hurt.”

“I worry for my mental health.”



## The need for support

Many RARE siblings don't have support systems available to them to discuss their feelings and emotions, which can mean they are bottled up and have a negative effect on their health. Outlets and support groups specifically for RARE siblings would ensure they have a safe space to decompress, share their feelings and have time away from their assumed role of responsibility, particularly with other RARE siblings, who *just know*.



“I would like more opportunities for young carers to have time away with others who understand.”

“I would like getaways or vacations for siblings.”

“I would like to make friends with other siblings.”

“We get to make friends at the conferences we go to.”

**“I would like support because I'm afraid that people might make fun of me or my sibling because we have autism or genetic disorders, and my anxiety levels go through the roof sometimes.”**

“I would like to meet up with people with different rare conditions but around the same age.”

“I'd love to have my daughter engage more with other families and siblings that have other siblings with rare diseases. To be able to have a support group. I have a network of support parents but a lot of their children are small, so to be able to have a support system for my daughter would be good.”



## The impact on education

The additional worry RARE siblings carry can impact their school life. They may regularly experience disturbed sleep, which will have a detrimental effect on their ability to concentrate at school. They may have a sibling admitted to hospital or whose health is deteriorating, again increasing the worry and concern they feel. They may be distracted, unhappy, bad-tempered or even badly behaved, and their attendance may be impacted. It is essential for these young people that school support is improved and extra provisions are put in place, and that RARE siblings are given the space and opportunity to share their feelings and fears. Increased understanding from the teaching staff can ensure that negative behaviour or poor concentration is recognised and not unfairly punished.



50%

of RARE siblings say  
they have no additional  
targeted support from  
their school



“

“I worry when my sister is in hospital. It makes me worried and I can become distracted in class sometimes.”

“I would like school support and awareness so people stop asking me questions.”

**“It’s hard because people don’t understand that we have to wait for transport from my daughter’s school to pick her up before I can take her sibling to school, and the school and all her classmates say ‘you are always late’. There’s no allowances or understanding of the situation. She could have been up all night because of her sister.”**





## The fiercest advocates

It is not unusual for those in the RARE community to experience ignorance, bullying and misinformation about their condition. Invisible illnesses especially seem to prompt unsolicited questions and unjustified doubt from others. Most people in the RARE community have been subjected to unkind comments and, worse, physical harm.

This unwanted and often hostile attention is not reserved just for the individual with the rare condition. RARE siblings can be on the receiving end too, and they can also find it mentally draining to have to answer endless questions. They worry about their sibling being bullied or treated unfairly.

While they may bicker at home, when someone hurts a RARE sibling's brother or sister, they become their most devoted ally. RARE siblings, the most loyal defenders, cannot sit idly by while their sibling is made fun of or hurt. They just need additional support when dealing with this cruel attention. Increased awareness is key to begin to tackle some of these issues and break down the walls of ignorance many have to deal with on a daily basis.



“

“It stressful and frustrating when people stare and call my brother stupid names like astronaut and beekeeper. How many 11-year-olds do you know that are beekeepers or space men? It's stupid to say that and makes no sense.”

**“It's hard when people talk about them. It can feel isolating.”**

“The most challenging thing is the fact that you are scared of being made fun of.”

“We get asked a lot of questions and I can find this hard.”

**“It's challenging when people stare at my sibling.”**

“It's hard for me to go outside and my brother not being able to walk, and it's kind of stressful because everybody's looking at him and it makes me mad.”

**“I don't like getting stared at and all the questions.”**





## Yearning for some *me time*

The demands of a rare disease very often dictate the amount of time a parent has for that child and in turn the RARE sibling. Inevitably, the child with a rare condition will take up more of their parents' valuable time. And while RARE siblings generally understand this, there are times, like all children, when they just want it to be about them. For the focus to be on them. They yearn for more one-on-one time with a parent.

60%

of RARE siblings say that their siblings' needs mean that their parents are not always able to attend school events or support them with their studies



“

“It would help me if I could get more time with my Mummy and Daddy.”

**“It feels like they are the favourite one because they get all the attention and it just leaves you feeling alone.”**

“My sister was in hospital for my sixth birthday, and so my daddy had to be in hospital while I was opening my presents, and my mummy was in hospital while I was having my birthday dinner.”

“My daughter loves to be made a fuss of. Life completely revolves around her sister and she just wants to be seen and heard and recognised for the incredibly funny, kind, special little girl that she is.”

**“I try to ensure my daughter has some one-to-one time each week to give her the opportunity to talk etc. but being able to provide this regularly is not always possible and this sucks!”**



RARE siblings can miss out on things that their peers and other families do. Holidays and days out can be particularly challenging when a rare disease features in family life. Such events involve a lot of planning, compromise and very often a change or cancellation of those plans. Their sibling may not be able to do and take part in things other siblings do. Days out may always seem to be more about catering for the child with a rare condition and less about considering the RARE siblings' abilities.



“

“I can't do the same stuff as I would with a normal sibling.”

“It's hard because there's things that I miss out on.”

**“There are some things that my brother can't do but it would be nice if we got some time to do that stuff.”**

“I can't play ordinary games with my sister.”

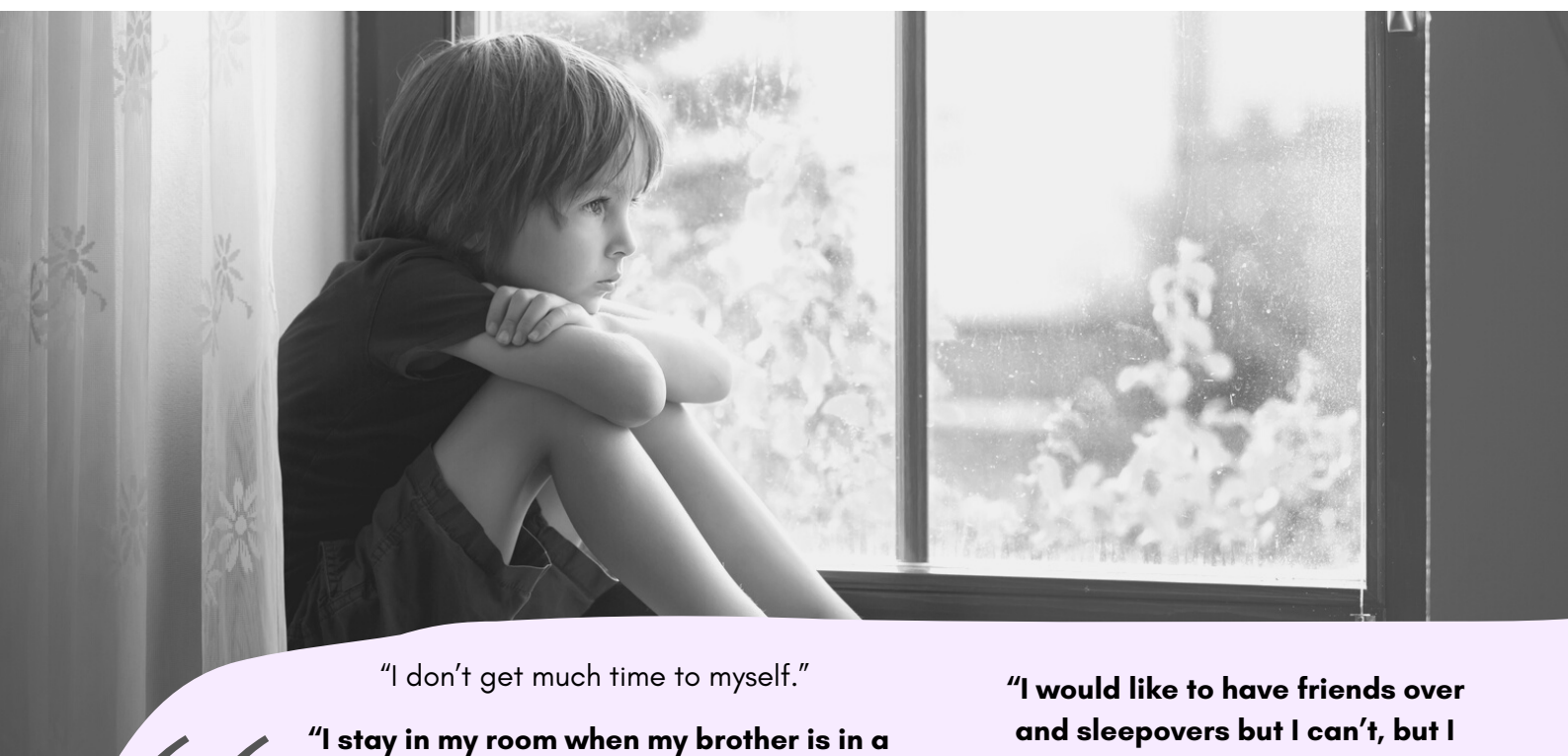
“It's difficult because my brother can't talk to me.”

**“I've only got my brother as my sibling, so if I want to go out and play football in the back garden I can't play with him like other families can, and so I'll go and ask my dad, but most of the time he's busy doing work or stuff around the house. And so I get my friends round and it's really good that I can play with them.”**

“You don't often have time to travel with your immediate family.”



While for many the home is a sanctuary from the noise of everyday life, for RARE siblings, the burden of rare disease can make the home more chaotic than they would like or need it to be. They may need to make allowances for their siblings' behaviour and needs. It may mean socialising and having friends to stay is hard, if not impossible. It can make them feel different, excluded and isolated. Again, it can seem like it is all about their sibling and not about them. All many of them want is "the ordinary". A bit of alone time, dedicated time with a parent, a fun day out or a treat. To not be different. To not be known, for once, as the sibling of a child with a rare condition. To be seen for who they are in their own right.



"I don't get much time to myself."

“

**"I stay in my room when my brother is in a meltdown. I can't have friends over. I have to be quiet when he is sensitive."**

"Sometimes my sister breaks my things."

"It's challenging that my brother always chooses to state the negatives about something that's gone on and never the positives. He is always difficult when he gets to go to bed at 10pm and he doesn't let us get to have a TV choice."

**"My sister cries all night and that can disturb my sleep."**

"My sister pulls my hair and ever since I got my ears pierced, she just tries to grab them and once she pulled them out."

**"I would like to have friends over and sleepovers but I can't, but I would still like to be invited to other people's houses."**

"My daughter has quite challenging behaviour due to her severe learning disability and this can be difficult to manage at times. Although she is fun, loving and full of adventure, this can mean that her sister doesn't get the calm space she needs at home. It means her boundaries are often crossed and I think this, mixed with the health worries, is the root cause of her anxiety."

**"For my daughter it's about accessing the ordinary and not feeling left behind."**



## The burden of fear

With many rare conditions there is an element of uncertainty about the future because the prognosis for the condition may not be clear. Just as RARE siblings take on the responsibility of care and concern for their brother or sister, they also carry the weight of this uncertain future on their shoulders, and that appears to be central to their fears. Providing these young people with an outlet and safe space to share their worries is key: they can be incredibly difficult topics to raise with parents, through fear of upsetting them and adding to their concerns. Dying and expectations about future care responsibilities are highly emotive subjects, so training for parents and carers on how to open up and facilitate conversations will help to ease some of the burden of the 'unknown' that these RARE siblings feel so keenly.



“

“I worry about dying or my parents getting sick and who would care for them.”

**“Even though I’m young I keep asking my parents what will happen with my brother when they pass away and they don’t really want to tell me so it doesn’t worry me, but it worries me more than not telling me, because I don’t know what will happen.”**

“I worry about people calling him names.”

“I worry if he ever gets badly hurt.”

“The biggest worry is the fear and anxiety.”

**“I worry about my sibling getting bullied, and protecting him and about the responsibility when I am older.”**

“I worry about my sister in hospital or about her seizures.”

“I worry about my sibling dying, or me getting sick.”

**“I worry about the future.”**

“I worry about being called names and about my sibling getting an infection.”



# the best thing about being a RARE family



"The bond we have and being so close."

"Sharing our story, having hope and faith and appreciating things."

"He's an awesome brother and there is literally the biggest group of people supporting him."

"We can help other people to understand."

"More friends, being more popular, more love, we can help others to understand and seeing my sibling at school."

"You learn to accept people for who they are."

"We are special and we get help."

"The RARE community, more opportunities and easy parking!"

"There are more opportunities, we do different things and special activities, we are different and more popular."

"Meeting new people and new opportunities."

"I get to learn new things."

"We go to different places, we have been in the newspaper and we help other families."

"She loves me."

"Meeting new people, taking part in new activities and spending more time together."

"Skipping lines!"

# RARE siblings: ages 17–25

As RARE siblings become older, the future obviously has a greater significance and proximity. RARE is definitely present in all their decisions regarding their future. RARE impacts their further education, including decisions around where to study, and potential employment options, and an element of compromise is often required. It greatly influences their relationships with their siblings, whether RARE or not; their parents; friends and partners. And it has a notable effect on their mental health and well-being.

When RARE siblings were asked to use five words to describe having a brother or sister with a rare condition, the top answers were 'challenging' and 'worrying'—a notable shift from the younger age group, who despite the various burdens RARE can impose on their lives, chose 'fun' as their top descriptive word.





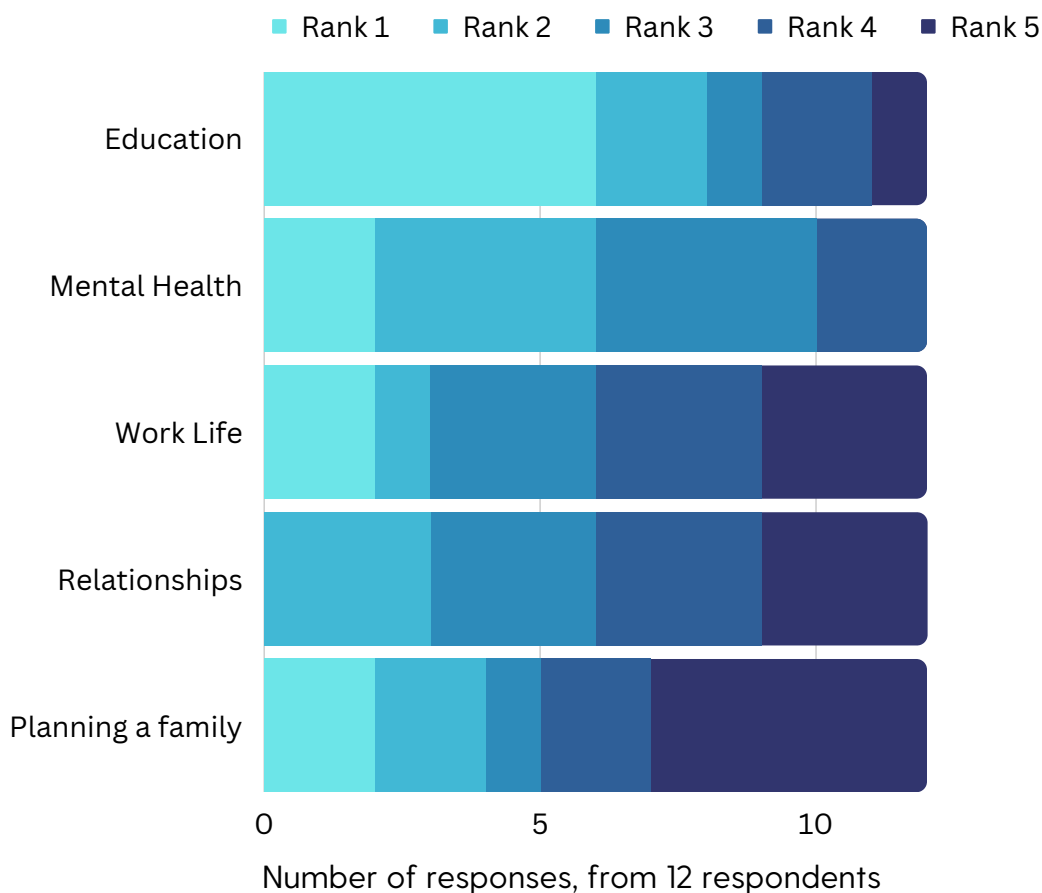
**"It takes a lot of patience, understanding and love to care for someone with a rare disease."**

"It's hard to be a young adult with a rare disease, especially an invisible illness—you look healthy, but you are struggling. People need to be more empathetic and understanding for those who are struggling but look fine."

"It's a real eye-opener to unsung challenges; it could make or mar your perception about life, God and spirituality."

"The experience provides a unique perspective. However, it's not something I would willingly choose had I had the choice."

## The impact of RARE



The RARE siblings were asked to rank the level of impact being in a RARE family had on different aspects of their lives: education, mental health, work life, relationships and planning a family. A ranking of 1 is most impactful to 5 which is least impactful.\*

The biggest impact RARE has on the siblings is on their education, followed by mental health, then work life and relationships, with family planning ranking as least impactful.

\*statistics relate to remote working group only



## The young carer

RARE siblings assume a lot of responsibility for the care of their brother or sister, both practically and emotionally. They help with day-to-day tasks, like dressing, personal hygiene and taking their sibling to appointments, but many also see themselves as having a supportive role, much like a counsellor, to be there when their sibling needs them, for comfort, reassurance and encouragement. These young people naturally fill these roles, whether intentionally or not, and it becomes a role for life that is factored into the majority of their life choices.

86%

help with the care of their sibling with a rare condition and consider themselves to be a caregiver

56%

say having a sibling with a rare disease affected/will affect when they leave home\*

“I take care of my sibling in so many ways. I used to feed her, lay her down on the bed and also help in keeping her clean.”

**“I am always considerate about my sibling and always shows up whenever he needs me.”**

“I help my sister physically, such as showering, getting dressed and eating. I also help take her to her enabling centre and I provide respite for my parents as she stays at my house with me for approximately half of the week. I take her out to different places to help her access her local community.”

**“I care for my sister by listening to any concerns she may have, or if she needs help with tasks.”**

“I help my sister with some chores she cannot carry out because of her rare disease. I help in giving her medications and looking after her.”

**“I have one other sibling who is three and is neurotypical with no signs of the rare genetic condition. My responsibilities as a caregiver are predominantly looking after my baby brother whilst my mother looks after the eldest brother with the rare disease.”**

“I help my sibling emotionally and physically; pushing the wheelchair, helping with mobility, personal care and small tasks like tying a shoe.”

“I help by dressing my sister, helping change her, showering, feeding, basic activities of daily living (ADLs) and promoting her social needs.”

“I help by any means necessary, sometimes getting diapers, clothing, food, helping with medical administrations, direct pressure, moving my brother, transport, etc.”





## Education and employment

Being a RARE sibling can have an impact on a young person's school experience. Fatigue from a disturbed night, along with worry for a sibling's health and well-being, can hinder a child's concentration. It is clear that increased support and understanding among staff is needed to support RARE siblings while in an educational setting, and could greatly impact their lived experience during this challenging time.

91%

said having a sibling with a rare condition affected their education\*

66%

said having a RARE sibling meant they had to take time out of school

48%

said their siblings' care needs meant that their parent/carer wasn't always able to attend school events

28%

said their school setting provided them with support

**"Previously, when I was at school, college and university, I would have to leave to take my brother to appointments, which meant missing out on learning and classes; however, I was able to catch up. In comparison to my peers, what I believed to be normal and not have an effect on me did, and I found that I would feel low and disappointed when I had missed a class I was looking forward to or a significant event happened."**

"I go to school late some of the time because of my sibling with a rare disease. I had to give up going to school on some occasions just to be with her."

"It has affected my performance and grades in school negatively."

**"During our early years in elementary school and high school, I had to always be available for my sibling in school. I was their only friend in school for a very long time and so had to ignore my other activities just to have enough time for them. I also had to miss classes to see to them."**

"My sibling's facial disorder affected me a lot during school. I had to bear being around my sibling all through school and couldn't keep other friends in school. This didn't really have direct impact on my performance but it affected my mental health adversely, and at a point in time I didn't want to attend the same school as my sibling."

**"I would like more understanding within school systems, and others, that having a rare disease sibling can be stressful and weigh on students sometimes. I feel that if they have a sibling with an individualised education program (IEP) that there should be extended support for the siblings as well."**

"My brother's condition did not affect my education. I was still able to have a normal education, although studying at home did become more difficult with the commotion that comes with caring for my brother."

"It really impacted my education which made me move from in-person study to full-time virtual."



Having RARE in the family can also play a significant part in RARE siblings' decisions about education; first, whether to pursue further education and go to college or university; second, how far from home they are prepared to travel. It even affects their choice of study: many are influenced by their experience as a carer, and this informs their career options.

55%

said having a RARE sibling impacted their choice of school\*

59%

said having a RARE sibling impacted their decision to attend college or university

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“My choice of school was such that I could be close to my house.”

“I want to study somewhere closer to home in case my family ever needs my help.”

**“I can’t go to the school of my choice and I had to switch my course of study because of time and my sibling.”**

“I chose to attend my local university to be close to home and to be able to support my sister.”

**“I was originally going to go to university close by but decided I need some independence and time where I didn’t have to help look after my sibling.”**

“I decided to study nursing, so that I can take better care of my sibling, like taking care of her skin, how to make her skin irritation better, chemical compounds that could possibly irritate her, how to properly change her bandages and how to take care of broken skin.”

“Growing up being a caregiver, I naturally pursued a career in care, specifically disabilities.”

“I am going to study medicine to hopefully gain more insight into autoimmune conditions.”

**“I’m going into psychology next year so that I can learn about better coping mechanisms for other siblings with special needs siblings and how I can better improve the communication between me and my family. It’s also helpful to learn about stress and the ways that it can impact individuals.”**

“I feel as though seeing my sister go through her diagnosis and treatment really opened my eyes to the healthcare profession and made me want to pursue a career in medicine.”

“I have chosen to study psychology in order to become an educational psychologist to help children with additional needs and rare conditions.”



Choices around further study can require some compromise from RARE siblings, and entering the world of work can also be affected by the responsibility of caring for a sibling with a rare condition. Increased support and signposting to agencies who can provide advice and resources to help with making important career decisions would ease the burden for RARE siblings.

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**“This was the most impactful aspect of my life with my siblings. A lot of time I had to go drop my sibling at school and stay till they felt comfortable. This caused me a lot of issues at my work as I just finished my associate’s and was preparing for my bachelor’s. I had to sometimes miss work or take leave from my casual work if I had to be available for my sibling to attend to something important, like preparing for a school project, going to get things etc.”**

“I work less hours because I have to attend to my sibling who has a rare disease.”

“I’m not working for now, searching for work is kind of hard due to the health status of my sibling. I can’t go out for hours as I have to feed him and also give him his medication.”

“My jobs and employment haven’t been directly affected by my caregiver role. Moreover, it has actually benefited me as my role in the NHS required skills I have established through being a young carer and those skills were transferable into work.”

“You can’t accept or apply to any job that will take too much of your time.”





# The mental health of RARE siblings

The extra responsibility of caring for a sibling and the burden of worry over their health can have a profound impact on the mental health and well-being of RARE siblings.



72%

said that having a sibling with a rare condition negatively affected their mental health

52%

said they had received no support at all

**“My mental health was impacted, as most times I felt down or depressed during times when I noticed that my sibling was also going through a down time. This impacted me mentally and I was always needing motivation or encouragement from myself to pull through. I also felt personally overwhelmed with feeling sorrow, depression and empathy as a result of the state of my sibling’s physical health.”**

“My mental health’s been generally impacted positively by this experience, but at younger ages I suffered a lot mentally as a result. I had times of depression and anger being around my family; however, with time I have been able to manage that effectively.”

“Specifically, through lockdown my mental health plummeted; normally I would be attending university or work, which gave me that respite I needed. However, lockdown meant my care role stepped up to being 24/7 care.”

**“I have been so unhappy and it really affects my mental health. My mental health was affected big time. That led to depression.”**

“My mental health was okay although I became a lot more emotional seeing my brother struggle. He lives an 80% normal life physically, but mentally/brain function is where he is struggling, and not being able to help this as much as you can with physical problems really tugged at my heart.”





While some RARE siblings have accessed professional therapy or young carers' support, most rely on family and friends for emotional support. Additional support is needed to nurture and guide these young people, particularly as they reach the point in their lives when they are making important decisions about their future. There also needs to be recognition that the support they need may differ from the support the younger groups of RARE siblings need. While emotional support is still essential, this group would also benefit from practical advice to help with their future choices.



"There is very little support for siblings, apart from young carers. I think support needs to be in place for post-18 sibling carers as this is when it really starts to impact the choices they can make for their own lives."







## Relationships

A RARE sibling's relationship with their parents can be complex. It can become strained due to the amount of attention they are required to give the sibling with a rare condition. RARE siblings can be left feeling overshadowed, not as important, and resentment can grow. This seems to be more apparent when the child is young; as they grow up, siblings recognise that, while difficult for them, it was necessary and inevitable for their parents to give more time and attention to the child with a rare disease. Special treats and rewards and protected one-on-one time with their parents can be so important in showing RARE siblings that they are equally loved and cared for. Most understand that time is stretched and really benefit from those small but vital gestures. Help for parents and children to start and facilitate honest and frank conversations around how they are feeling would be useful and hopefully stop early resentment and jealousy from building.



**“Growing up, my brother rightly received a lot of my parents’ attention. However, I felt disconnected from my parents and was very envious of the attention my brother received, which I felt guilty for and never expressed. Only in my late adolescent years did I come to terms with this and understand. Through difficult talks we established a ‘family time’.”**

“Me and my mum have become extremely close as I have helped her a lot in fighting for my brother. We share the struggle and have each other's back. It was hard growing up not being able to have typical family days out, and if we did, it was much, much harder and less enjoyable.”

“There are so many barriers in society, and it is difficult for people with rare diseases to go about their life. It directly affects the family and what they can do, from going on holiday to going out for dinner. It requires a lot more effort than meets the eye.”

**“This impacted my relationship with my parents adversely, I had a sour relationship with my mum because she always had me do things for my siblings even when I didn't want to. I nursed a bit of resentment at younger ages for my family.”**

“I would like people to know the value of having a family without someone suffering from a rare disease.”



Conversely, being in a RARE family may bring family members closer, and RARE siblings speak of more time together and an increased appreciation of others. Relationships with other siblings who do not have a rare condition can be strengthened by their mutual understanding and shared burden.



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**“Wow, this has really impacted positively, I have been able to develop a very strong relationship with my siblings, I have a better understanding of their psychology, emotions, feelings and thoughts, which have changed my outlook about life.”**

“I’m on a good relationship status with my parents and also the caregiver because they have been of great help to me.”

**“Me and my younger sister became extremely close as we understand the struggle together.”**

“Our parents support us very well, with advice, care, money, and emotionally.”

“It’s tough, it can be draining, but it’s family and you love your family and choose to do right by them because you know that they would do right by you too.”

**“It opens your eyes to a much wider world and it’s very rewarding to support someone, despite the challenging moments.”**

“Now my brother is 12 and I’m 24, we have a great relationship. I’m able to pick him up from school, have him stay over at my home and I’ve grown to understand him as I’ve sort of acted like his second parent growing up. We have a great bond which I’m happy about.”



**A lot can be expected of RARE siblings which can have an adverse effect on socialising, meeting and making new friends and doing the same activities as their peers. The compromises RARE siblings make and the need to be available for their sibling can make it difficult to hold on to and nurture friendships and romantic relationships.**



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“Relationships and friendships were impacted due to my sibling’s care needs. Friends were more understanding and close friends will ask how my brother is doing, how I am doing and speak with him. On the other hand, past relationships haven’t worked quite as well—most men I have been in relationships with have not understood my role as a caregiver, despite information and personal conversations. Past relationships have expected me to drop everything to go with them to places; however, this is not the case for me as a caregiver—I must arrange care for my brother in advance so he is safe.

Unfortunately, due to this lack of understanding and compassion, many of my relationships have ended. This has significantly hit me as partners have said it is not me, it is the lack of ‘spontaneity’ and ‘adventure’ which is prevented from my tie to caring.”

**“This affected a lot of my friendships back in elementary and high school, I had to always be around my siblings and hence spent less time with my own friends. I was only able to keep up if my sibling was going to be around and this is not what most of my younger friends liked so much. It impacted me to an extent that I could no longer have ‘friends’.”**

“My friendships and relationships have been unaffected. Although my partner now has grown to love my brother as his own, I was worried he wasn’t going to be supportive/understanding of this at first.”

“Just a few friends support me.”

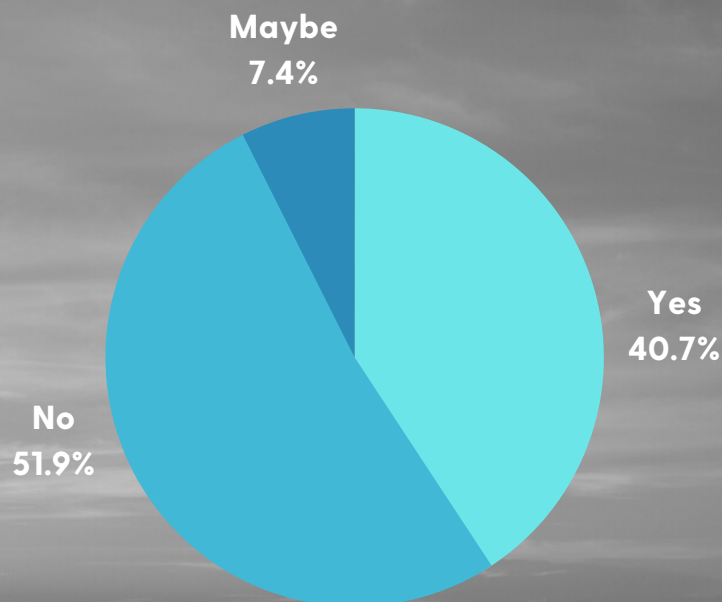
**“It really affected my relationship with my friends because I’m always home with my sibling.”**





## Looking to the future

**Has having a sibling with a rare condition has affected your decision to have a family?**



**82%**

said they felt they had been given enough information on the subject and that it had been helpful\*

**64%**

said they felt they required no further information\*

RARE siblings are generally well-informed on matters of future family planning, and that doesn't appear to be paramount in their thoughts for the future. Their key burden is their concern about the health and future prospects of their sibling. They worry about a deterioration in their sibling's health and well-being, and fear for possible limitations on their future: will they be able to live alone, will they require full-time care, will they have the possibility of employment and independence? The older they get, the more RARE siblings can feel a sense of guilt over the life they are living and the opportunities open to them that may not be possible for their sibling. They will also consider their sibling's future when their parents are no longer around or in good health, and whether their care will fall solely to them. Again, honest and continual dialogue around these issues, as well as signposting to the help and resources that are available, can go some way to reassuring RARE siblings and removing the inevitable uncertainty.





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**“I’m concerned my brother’s mental limitations will affect his chance of a career/making a living. He struggles hugely academically, also with anxiety and self-esteem issues. And his condition develops as he grows, so we are unsure of how his health will be in the future. I feel it’s partly my responsibility to prepare for this.”**

“I am only concerned whether or not a treatment will arise which could help my sister’s autoimmune condition, myasthenia gravis, and hope to be able to create a treatment in the future for her.”

“I hope everything gets better in the future.”

“I do not have any current direct concerns for the future; however, thinking in the long term—when my brother becomes particularly vulnerable and my parents have passed—does worry me, and I fear for him, not myself. Although the worry is not significant, I do have anxiety regarding unexpected tumour growths and cancers that can appear and all of a sudden limit my brother’s life (never knowing how much time I really have with him).”

**“Relating to me and the impact on me—I feel immense pressure and anxiety where I feel guilty for not spending time with him in case he passes due to complications. This influences my social life mostly.”**

# The best thing about being a RARE family

"They are God-sent."

"It's an interesting story to tell people and I often get to educate people on Gaucher specifically, because most people don't know what it is."

"Having someone so close to me who inspires me daily."

"My brother is the reason I wake up in the morning."

"I love being part of the rare disease community, advocating for our rights, and learning more about the associations between different diseases and genetics. The support in the rare disease community is also great (among other patients)."

"Helping your sibling to achieve all that they can in life."

"My brother is a funny and unique character who loves to laugh and play around."

"It makes me think about my siblings before myself and it makes me love them more."

"No matter what, she's always happy and that's not something you see every day."

"It teaches empathy and life skills other kids my age wouldn't otherwise have."



# **RARE** **REVOLUTION** MAGAZINE

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