RTS support group

# A Family Guide to Living with Rubinstein-Taybi Syndrome


UCL

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# A Warm Welcome

**This guide has been produced by the Rubinstein-Taybi Syndrome Support Group, a UK registered charity. Formed in 1986, the group offers information and support to families and people with a diagnosis of Rubinstein-Taybi Syndrome (RTS).**

We hope you find this guide helpful, and can use it with professionals involved in your care, your child's care, or the care of someone you support, for example, your paediatrician, support worker or teacher.

This version of the guide was a collaborative effort between the RTS UK charitable organisation, Dr Liz Halstead from University College London (UCL), Dr Jane Waite from Aston University and parents and caregivers of RTS. We thank the families who have shared stories and information.


*The RTS Support Group committee at the RTS Conference 2022*

### Other Resources

- RTS International Guidelines[1]
- RTS International Guidelines (plain English version)[2]
- Further Inform Neurogenetic Disorders (FIND)
- National Organization for Rare Disorders (NORD)

**Note**: This guide was written in the UK for UK-based families, and practices and provision of facilities may be different in other countries. We have included information directly (with permission) from the publication "Understanding Rubinstein-Taybi Syndrome: A guide for families and professionals"[3] produced by Cincinnati Children's Hospital in conjunction with the University of Cincinnati and the University of Cincinnati Center for Excellence in Developmental Disorders (UCCEDD).

The contents of this guide have been written by parents and carers from the Rubinstein-Taybi Syndrome Support Group, using their own experience as well as information provided by acknowledged medical and psychology professionals. The professionals have aimed to ensure, to the best of their ability, that any facts given are as accurate as they can be given the current state of medical knowledge about the syndrome. All content is provided in good faith, and the Support Group cannot accept responsibility for any errors, inaccuracies or omissions, or for the results of anyone acting or not acting upon any statement in this guide.

# Meet Courtney

**Courtney is a PhD student conducting research into the emotional experiences and wellbeing of individuals with RTS.**

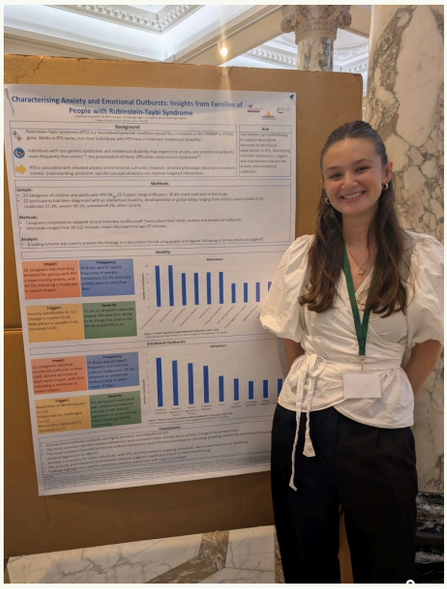
*Courtney*

"Over the course of my PhD, I've had the privilege of meeting many children and adults with Rubinstein–Taybi Syndrome (RTS) and their families. Each encounter has been unique, and one of the most striking things I've learned is just how different every individual with RTS is. Each person brings their own personality, sense of humour, and strengths to the assessments, whether that's through excellent communication, creativity, determination, or simply their joy in connecting with others. These experiences have given me a deep appreciation for the individuality of each person with RTS and the resilience and warmth of their families.

A common theme across my visits has been a shared love of music and dance. Many meetings featured spontaneous dance breaks, which quickly became one of my favourite parts of the day! Music often acted as a motivator and a way to keep my research assessments engaging and fun, helping to bring out the best in participants.

I've also been consistently struck by the sociability and kindness of the individuals I've met. Many welcomed me into their homes with genuine enthusiasm and curiosity, eager to show me their favourite things or help me set up my equipment. On more than one occasion, a participant with RTS stepped in to assist when my assessment materials got the better of me! These moments of warmth, humour, and connection have been the most memorable part of my PhD, reminding me how rewarding and joyful it is to work alongside this community."

*— Courtney Greenhill, Aston University*




*Courtney at a conference presenting her RTS research*

# The History of RTS

*Dr Rubinstein and Dr Taybi, respectively*

In 1958, three Greek surgeons, Michail, Matsoukas and Theodorou identified Rubinstein-Taybi syndrome (RTS).

Dr. Jack H. Rubinstein, a developmental paediatrician at the University of Cincinnati (UC) Medical Center, and Dr. Hooshang Taybi, a paediatric radiologist at the University of Oklahoma, were introduced by a mutual colleague who had noticed they were both observing unrelated children with similar physical and intellectual disabilities.

Upon meeting, the two decided to combine their efforts and research. Together in the early 1960's the pair identified the characteristics that make up what was originally named "broad thumb-hallux syndrome" and is now called **Rubinstein-Taybi syndrome (RTS)**.

# The Genetics of RTS

RTS is a rare genetic condition that affects approximately **1 in 100,000 to 125,000 newborns** each year worldwide[4-7]. In 60-70% of cases, it is the result of mutations in the CREBBP gene on chromosome 16p13.3[1,4-7], also referred to as **RTS Type 1**. Individuals with this form of RTS have many of the typical physical characteristics of the syndrome, small stature, large, angular thumbs and broad first toes, a distinct angular nose, thick hair and eyelashes, downward slanting eyes and a narrow palate[4-7]. Sometimes at birth, infants show a small reddish-pink mark on their forehead. Intellectual disability is common and can range from mild to severe[4-7].

An even rarer genetic variation that affects 8-10% of diagnosed individuals, occurs on the EP300 gene on chromosome 22[1,7,8]. This is also referred to as **RTS Type 2**. These individuals may show the same characteristics as in RTS Type 1, but facial features may be milder, thumbs are less likely to be angled outward, and intellectual disability may be milder in some cases[5].

Genetic testing, which evaluates the genes by sequencing and deletion testing, may confirm a diagnosis of RTS.

**In about 20-25% of cases, children with typical features of RTS do not have an identified mutation in CREBBP or EP300. In those individuals the cause of RTS is not yet known[6].**

# The Diagnosis of RTS

## How is RTS Diagnosed?

RTS is a rare genetic condition that affects a child's physical features, growth, and learning. Many children with RTS grow and thrive with the right support, therapies, and encouragement from family and professionals.

**Diagnosis** can happen at different times:

- At birth, if physical signs are noticed by the healthcare team.
- Later in infancy or childhood, when developmental differences become more noticeable.
- Occasionally in adolescence, particularly in individuals with RTS Type 2, where physical features are subtler[4,6].

A **genetic test** can confirm RTS. This involves taking a small blood sample to look for changes in the CREBBP or EP300 genes[4-6]. If the characteristics of RTS are not easily recognisable, most doctors will start with a genetic microarray, which checks for broader chromosome changes; if the characteristics point very strongly to RTS, specific testing for the RTS genes is performed[5]. Increasingly, newer tests are used which check both for broader chromosome changes and for specific CREBBP and EP300 in one go. Likely, this will be the test used in the near future.

Results may take several weeks or months. In most cases, they are clear-cut, but sometimes the laboratory finds a "variant of uncertain significance" (VUS), a result that needs more interpretation[5]. Your geneticist or genetic counsellor can explain these findings and what they mean for your child.

Families can request referral to a genetics clinic through their GP or paediatrician. While testing is usually covered in the NHS (or through most health systems), it is a good idea to check insurance or funding options outside of the UK[5].

RTS can occasionally be difficult to confirm, even with extensive testing[6]. Some children may first receive a "clinical diagnosis" based on appearance and development rather than a confirmed genetic report[9,10].

For **further information** on common characteristics of RTS and how RTS is diagnosed please refer to the following resources:

- RTS International Guidelines
- The RTS Support Group UK have produced a plain English version of the RTS International Guidelines

# The Diagnosis of RTS

## What Causes RTS?

After diagnosis, families often ask what caused RTS and whether it could happen again.

In almost all cases, **RTS is not inherited from a parent**. RTS usually happens because of a new (de novo) change in one of two genes called CREBBP or EP300[4,5,8]. These changes occur by chance when a baby is first developing, so parents could not have caused or prevented it. The likelihood for such parents of having another child with RTS is **less than 1%**[10,11]. However, someone who already has RTS has a **50% chance** of passing the condition on to their own child[10].

Because RTS is usually caused by a new change, the chance of having another child with RTS is very low. A genetic test can confirm whether the change is new or inherited. Families can speak with a genetic counsellor to understand the results and discuss any future pregnancies[12].

*Primary features of the clinical diagnostic criteria of face and limbs for RTS*

# The Diagnosis of RTS

## Parents' Experiences and Emotions

Receiving a diagnosis of RTS can bring a range of emotions, which may change over time[13]. There is no single "right" way to feel. Common reactions include:

### Denial, Shock or Numbness

Not wanting to believe the diagnosis or needing time to adjust.

### Euphoria or Optimism

Feeling hopeful and determined to make the best of the situation.

### Pining or Searching

Wondering whether something could have been done differently.

### Anger

Frustration at not having control or wanting to find someone to blame.

### Grief

Mourning the loss of the "expected" future and adjusting to new hopes and plans for your child.

### Acceptance

In time, most parents find balance and strength, focusing on their child's personality and achievements.

### Guilt

Many parents blame themselves, but there is no evidence that anything you did caused RTS; it is a genetic condition that occurs randomly. Other family members may feel this guilt too.

### Depression or Apathy

Feeling tired, sad, or unmotivated; losing interest in things. If these feelings persist, speak to your GP or a healthcare professional for help.

### Remember

You are not alone. These feelings are natural and, with time and support, most families adapt and find joy in their child's progress.

Talking with other families who understand RTS can be an enormous help. Many parents find comfort and practical advice by joining support groups (such as RTS UK) or connecting with experienced professionals.

### Recommended Resources

Genetic and Rare Diseases Information Center (GARD) • MedlinePlus • Contact UK

Unique – Rare Chromosome Disorder Support Group

# The Diagnosis of RTS

## Welcome to Holland (By Emily Perl Kinglsey)

**I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....**

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The Gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

# Key Facts for Families

## What is RTS?

RTS is a rare genetic condition that affects about 1 in 100,000–125,000 babies. It can influence growth, physical features, and learning, but every child is unique and develops at their own pace.

## How RTS is diagnosed

- Diagnosis can happen at birth, in early childhood, or later.
- Doctors may notice features such as broad thumbs and toes, a distinctive nose, thick hair or eyelashes, and a smaller stature.
- Genetic testing (a simple blood test) most often confirms the diagnosis.
- Sometimes the diagnosis is made based on physical features and development alone.

## What happens next?

Children with RTS often benefit from:

- Early developmental and educational support (speech, occupational, and physiotherapy).
- Regular medical check-ups to monitor growth, heart, and other systems.
- A team approach involving paediatricians, therapists, and specialists.

## Why it happens

- RTS is usually caused by a new ("de novo") genetic change in one of two genes: CREBBP or EP300.
- These changes happen by chance when a baby is developing.
- Parents did nothing to cause RTS.
- The chance of having another child with RTS is very low (less than 1%), but a genetic counsellor can give individual advice.

## How parents may feel

Getting a diagnosis can bring mixed emotions; relief to have an answer, but also shock, sadness, or worry. These feelings are normal.

Many families find comfort in:

- Talking with other parents who understand.
- Asking questions when ready, there's no rush.
- Seeking help if feeling low or overwhelmed; your GP or a counsellor can support you.

## Remember

- RTS is no one's fault.
- Every child's journey is different.
- With love, support, and understanding, children with RTS can achieve great things and bring incredible joy to their families.

# Meet Aara

**Aara was diagnosed with RTS at 6 months old.**

*Aara*

"As first-time parents Abbas and I had no clue what we were doing, the usual thoughts kept floating in and out of our minds, has Aara eaten enough? Why is she crying? Why is she sleeping so much? But in my heart, I knew there was something different with my little girl.

When meeting my NCT friends, I could tell that Aara was developing at a much slower pace than the other children, out of all the 9 babies Aara always seemed miles behind. It was then I expressed my concerns to my husband and my parents at first, however, they convinced me that all children develop at different rates and Aara would catch up. To be honest that is exactly want I wanted to hear, maybe I was in denial... but to me Aara is perfect (just like any child is to their parents) and I convinced myself it was all in my head.

The paediatrician advised that we should send Aara for genetic testing and further explained most children in the UK are sent for genetic testing even for small issues. I was reluctant as I convinced myself my "baby is normal" as well as the fact I had an amnio where our results were given the all clear during pregnancy. The doctor advised if it is available let's get this done and eventually, I accepted referral to a geneticist.

In August 2017, we arrived at the hospital to meet the geneticist. We laid Aara on the bed stripped her down to her nappy and the geneticist started taking photos of her and pointing out features of Aara's body that could be a sign that highlighted why there may be a genetic issue.

Some of the things listed:

- Broad thumbs and toes
- She was not sitting up at 10 months
- She was not babbling or vocalizing much
- She had a small head size
- Her height and weight are on the small side based on the growth charts

This was the hardest thing to hear, essentially this was a doctor pointing out faults with my daughter. Of all the appointments I have been to, from forcing her to stay still for a CT scan or putting in a cannula on her hand, this was the most difficult one to get through.

# Meet Aara

**Aara was diagnosed with RTS at 6 months old.**

*Aara*

The geneticist then was jotting down notes and organising the photos she had taken. I remember us staring at her, waiting to hear the professional opinion and in three seconds she changed our lives and said, “Aara most likely has a genetic disorder”. My heart stopped; I could feel a big gulp in my throat and my eyes filled with water. At that moment Abbas said, “But we did an amnio and everything came out normal on that test how can she have a genetic disorder?”. Obviously, the amnio cannot test for every genetic disorder and therefore this is potentially a rare disorder. The plan now was to go for a blood test (all three of us) and then the doctors would research based on the results and Aara’s physical features to see if they could provide a diagnosis.

In December 2017, we received a letter saying the results had arrived and we were booked into to see the geneticist in January 2018. I mean 2 days before Christmas we get told we have a diagnosis, but we won’t tell you what it is for another month. To be fair, the NHS have been great, but this was the one thing that infuriated me. The Christmas holidays were just a blur, family telling us not to worry about it but how can you not? Every day until the 24th of January felt like a lifetime…

The big day finally arrived. I remember thinking that whatever we were told today we still wouldn’t know what it meant for the future. I think with anything the fear of the unknown is so difficult to deal with. We met with our geneticist, who said “This is an information booklet in relation to the genetic disorder Aara has been diagnosed with from her test results. Aara has Rubinstein-Taybi Syndrome, and this booklet explains everything you need to know”. I could feel the gulp in my throat and water gushing to my eyes and mumbled “What does that mean?”

We came away from that appointment no clearer, but with the name RTS, and hundreds of pages of documentation to read through about the changes in genes and all the problems we could face, along with the disclaimer that every child is different. As a mother you picture the future and the happiness and life your daughter will lead. This felt like life had been taken away from us. It’s amazing at that point nothing had changed in Aara from the day before we were told she had RTS but inside it was as if my daughter had died. With time, I can say that my original dreams of parenthood have now been replaced with new and different ones.”

*— Abbas and Zohra, Aara’s parents*

# Developmental Milestones Overview

Children with RTS develop at their own pace. Developmental milestones such as sitting, walking, talking, or playing may take longer to achieve, but every step forward is meaningful. Just like other children, no two individuals with RTS are the same, their progress, abilities, and personalities are **unique**.

Many children with RTS benefit from early and ongoing support to help them reach their potential. This can include physiotherapy, speech and language therapy, and educational or behavioural support.

**The table below lists the average age and range of milestones attained and should be used only as a guide and for reference[4].**

| Skill | Range for Typically Developing Children (months) | Range for Children with RTS (months) | Average for Children with RTS (months) |
|---|---|---|---|
| **Roll Over** | 2-5 | 2-24 | 7 |
| **Sit Up** | 5-8 | 6-30 | 11 |
| **Crawl** | 7-10 | 8-30 | 15 |
| **First Word** | 9-13 | 6-57 | 25 |
| **Walk** | 11-15 | 15-54 | 30 |
| **Potty-Trained** | 24-27 | 30-216 | 63 |
| **Word Phrases** | 14-24 | 24-156 | 65 |
| **Ride Bicycle** | 36-48 | 42-246 | 68 |

# Developmental Milestones Overview

## Learning and Cognitive Development

**Cognitive development** is how children think, learn, remember, and solve problems. This begins before birth and continues throughout childhood[14,15]. In the early months, babies learn by following faces and sounds, exploring objects, and reacting to voices and touch. Over time, they learn to recognise people, understand words, and copy actions such as waving[14,15].

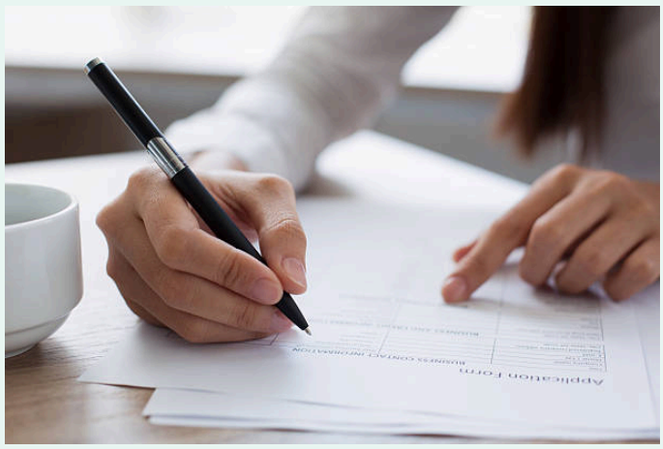
In RTS, children can experience **delays in learning and thinking skills[4,9]**. The level of intellectual disability can vary widely with some children learning practical skills with extra support, while others may have more significant learning needs.

Because the brain develops most rapidly in the first few years of life, early intervention is especially important[14]. Families in the UK can access **Early Years support** through:

- Your local council's Early Years SEN team
- Your GP or health visitor
- NHS community child development services

Once your child reaches school age, an **Education, Health and Care Plan (EHCP)** can help ensure that your child's learning and therapy needs are met in school.

Adults with RTS may continue to need support with learning and memory. Research suggests that some may experience changes in cognitive ability as they age, so regular reviews and tailored learning activities are recommended[4,5,16].



***(Please see Appendix A for EHCP Tips)***

**Recommended Resources**

NHS • IPSEA • Contact UK

# Developmental Milestones Overview

## Physical and Motor Development

Children with RTS often have low muscle tone (hypotonia), which can affect balance, coordination, and fine motor skills[4,9]. This can delay physical milestones like sitting, crawling, walking, and feeding.

Physiotherapy and occupational therapy can help strengthen muscles, improve coordination, and encourage independence with daily tasks such as dressing or using cutlery[9,14]. These therapies can be accessed through the NHS, or privately, and may also be provided through your child's EHCP.

Many children enjoy physical activities that build strength and balance in a fun way, such as swimming, dancing, horse riding, or sensory play involving sand, water, or soft play equipment.

**Recommended Resources**

NHS • Riding for the Disabled Association

## Communication and Language Development

**More than 90%** of children with RTS experience **significant speech or language delays**[4,9,17]. Some children may understand far more than they can express verbally. Because the same muscles are used for eating and speaking, early feeding difficulties can sometimes indicate future speech challenges.

Early involvement from a **speech and language therapist** is highly recommended[18]. Therapists can help identify the best ways for your child to **communicate**, including:

- Sign language or Makaton
- Picture Exchange Communication System (PECS)
- Communication boards or assistive technology
- Augmentative and alternative communication (AAC) devices

Speech and communication support may be offered through the NHS, your local authority, or school. Continuing therapy through school years and adolescence helps maintain progress as communication needs change.

Some parents worry that learning an alternative communication system may delay speech. However, there is no evidence base for this and there are lots of advantages for children having an alternative communication method.

**Recommended Resources**

Royal College of Speech & Language Therapists

The Communication Trust • Makaton blog post

Speech and Language Therapy blog post

# Developmental Milestones Overview

## Social and Emotional Development

Many children and adults with RTS are naturally warm, sociable, and affectionate, and may enjoy closeness, eye contact, and being around others[19]. These strengths can support positive social relationships, though some individuals may experience frustration or find changes to routine difficult.

When communication is challenging, emotions may be expressed through behaviour[4,19]. These behaviours usually reflect communication needs, sensory sensitivities, discomfort, or anxiety, rather than defiance.

Some individuals with RTS show repetitive or stereotyped behaviours or have a strong preference for routine. These behaviours are not, in themselves, a cause for concern and are not usually targeted for intervention unless they are causing significant distress or having a substantial impact on daily life. Support focuses on understanding the purpose of the behaviour and reducing underlying stress, rather than stopping the behaviour itself.

It is important to distinguish these patterns from behaviours of concern, such as self-injury, aggression, or destruction of property, which may place the individual or others at risk and do require targeted assessment and support. If behaviours are challenging or interfere with daily life, a psychologist, behavioural therapist, or mental health professional can help identify triggers and develop positive support strategies.

Behavioural and emotional needs may change over time, particularly during life transitions such as starting school, puberty, or changes in caregivers. **Support should be proportionate and introduced when needed,** helping individuals with RTS manage emotions and cope with change safely and effectively.

**Recommended Resources**

YoungMinds • The National Autistic Society

Challenging Behaviour Foundation

Further Inform Neurogenetic Disorders

## Growth and Health

**Growth delay** is one of the most consistent features of RTS. Babies may be born a typical size but tend to fall below average growth lines during infancy. This slower growth affects height, weight, and head size. Children with RTS usually remain smaller than average as adults.

RTS-specific growth charts are available to help families and healthcare professionals monitor progress.

***(Please see Appendix B for Growth Charts)***

# Developmental Milestones Overview

## Encouraging Development Through Play

Children with RTS learn best through structured play, repetition, and positive reinforcement.

As children grow, participation in inclusive community groups, such as Scouts, Brownies, youth theatre, or disability sports, can support social skills and independence.

### Recommended Resources

Scope • Family Fund

Some activities families report they find especially helpful include:

- **Water play and swimming**: Supports coordination and confidence
- **Horse riding**: Builds balance and self-esteem
- **Music therapy**: Encourages speech, rhythm, and focus
- **Outdoor play**: Cycling, swings, and slides for muscle tone
- **Books and storytelling**: Strengthens language and imagination

### Key Messages for Families

- Every child with RTS develops in their own way; celebrate each milestone.
- Early support through NHS and educational services makes a real difference.
- Growth and development can be tracked using RTS-specific growth charts.
- Combining therapies, play, and community inclusion helps your child thrive.

*Aara and her family cycling at the Watford Cycle Hub*

# Support for Families at Every Age

## Newborn (0-1 Years)

*(Please see "having a baby with RTS" in International Guidelines and plain English documents)*

Every baby with RTS is **unique**, and while many share some early physical features and health challenges, their personalities and potential are individual. Many parents describe their babies as warm, affectionate, and sociable from an early age. Life expectancy in RTS is usually typical, and children continue to learn and develop throughout their lives.

### Early Appearance

Many babies with RTS have a distinct appearance at birth that may be recognised by an experienced paediatrician or clinical geneticist. **Common early features** can include:

- A prominent forehead, sometimes with a small reddish-pink birthmark (often called a "stork bite")
- Downward-slanting eyes, long eyelashes, and sometimes a small mouth with a high-arched palate
- Broad thumbs or big toes, which are often angled or wider than usual
- Thick dark hair and a larger soft spot (fontanelle) on the head

These features can change with time. Some babies, especially those with changes in the EP300 gene, may have milder or less obvious characteristics.

### Growth

At birth, most babies with RTS are within the typical range for weight and size. However, their growth often slows during infancy[4,21,22]. Doctors use RTS-specific growth charts to monitor development more accurately than standard NHS charts.

*(Please see Appendix B for Growth Charts)*

*Anna*

# Support for Families at Every Age

## Newborn (0-1 Years)

### Healthcare

#### Heart

Around one-third of babies with RTS are born with a heart difference[20]. They may have a hole between the major blood vessels or within the heart chambers. Usually these would close by the time a baby is born. Everyone with RTS should have heart tests, when they are diagnosed. This should include a heart ultrasound scan. A small number may need surgery later in childhood.

#### Sleep

Some babies sleep a lot in the first months. If your baby is very sleepy and not feeding well or losing weight, seek medical advice.

***(Please see Appendix C for Sleep Tips)***

#### Chest and Breathing

Babies with RTS can be prone to chest infections and colds, which may make feeding harder[4,9,10,17]. Keeping up with vaccinations and attending regular GP or hospital reviews can help manage these issues early.

#### Eyes, Kidneys and Hearing

Newborns with RTS should have:

- An eye test (to check for glaucoma or structural differences)
- A renal ultrasound (to check for kidney differences)
- Standard newborn hearing screening and vaccinations, as for all babies

#### Boys

Sometimes one or both testicles don't descend naturally[4,9,17]; your GP or paediatrician can arrange review and referral if needed.

#### Blood Sugar (Hypoglycaemia)

Low blood sugar levels can occur occasionally in newborns with RTS but are usually temporary and treatable with frequent feeds or glucose support. Persistent hypoglycaemia is very rare. If your baby is jittery, has weak muscles or has seizures, the doctors should test for low blood sugar.

# Support for Families at Every Age

## Newborn (0-1 Years)

### Healthcare

#### Feeding

Feeding difficulties are very common in the first year of life[4,9,10,17]. Babies with RTS may:

- Feed slowly or take a long time to complete feeds
- Struggle with breastfeeding due to low muscle tone (hypotonia) or poor coordination when sucking and swallowing
- Vomit frequently, sometimes with force ("projectile vomiting") due to gastro-oesophageal reflux
- Lose or gain weight slowly in the early months

These feeding issues can be stressful for families, but most babies improve with time and support. Some babies may need temporary help with feeding, such as a nasogastric or gastrostomy (G-tube), but this is usually short-term.

#### What Can Families Expect?

- Feeding and early growth may be challenging, but most babies improve by the end of their first year.
- Regular medical reviews help identify and manage any associated health concerns.
- With care and support, children with RTS continue to develop new skills and lead fulfilling lives.
- Parents often describe their children as happy, affectionate, and sociable.

#### Who Can Help?

- **Speech and language therapist/feeding specialist:** For swallowing and positioning
- **Paediatric dietitian:** For nutrition and weight management
- **Paediatric gastroenterologist:** For reflux or vomiting that persists

# Support for Families at Every Age

## Checklist for Families (Newborn)

You can use this checklist during appointments with your GP, paediatrician, or specialist team:

### Diagnosis and Early Support

- [ ] Has genetic testing confirmed RTS (CREBBP or EP300)?
- [ ] Have we been referred to a clinical geneticist or specialist nurse?
- [ ] Have we received written information or signposting to family support groups (e.g., RTS Support Group UK)?

### Feeding and Growth

- [ ] Is a feeding plan in place (e.g., breastfeeding support, reflux management)?
- [ ] Has my baby been referred to a dietitian or feeding team if needed?
- [ ] Is growth being tracked on RTS-specific growth charts (Stevens et al., 1990; Beets et al., 2014)?

### Health Screening and Follow-Up

- [ ] Has a heart check (echocardiogram) been completed or scheduled?
- [ ] Has my baby had an eye examination and kidney ultrasound?
- [ ] Are hearing screening and routine vaccinations up to date?
- [ ] Have blood sugar levels been checked if my baby seemed unwell or drowsy?

### Ongoing Care and Support

- [ ] Do we have regular follow-up with a community paediatrician or multidisciplinary team?
- [ ] Do we know who to contact if feeding or breathing problems worsen?
- [ ] Have we been referred for Early Years support or developmental therapy?
- [ ] Have we been given information about local respite, parent networks, or family support services?

# Support for Families at Every Age

## Practical Tips from Families (Newborn)

***(These tips are shared from other parents of children with RTS. Always consult with your child's paediatrician or specialist prior to implementing these tips)***

- Make a 'get to know you' appointment with your GP to introduce them to your baby. You 'll see them a lot so it's nice for them to be invested from the start and often means no messing around.
- Start Disability Living Allowance forms as soon as you can. It feels overwhelming to do but it takes time to come through.
- Accept any and every therapy you can get: speech and language (feeding and communication); physio; dietician; portage; OT. It's best to get in the system early. If accessing these services privately, be sure to check the specialist's' registration and qualifications.
- Get a cold-water steriliser if you are NG tube feeding to save time when you are sterilising en masse.
- Keep a diary of feeds, weight checks and reflux symptoms to share with your paediatrician.
- Go to baby sign and sensory classes. Be prepared that it will be hard to see 'typical' babies. But the more you get chatting to people you realise how many babies have things going on with them.
- Get your family involved early; there is often a nervousness that comes with the unfamiliar and more medically complex babies. The sooner they get involved the sooner they build confidence and treat them like every other family member.
- Be prepared for family members and friends to deny your child's diagnosis when they are little 'I had a friend who had a baby who also wasn't rolling at this age and they're just fine'. It comes from a good place and doesn't invalidate your baby or all the extra work you are putting in.
- Try different feeding positions or specialist bottles if advised.

**Recommended Resources**

NHS • Contact UK • Genetic Alliance UK

*For more information on **heart murmurs, chest infections, undescended testicles, hypoglycaemia** and **vomiting**, please see the International Guidelines and plain English document.*

***Please also seek medical attention.***

# Meet Anna

**Anna is 10 months old and slowly and steadily hitting her milestones.**

*Anna*

"Following a difficult pregnancy in which I suffered from severe polyhydramnios (excess fluid) caused by the baby not swallowing, Anna was born six weeks early on Christmas Eve via emergency c-section. The challenges in pregnancy to that point had been put down to a cyst in her abdomen with all genetic tests having come back clear multiple times. Anna was born with a head of dark hair (like me, we thought), very long eye lashes (like her brother, we thought) and a strawberry birthmark on her forehead (how sweet, we thought). She had an episode of high heart rate at 10 days old and got transferred to the Royal Brompton where it was discovered she had a hole in the heart (PDA) and the left side of her heart was dilated - genetic testing started again.

At six weeks old she had surgery to close the hole in her heart and the next day she simply wasn't right (now we know this was a bad reaction to anaesthetic, common in RTS). By that evening she was intubated and back in intensive care. The next day, reeling from her unexpected decline, a doctor very casually and unexpectedly told us they had rushed through a provisional genetic report, and she had Rubenstein Taybi Syndrome (Type 2). In a bid to quell our flabbergasted state the doctor said she would simply be 'short with large thumbs and toes and have severe intellectual and motility challenges', typed the name of the syndrome into my husband's phone and left. A frantic call to our genetic counsellor later and a two week wait for the official report and the diagnosis was confirmed.

Anna recovered from this episode, and we got out of hospital when she was 10 weeks old. Unsurprisingly given Anna's swallowing issues in the womb, feeding has been a challenge, and we came home with an NG tube. After she ninja pulled out the tube for the third time in a month and her persistent lack of weight gain I called her paediatrician and said I wanted to try her without it. They reluctantly agreed and she has thrived ever since. She is now happily sitting at the 25th centile on the weight chart (we ignore height!) and is the happiest baby.

She is slow and steady with her milestones but is getting there. At 10 months (8.5 months corrected because of her prematurity) she is just starting to attempt crawling. I have found these months very hard and selfishly I do sometimes wish I didn't know her diagnosis as I feel it spoiled our first few months together. I struggled to see past it, past the doctor's one line description of the syndrome and found myself frantically researching all day and all night. However, it has allowed us to put multiple early interventions in place, advocate for her and give her the best shot possible at reaching her potential. It has taken time, but I now know her for her and not her diagnosis - she is exceeding expectations in every way and, in summary, she is brilliant."

— ***Abbie, Anna's mum***

# Support for Families at Every Age

## Early Childhood (1-5 Years)

As your child grows, you'll begin to see more of their personality and progress in their development. Many children with RTS are cheerful, sociable, and affectionate. Early years are also a time to build routines and relationships with professionals who can support your child's learning and health.

### Care Coordination

Caring for a young child with RTS can sometimes feel overwhelming, juggling appointments, feeding routines, sleep, and therapies, all while balancing everyday life. Having a clear plan and coordinated approach can make a big difference.

In the UK, a community paediatrician usually plays a key role in coordinating your child's care across different specialists (e.g., cardiology, genetics, physiotherapy), with support from your GP where needed. Many families find it helpful to ask for a **Named Key Worker** or **Care Coordinator**, often provided through local NHS Community Child Health or Early Support teams.

**Tips**

- Keep a care folder or notebook with your child's medical letters, therapy reports, medication list, and appointment contacts.
- You can use free NHS templates such as the **My Health and Care Passport**.
- Bring this folder to all appointments so each professional has up-to-date information.
- Ask your local **Integrated Care Board (ICB)** or **Children with Disabilities Team** about access to coordinated health and social care planning under the Children and Families Act 2014.
- Charities such as Contact UK and Genetic Alliance UK offer practical guides and printable "care notebook" templates.

# Support for Families at Every Age

## Early Childhood (1-5 Years)

### Learning and Development

Every child with RTS develops at their own pace. Some children may take longer to reach milestones such as walking or talking, but early support makes a difference. Local authorities can offer **Early Years SEN (Special Educational Needs)** support and access to early education funding from **age 2** for children with additional needs.

Ask your GP or paediatrician for **referrals** to:

- **Physiotherapy:** For movement and coordination
- **Speech and language therapy:** For communication and feeding
- **Occupational therapy:** To help with play, self-care, and sensory needs

### Healthcare

#### Weight

Some children begin to gain excess weight early. Encourage regular physical activity such as swimming, dancing, or walking; many local councils and charities offer inclusive sports.

#### Dental

Children with RTS may have a high-arched palate or crowded teeth, so dental care is particularly important[9,23]. Register with a dental service early, and brush twice daily with fluoride toothpaste. Avoid putting your child to bed with a bottle or sippy cup.

***(Please see Appendix D for Dental Tips)***

#### Skin

Some children develop keloid scars (raised, pinkish bumps) after minor injuries or surgery[22]. These are harmless but can be uncomfortable; a dermatologist can advise on treatments.

#### Back and Mobility

If your child develops new walking difficulties, worsening constipation, or back pain, speak to your doctor about possible spinal (tethered cord) issues[9,17,23,24].

#### Sleep

Snoring, restless sleep, or pauses in breathing can be signs of sleep apnoea[9]. If you notice these, ask for a sleep study through your GP or ENT team.

***(Please see Appendix C for Sleep Tips)***

#### Constipation

Common in RTS and may cause discomfort or behaviour changes. A high-fibre diet, good hydration, and, if needed, prescribed laxatives can help[4,5,9,17].

# Support for Families at Every Age

## Checklist for Families (Early Childhood)

You can use this list to keep track of your child's appointments, questions, and progress. Take it with you to GP, paediatric, therapy, or hospital visits:

### Development and Learning

- [ ] Has my child been referred to Early Years services through our local council?
- [ ] Have we accessed physiotherapy, speech and language, and occupational therapy?
- [ ] Does my child have or need an Education, Health and Care Plan (EHCP)?
- [ ] Are milestones (e.g. walking, talking, toileting) being tracked and supported?

### Health and Daily Care

- [ ] Is constipation a concern, and have we discussed diet, hydration, or medication with our GP?
- [ ] Are there any concerns with growth, weight, or eating habits?
- [ ] Has my child seen a dentist (NHS community dental service if needed)?
- [ ] Have we asked about skin care or keloids after surgery or injury?
- [ ] Have we noticed any new walking difficulties, pain, or posture changes (possible tethered cord)?
- [ ] Has my child been checked for sleep apnoea or breathing problems (e.g. snoring, restless sleep)?

### Social and Family Life

- [ ] Does my child attend an inclusive nursery, playgroup, or SEND setting?
- [ ] Are we supporting communication at home (signs, visuals, or devices)?
- [ ] Do we have consistent strategies in place for behaviour and routines?
- [ ] Are we encouraging play, friendships, and activities with typical and SEND peers?

### Care Coordination and Support

- [ ] Do we have a named key worker or care coordinator (GP, nurse, or paediatrician)?
- [ ] Are all specialists sharing information and reports with each other?
- [ ] Do we bring our care folder to every appointment?
- [ ] Do we know how to access short breaks or respite care if needed?
- [ ] Have we contacted our local Integrated Care Board (ICB) or Children with Disabilities Team for social care support?

# Support for Families at Every Age

## Practical Tips from Families (Early Childhood)

***(These tips are shared from other parents of children with RTS. Always consult with your child's paediatrician or specialist prior to implementing these tips)***

- Encourage play with both typical and additional-needs peers; local SEND playgroups and inclusive activities help children build social skills.
- Use visual supports, simple sign language or picture symbols to support communication.
- Using songs, rhymes, or sensory toys can help with learning and daily routines; many children respond well to music and repetition.
- Maintain clear and consistent routines to support behaviour and reduce your child's anxiety.
- Take time for yourself; use local respite and short-break services where available (ask your social worker or GP).
- Connect with other support organisations (e.g., Contact UK, Scope, Family Fund)
- Toilet training will likely be delayed. Don't stress and push to do it before they are ready; stop and wait before trying again.
- Always take the child to the toilet between 20/30 minutes after they have eaten and then sit there until they go.
- Set alarms to take the child to the toilet, constantly try to sign toilet and celebrate when they manage to go on the toilet.
- Show the child their personalised flash cards of their toilet (ask school to do the same).

**Recommended Resources**

RTS UK • Contact UK • Scope • Family Fund • NHS • Genetic Alliance UK

*For more information on* ***sleep apnoea, constipation, keloids scars, back pain, high-arched palate*** *and* ***crowded teeth,*** *please see the International Guidelines and plain English document.*

***Please also seek medical attention.***

# Meet Willow

**Willow is 3 years old and is strong, determined, affectionate, and resilient.**

*Willow*

"Willow was born in 2022 and is now nearly four years old. She has Rubinstein-Taybi Syndrome (RTS), type CREBBP. She lives at home with her mum, Gemma, her dad, Danny, and her older brother, Wren, who is two years older than she is. Together, we are a busy and loving family, navigating life with both its challenges and its joys.

Willow is full of personality. She has wild dark hair that perfectly matches her wild spirit. She is affectionate, determined, and wonderfully strong-willed. In many ways, she is a typical three-year-old. She loves books, dancing, singing, and anything brightly coloured. She adores trying to join in with whatever her big brother Wren is doing whether that is playing, building, or charging around the house. Wren is neurodiverse, and although the siblings share some similar behavioural challenges, they also share a very special bond. Watching them grow alongside one another, each with their own strengths and differences, is one of the greatest privileges of our lives.

Willow has strength far beyond what her tiny frame suggests. She also has a temper that can surprise those who do not know her well. Learning to understand what is Rubinstein-Taybi Syndrome, what is typical toddler behaviour, and what is simply "pure Willow" has been an ongoing and sometimes humbling journey for us. Willow is currently non-verbal but communicates in her own ways and often her own made up signs! As a family, we are working on learning Makaton together. She has a regular speech and language therapist to support her ongoing development and the aim is to ensure Willow can communicate her needs to others. Willow is loving and affectionate, with a remarkable ability to win the hearts of everyone she meets.

Developmentally, Willow sits somewhere between worlds. In some areas she is very much a three-year-old; in others, she functions closer to a 12–18-month developmental stage. She takes longer to master new skills, but when she decides she is ready, she approaches them with fierce determination. She took a long time to become mobile and began by crawling backwards! After lots of support from her physio just before her third birthday, she began taking big, purposeful steps, and by three and a half she was walking. Whilst she is still developing in other areas she shows determination and a curiosity to the world around her.

Accessing the right educational setting for Willow has been a journey in itself. When the time came to consider preschool, it quickly became clear that finding a suitable placement would not be straightforward. Some settings felt she would not "keep up" in the toddler room, yet she was clearly too advanced for the baby room. She did not neatly fit into a box, and that meant we needed to think creatively and advocate more than we had ever expected.

# Meet Willow

**Willow is 3 years old and is strong, determined, affectionate, and resilient.**

*Willow enjoying a swim*

The local Child Development Centre and Willow's key person made an enormous difference. They supported us in applying for her EHCP and worked closely with the preschool setting, attending meetings and helping staff understand how best to support her. Their involvement ensured that the environment, expectations and strategies were appropriate for Willow's needs. The EHCP process was not simple. We quickly learned that there is no clear rulebook or step-by-step guide for navigating these systems. We asked questions, gathered evidence, learned new terminology, and advocated firmly sometimes in ways that initially felt uncomfortable. As a family, we celebrate Willow's wins and milestones. However, the EHCP process often requires a focus on what a child needs on their most challenging days. This shift in perspective can feel counterintuitive, but it is necessary in order to plan effectively for the long term.

A phase amendment to Willow's EHCP was pursued to ensure that it accurately reflected her needs. That amendment ultimately resulted in her securing a place at a local SEN school to begin Reception in September 2026. While we understandably feel apprehensive about this next step, we also feel far more confident than we once did. We understand the systems more clearly and know how important it is to surround ourselves with people who can support and advocate alongside us. Willow currently attends preschool three mornings a week with 1:1 support and continues to grow in confidence within that environment. Seeing her included, supported and valued has made every meeting and every piece of paperwork worthwhile.

Hospital visits, ongoing assessments and CPAP remains part of Willow's life. We are grateful for the ongoing support of her respiratory consultant at Southampton Children's Hospital, who continues to work closely with us as Willow becomes less tolerant of her overnight mask and alternative options are explored. Her care still involves what can feel like a head-to-toe checklist of professionals -ophthalmology, cardiology, respiratory, physiotherapy, orthotics, speech and language therapy, and more. What once felt overwhelming has gradually become part of our family's normal rhythm. We focus on what Willow needs in the present, addressing each phase as it comes.

The RTS family support network has been an invaluable source of knowledge, reassurance and practical advice. Guidance from families who have walked this path before has made an enormous difference. Often, the most powerful support comes from those who truly understand. Rubinstein-Taybi Syndrome is part of Willow's story, but it does not define her. She is joyful, stubborn, loving and unforgettable. She is Willow and she lights up every room she enters."

*— Gemma, Willow's mum*

# Support for Families at Every Age

## Younger Children (6-11 Years)

Seeing your child attend school, make friends, and learn new skills is an exciting milestone. Many children with RTS enjoy school and thrive when given the right support.

Your child's school experience may look different depending on their needs, but every achievement, no matter how small, is a big step forward.

### School Support

At this age, your child will be developing their independence and confidence. They may need extra support at school to help them achieve their full potential.

In the UK, children with RTS are usually supported through **Special Educational Needs and Disabilities (SEND)** provision. This may include:

- An **Education, Health and Care Plan (EHCP)** setting out your child's learning goals and support needs.
- Support from a **teaching assistant, speech and language therapist,** or **occupational therapist.**
- **Assistive technology** or **communication aids** to help your child express themselves.

**Tip**: Keep a copy of your child's EHCP, school reports, and therapy notes together in your care folder. Bring it to meetings so everyone can work towards the same goals.

***(Please see Appendix A for EHCP Tips)***

### Communication and Social Skills

Children with RTS may continue to experience speech or language delays. Support from a **speech and language therapist (SALT)** can help improve communication and reduce frustration.

For children who find speech difficult, **augmentative and alternative communication (AAC)** tools, such as picture boards, symbols, or electronic devices can make a huge difference. These tools also help children connect socially, build friendships at school and reduce the likelihood of your child developing behaviours of concern.

# Support for Families at Every Age

## Younger Children (6-11 Years)

### Friendship and Inclusion

Children with RTS are known for their warm, friendly nature, but some may struggle with behaviour changes or frustration, especially when routines change or communication is difficult.

**Tips**

- Keep daily routines predictable and visual.
- Praise effort, not just achievement.
- If you are concerned about your child's behaviour, work with school staff and, if needed, a child psychologist or behavioural specialist.
- Access resources about behaviours of concern to understand how these develop; understanding why behaviours occur may reduce the risk of them developing (FIND, Challenging Behaviour Foundation).
- Support your child to join in both mainstream activities and SEND-friendly groups; this builds confidence and lifelong friendships.
- All children benefit from being part of their local community; clubs like Scouts, Guides, inclusive sports, and arts sessions can offer great opportunities to socialise and grow.

### Healthcare

**Dental**

Children with RTS often have crowded teeth, a small mouth, or a high-arched palate, which can make brushing tricky. Some may have one or two "talon-shaped" teeth, which are harmless but may look unusual[4,5,9,17].

*(Please see Appendix D for Dental Tips)*

**Weight Management**

Some children with RTS begin to gain extra weight during the school years, particularly boys. Girls are more likely to gain weight in adolescence. Encouraging a healthy diet and regular activity helps your child stay well and confident[4,9,21,26].

# Support for Families at Every Age

## Checklist for Families (Younger Children)

Use this checklist at appointments or school reviews to help plan your child's care and learning support:

### Health and Daily Care

- [ ] Regular dental check-ups (community dentist if needed)
- [ ] Growth and weight monitored (using RTS growth charts if available)
- [ ] Hearing and vision checked annually
- [ ] Support in place for constipation or reflux if relevant
- [ ] Review of any heart, kidney, or orthopaedic conditions
- [ ] Sleep and behaviour discussed with GP if concerns persist with referrals to specialist services (e.g., sleep services, psychology services, behavioural support teams)

### Education and Development

- [ ] EHCP in place or under review
- [ ] School-based therapy support (SALT, OT, physiotherapy)
- [ ] Communication aids or assistive technology in use if needed
- [ ] Behaviour plan or emotional support strategies in place
- [ ] Opportunities for inclusion in community or after-school activities

### Family and Wellbeing

- [ ] Carer's assessment or family support through local council if needed
- [ ] Regular contact with RTS UK or local parent groups
- [ ] Time for self-care or short breaks identified

# Support for Families at Every Age

## Practical Tips from Families (Younger Children)

***(These tips are shared from other parents of children with RTS. Always consult with your child's paediatrician or specialist prior to implementing these tips)***

- Keep in touch with your child's medical team, even during stable periods, to help plan for future needs.
- Use an electric toothbrush if your child tolerates it better.
- Attend school review meetings regularly and don't hesitate to ask for updates or adjustments to the EHCP.
- Help your child practice independence at home; dressing, tidying toys or helping with small chores.
- Talk with your child about what they enjoy and what helps them learn best.
- Begin gentle conversations about their future; hopes, dreams and what makes them happy.
- Encourage fun physical activities like swimming, dance, football or walks in the park. Try inclusive local clubs.
- Use visual menus and simple routines to support healthy eating.
- If you're concerned about weight gain or growth, ask your GP for referral to a paediatric dietician.
- When cutting nails, lightly squeeze the top of the finger before trimming to reduce sensory issues.
- For light sensitivity, if your child wears glasses, ask for reaction lenses.
- Always take the child to the toilet between 20/30 minutes after they have eaten and then sit there until they go.
- Set alarms to take the child to the toilet, constantly try to sign toilet and celebrate when they manage to go on the toilet.
- Show the child their personalised flash cards of their toilet (ask school to do the same).

### Recommended Resources

RTS UK • Scope • Family Fund • IPSEA • Contact UK
Royal College of Speech and Language Therapists • ACE Centre • Your local SENDIASS

*For more information on **crowded teeth** and **high-arched palate**, please see the International Guidelines and plain English document.*

***Please also seek medical attention.***

# Meet Phoenix

**Phoenix is 5 years old, recently started Reception and likes to play with her sister.**

*Phoenix*

"Our youngest daughter, Phoenix, was born in the peak week of the first lockdown. She was diagnosed with Rubinstein-Taybi Syndrome in November 2021 at 19 months old. I had a normal pregnancy until my 36-week scan when excessive amniotic fluid (polyhydramnios) was detected.

Phoenix was born with a red mark on her head and found it hard to swallow. She presented with a funny shaped ear and head and a squint, which required glasses just before her first birthday! Following a visit to a paediatrician spurred on by evident delays in her development and the fact that she couldn't sit properly even though she had turned one, we were advised to look into genetic testing and start physiotherapy and speech and language sessions. Phoenix responded well to physiotherapy and was walking shortly after her second birthday.

When I looked into getting her a place in nursery, I was advised that the nursery which her sister had attended, would not be able to meet her needs and so I fought hard to get her an EHCP. This was a challenging process, and I had to appeal the initial decision to not even review Phoenix, but I am glad we refused to give up! Phoenix has benefited greatly from having a Learning Support Assistant (LSA) from a very young age as she would not have been able to access the curriculum without one. This has most likely been instrumental in the fact that she has just joined reception in a mainstream school.

Through Phoenix's EHCP, we had several contacts at the nursery and in local centres with Physiotherapists, Occupational Therapists and Speech and Language Therapists. This required constant monitoring, however, as there were sometimes problems with over subscription to these services, but I do believe that these really helped Phoenix, especially the physiotherapy. We learnt Makaton as a family, and this helped communication. We have always talked to Phoenix normally as she seems to fully understand what we say to her (and when she is unresponsive it is normally out of choice!)

When the time came for us to apply to primary schools, we did look at a special needs school as well as her current school. It was really hard to make a decision, but we spoke at length to the SENCOs at both schools. It was agreed that if she attended the special school, she would be one of the more capable children and this could inhibit her development whereas if she was to attend the mainstream option (which also has a provision for children with Autism and ADHD), this might enable her to meet her full potential. The mainstream school is also next to a special needs facility, and we were assured that this would be a source of additional advice for supporting Phoenix if it was needed.

# Meet Phoenix

**Phoenix is 5 years old, recently started Reception and likes to play with her sister.**

*Phoenix*

We therefore arranged for the SENCO from the Mainstream school to visit Phoenix in nursery so that they could see how she operates in an educational setting. They suggested that due to her stage of development and small stature, she would benefit from deferring a year. This has also helped a great deal. Phoenix has an April birthday, and we have seen numerous developmental leaps since she turned 5.

Having only been able to say “mama” since she was 2, she has slowly started to say other words and since going into reception in September, she has learnt the alphabet and has started to form sentences! Whilst her speech is often unclear and at times difficult to understand, she is gradually working out how to use her mouth properly (she has low muscle tone) to be able to sound the various consonants. Last week I walked into her bedroom, and she was sounding out words in her phonics book out of choice!

Phoenix is an extremely determined little girl, and it seems that she does things at her own pace. When she is not ready to do something, she will throw a full tantrum, only to perform the task at a later date and time of her choice. There have of course been several challenges along the way, but we endeavour to focus on the positives, of which there are many. Her LSA has always pushed her to do the same things as “typical” children and has encouraged us not to differentiate too much from her sister… this has really helped with her development.

Phoenix was also diagnosed with autism last year and this has helped people understand some of the ways that she presents as it is more understood than her syndrome.
We take each day as it comes, and we have learnt so much from her. We are getting particular pleasure at watching the improvements in the interaction with her sister as they are starting to form a real attachment and are finally beginning to play together and make each other laugh.

We are grateful to the RTS Support Group for bringing together so many families who have their own experience with RTS. It has certainly helped us on our journey with Phoenix…”

— ***Elisa, Phoenix’s mum***

# Support for Families at Every Age

## Adolescence (11-18 Years)

### Navigating Puberty

Adolescence can be a time of exciting change, and sometimes new challenges for every young person and their family.

For young people with RTS, puberty usually begins around the same time as their peers, **between 9 and 12 years** of age[9,17,21]. Physical changes and hormonal shifts happen at a typical pace, but understanding, emotions, and confidence may develop at a different rate.

Parents often find this stage easier when they plan ahead, keep communication open, and build strong routines around health, hygiene, relationships, and self-care.

### Physical Changes

Most young people with RTS go through puberty typically.

**Girls:** Breast development usually begins around 10–12 years, with periods starting about 1–2 years later (average age 13–14)[17].

**Boys:** Puberty tends to start between 9 and 13 years.

It can help to talk to your child early about what to expect. Use clear, factual language and visual aids or storybooks to explain changes such as hair growth, body odour, erections, and menstruation.

### Sexual Health

Adolescents with RTS develop the same natural curiosity about relationships as their peers[4,9,10].

They may want friendships or even romantic connections, and these should be supported with clear, respectful boundaries and education suited to their level of understanding.

**Tips**

- Talk about private vs public behaviour, consent, and personal space.
- Use visual stories or social scripts to explain safe touch and appropriate affection.
- Teach who they can trust if they feel uncomfortable or unsure.
- Encourage safe friendships through youth clubs, school, or supported groups.
- Discuss contraception and pregnancy prevention if relevant; your GP or sexual health clinic can help..
- People with RTS may wish to discuss options with a genetic counsellor if they wish to have a family of their own.

### Sleep

Teenagers with RTS, like their peers, may want to stay up late and sleep in longer. This is due to natural changes in melatonin and body clock rhythms[27].

***(Please see Appendix C for Sleep Tips)***

# Support for Families at Every Age

## Adolescence (11-18 Years)

### Healthy Lifestyle

Teenagers, especially girls, may begin to gain extra weight at this age[4,9,10,21,26].

Encourage balance rather than restriction.

**Tips**

- Eat regular meals with fruits, vegetables, and wholegrains.
- Limit sugary snacks and drinks.
- Stay active through activities your teen enjoys; walking, swimming, dance, or cycling.
- Many local councils offer inclusive sport and fitness programmes for young people with additional needs.
- If weight gain becomes a concern, ask your GP for referral to a dietitian or community health team.

### Behaviour

Hormonal changes and social pressures can affect mood and behaviour. Teens with RTS may become more sensitive, frustrated, or anxious, especially during big life changes.

**Tips**

- Keep daily routines consistent (but not overly rigid) and use visual schedules to support transitions.
- Prepare for new or noisy environments by explaining what to expect.
- Use calming strategies such as deep breathing, music, or sensory activities.
- Seek help from a child psychologist or CAMHS (Child and Adolescent Mental Health Service) if behaviour begins to impact wellbeing.

### Future Planning

During secondary school, your child's **Education, Health and Care Plan (EHCP)** should be reviewed regularly. It can include new goals such as developing independence, social skills, or planning for life after school. ***(Please see Appendix A for EHCP Tips)***

**Talk to your child's school about:**

- Life skills training (e.g. travel, cooking, money handling)
- Opportunities for supported work experience or volunteering
- Preparing for transition to college, apprenticeships, or day programmes

# Support for Families at Every Age

## Checklist for Families (Adolescence)

Use this checklist to guide appointments or school planning meetings:

### Health and Development

- [ ] Annual GP and dental check-ups
- [ ] Vision and hearing reviewed regularly
- [ ] Growth and weight monitored using RTS growth charts
- [ ] Review of puberty and menstrual health
- [ ] Discussion about contraception or sexual health if relevant
- [ ] Sleep patterns discussed with GP or paediatrician
- [ ] Emotional wellbeing or behaviour reviewed by school or CAMHS

### Education and Independence

- [ ] EHCP reviewed and updated yearly
- [ ] Transition planning for post-16 options started (college, supported internships, etc.)
- [ ] Support for life skills, social skills, and independence
- [ ] Access to inclusive or supported youth clubs and sports

### Family and Support

- [ ] Regular contact with RTS UK or local support network
- [ ] Information on respite, short breaks, or carer support
- [ ] Parent wellbeing check-in with GP or local carers' service

# Support for Families at Every Age

## Practical Tips from Families (Adolescence)

***(These tips are shared from other parents of children with RTS. Always consult with your child's paediatrician or specialist prior to implementing these tips)***

- Keep honest, age-appropriate communication about health, body changes and relationships.
- Continue with regular health check-ups; teeth, vision, growth, heart and sleep.
- Maintain links with school therapists and your GP to monitor changes in learning or behaviour.
- Encourage safe independence (travelling with supervision, managing money, making small decisions).
- Keep your child involved in community clubs or volunteering to build confidence and friendships.
- Look after your own wellbeing; connect with other RTS families through RTS UK.
- Create a simple morning routine for showering, dental care, deodorant, and hygiene.
- Practice how to manage periods before they begin, include packing supplies in a school bag and knowing who to ask for help.
- For boys, explain body changes such as erections or nocturnal emissions in calm, factual terms.
- If periods are very heavy or irregular, your GP may suggest contraceptive options such as the pill to help regulate cycles.
- Reinforce that these topics are private, and talk about who they can safely discuss them with (e.g. parents, GP, school nurse).
- If your teen shows discomfort or touches private areas frequently, it may signal irritation or infection; check with your GP.
- If periods cause pain or distress, your GP can refer you to a paediatric gynaecologist or discuss options to help manage cycles safely.
- When cutting nails, lightly squeeze the top of the finger before trimming to reduce sensory issues.
- For light sensitivity, if your child wears glasses, ask for reaction lenses.

**Recommended Resources**

RTS UK • Scope • Brook • NHS • Mencap • YoungMinds • Preparing for Adulthood
Mind • Your local CAMHS • Your local SENDIASS

# Meet Morgan

**Morgan is 17 years old, likes to make people laugh and enjoys trains.**


*Morgan with a skip lorry*

"My name is Morgan, I am currently (2+4) x 3-1 years old, I was diagnosed with RTS when I was 14, this along with my other conditions makes me very unique and interesting. I have been to the RTS conferences since I was diagnosed, while I was there I met a man called Greg who is very similar to me, his face and eyebrows are the same shape as mine, we look so similar some people might think we are twins.

I have had a variety of unique hobbies over the years including guttering, fireplaces, arm barriers and level crossings. My current hobbies are rubbish skips, Rick Astley, collecting band T-shirts, maths and trains. Maths and trains have been hobbies for a long time.

I am very good at maths, recently I sat the higher maths GCSE and I have a B. I like to tell jokes and make people laugh; I would like to be famous.

If you have just been diagnosed, remember that your diagnosis means that you are unique and it is something that you should be proud of, you can have whatever hobbies you want to have and ignore anyone who tells you otherwise."

— ***Morgan***

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"Morgan was born at term and was a very quiet, placid baby, too much so in ways such as no real response to doctors examining him as a younger child.

Morgan's early development was very delayed he didn't start sitting, rolling over or pulling to stand until he was around 1 year old, he took his first steps at around 2 and a half years.

Morgan has worn glasses since baby age due to being longsighted, he is very sensitive to light changes e.g., going from inside to outside and asking that he is given reaction lenses has made a big difference to him.

Morgan's speech was delayed with it taking until 5 years of age for non familiar people to understand him, although initially delayed he did quickly transition to sounding like a little professor using long words I wasn't aware he knew such as asking to go to Bedfordshire when he was tired, he has always been a good sleeper and very sensible with it, he has researched the amount of sleep he should have for his age and looks to stick with it.

# Meet Morgan

**Morgan is 17 years old, likes to make people laugh and enjoys trains.**

*Morgan at a train station*

At an early age due to his developmental delay Morgan had numerous genetic blood tests with nothing detected and at age 5 he was diagnosed as autistic, something which I now wonder if it would have been diagnosed if his RTS diagnosis came first due to Autistic traits being identified as a characteristic of RTS.

At 11, Morgan woke one day refusing to walk, after difficulty in getting a reason explained by Morgan and numerous medical reviews, he was diagnosed with spinal compression fractures and idiopathic Juvenile osteoporosis another rare syndrome. It was at this point we agreed further genetic testing was needed and after travelling the world Morgan's bloods made it to Germany where a diagnosis of RTS was made.

Morgan is a unique superstar who loves making people laugh and regularly does with his dad jokes, he has a passion to be famous and when you meet him you will see why we believe this will happen for him one day. Morgan is a joy to be around including his blunt honesty which we all wish we were confident enough to have ourselves."

— ***Kate, Morgan's mum***

*Morgan with Rick Astley*

*Morgan with Greg*

# Support for Families at Every Age

## Transitioning to Adulthood (16-25 Years)

The move from school to adulthood is an exciting and sometimes emotional stage. For young people with RTS, it's a time to explore independence, develop life skills, and plan what comes next; whether that's further education, supported work, volunteering, or community activities.

Every young person has their own strengths, hopes, and dreams. Starting early, with support from family, school, and health professionals, helps make the transition smoother and more positive.

### Life After School

In the UK, **transition planning** usually begins around **age 14**, when your child's Education, Health and Care Plan (EHCP) starts to focus more on preparing for adulthood. ***(Please see Appendix A for EHCP Tips)***

This **plan** should identify your young person's:

- Interests, strengths and goals
- Learning and work aspirations
- Independent living skills
- Health and wellbeing needs
- Social and community participation

**Tips**

- At your child's annual EHCP review, ask the school and local authority about Preparing for Adulthood (PfA) outcomes. These include education, employment, independent living, and friendships or relationships.
- Ask your child's school about supported internships, college courses, or day programmes. Many local authorities offer "Transitions Teams" who can guide families through the process.

### Employment and Volunteering

Many adults with RTS enjoy structured routines and benefit from meaningful **activities**. Depending on their abilities and interests, this might include:

- Volunteering in the community
- Part-time or supported employment
- Attending a specialist college or day centre
- Joining local clubs, sports, or arts programmes

Organisations such as Mencap or Scope run employment and skills schemes for young people with learning disabilities.

# Support for Families at Every Age

## Transitioning to Adulthood (16-25 Years)

### Independent Living

As your young person matures, your family may start thinking about where they'll live in the future. Some adults with RTS live at home with family, while others move into supported or shared housing within their community.

Options may include:

- Living at home with support from carers or respite services
- Shared supported housing with other young adults
- Supported living schemes offering independence with help as needed
- Your local council's Adult Social Care Team can carry out a **Care Act Needs Assessment** to determine what support your family is entitled to. They can also advise on funding and housing options.

### Finances and Benefits

Turning 16 or 18 can bring important financial and legal changes.

**Age 16:** Young people can apply for Personal Independence Payment (PIP) to help with extra costs of disability.

**Age 18:** Most become eligible for Universal Credit, which can include a disability element.

Families can also explore Carer's Allowance if they provide substantial daily support. Once your child turns 18, they are legally an adult and can make their own decisions unless assessed otherwise. Some families choose to put **legal supports** in place, such as:

- Lasting Power of Attorney (LPA) for health or finances
- Appointeeship to manage benefits
- Deputyship through the Court of Protection (for more complex needs)
- Supported decision-making, allowing independence with guidance

### Transitioning Healthcare

It's important to plan the move from paediatric to **adult health services** before age 18. Ask your child's GP or paediatrician:

- When will my child transfer to adult care?
- Can we meet the new adult healthcare team in advance?
- What medical records should we bring?
- Keeping an up-to-date care notebook or health passport helps new doctors understand your child's medical history, medication, and support needs.

# Support for Families at Every Age

## Checklist for Families (Transitioning to Adulthood)

Use this checklist to guide appointments or school planning meetings:

### Health and Care

- [ ] Transition plan discussed with paediatric and GP teams
- [ ] Medical summary and health passport prepared
- [ ] Adult healthcare providers identified (GP, specialists, dentist)
- [ ] Regular reviews for heart, sleep, or growth concerns
- [ ] Consent, confidentiality, and decision-making options discussed

### Education and Employment

- [ ] EHCP reviewed with “Preparing for Adulthood” goals
- [ ] Post-16/19 education or supported college options explored
- [ ] Work experience, volunteering, or supported internships arranged
- [ ] Travel or life skills training started

### Living and Finance

- [ ] Care Act needs assessment requested from local council
- [ ] PIP, Universal Credit, and Carer’s Allowance checked or applied for
- [ ] Discussion held on housing, supported living, or staying at home
- [ ] Legal supports explored (LPA, appointeeship, deputyship)

### Family and Community

- [ ] Connected with local carer or RTS support group
- [ ] Short breaks or respite accessed through Adult Social Care
- [ ] Social and leisure opportunities identified for young adult

# Support for Families at Every Age

## Practical Tips from Families (Transitioning to Adulthood)

***(These tips are shared from other parents of children with RTS. Always consult with your child's paediatrician or specialist prior to implementing these tips)***

- Start transition planning early, ideally by age 14.
- Keep your child involved in all discussions about their future.
- Update their EHCP annually to reflect changing needs and aspirations.
- Visit potential colleges, supported living schemes or workplaces together.
- Encourage independence in small steps; travel training, budgeting or cooking.
- Stay connected with other RTS families for shared experiences and ideas.
- Remember that adulthood is a journey; each step builds confidence.

**Recommended Resources**

RTS UK • Preparing for Adulthood • Contact UK (Transition) • Contact UK (Benefits)
Mencap (Employment) • Mencap (Mental Capacity Act) • Scope • Shelter • GOV.UK
Citizens Advice • Turn2Us • NHS (Adult Care) • NHS (Transition) • Together for Short Lives
Your local SENDIASS

# Meet Greg

**Greg is 23 years old and is doing an apprenticeship at a hotel in Bournemouth.**

*Greg playing cricket*

"Greg was born in 2002 and is now 23. His parents are Julian and Anne, and he has a brother, Mark, who is five years older.

Greg's life as a newborn was remarkable mainly due to the absence of sleep. If indeed it was possible to get him to sleep, it was mainly because of him being held firmly in Anne's arms. This behaviour lasted for the first five or six years and there were too many nights where after a couple of hours in bed he would then be awake for the rest of the night. We tried a sleep study to see if he had sleep apnoea, but he slept for such short intervals the outcome was inconclusive. He was prescribed melatonin, but this had no appreciable effect.

Alongside this, Anne was increasingly concerned that there were unidentified issues present. Greg was late to achieve all his milestones, but no diagnosis was reached other than a developmental delay. He showed no concept of fear and would talk to anyone.

Mark was an active child and enjoyed sports, so Greg sought to join in with this and whilst not able to take part at the same level as Mark he enjoyed trampolining and swimming. Having spent his junior school years at a private school which allowed for small class sizes, it was felt that Greg's educational needs would be better met if he moved to a special school for his secondary education. At this stage it was clear that Greg was struggling with an intellectual delay, fine motor skill problems, dyspraxia and difficulty with his expressive speech. He was also diagnosed with ADHD. From an educational perspective, this move was not a total success, but it allowed Greg to explore adapted sports, and he started playing football for a local disability team and he also joined the Hampshire Cricket Club disability programme. The benefit of this was that these were mixed disability teams and so he was not mixing just with those with an intellectual disability but a group of wider ranging individuals.

During his secondary school years, Greg, who had taken part in the DDD study was diagnosed at age 14 with RTS Type 2 (EP300) and this helped explain other issues such as his tendency to gag and be sick if he ate too quickly, dental issues, and aspects of his appearance. The diagnosis was difficult for Greg to understand, and he had a period of feeling very isolated by virtue of his "differentness". It was a real turning point when we went to our first RTS conference for him to see others like him.

# Meet Greg

**Greg is 23 years old and is doing an apprenticeship at a hotel in Bournemouth.**


*Greg at his apprenticeship*

In 2020, Greg started at Foxes Hospitality and Catering College in Minehead, Somerset where he completed a NVQ level 1 qualification in Hospitality in July 2022. Greg has always been a very sociable boy and, having grown up primarily in an older family, he has been comfortable talking to adults from a young age. Having left College, he then was focussed on finding work, taking his lead from his brother who was by now well established in his career. Mark has been a real mentor for Greg. Mark had a job in a local newsagents while he was at school so Greg decided he wanted to be a paper boy (ably assisted by Mum!!). Mark had holiday jobs during university so again Greg wanted to ensure he was gainfully employed. Some of the jobs Greg applied for led to truly horrid rejections and while he moved on quite quicky from the disappointment, his parents struggled to develop the necessary thick skin. One of his most enjoyable placements was to volunteer at a local charity shop. Greg was very fortunate that the manager treated him very much like other members of the team. Anne popped in one day only to find him “out the back” as it was his turn to make the coffee.

In August 2023, Greg was introduced through a friend to a family run hotel in Bournemouth. After working in their restaurant for a year, they offered him an apprenticeship which is due to finish soon and the offer of a permanent job after that looks to be on the table. The hotel is award winning for its inclusivity and was the first hotel in the UK to have a changing places bathroom. Greg is however the first apprentice they have taken on with additional needs. The offer was conditional on him being the same as other apprentices – no lifts in from Mum if it was an early start. Rather he was expected to travel under his own steam. Thank goodness for the Government Access to Work scheme which has been invaluable. The main delight however has been for him to work in a mainstream environment where he is seen just as Greg. He may need to take a bit more time to learn a new skill, but he is never late, or off sick and is recognised as a core member of the front of house team.

The next major step will be for Greg to move from the family home. We are confident he will be able to live independently in time, but he will need on-going support not least with financial matters and maintaining a healthy diet. This transition will be the next big thing. Poor sleep is no longer a concern mainly due to Greg’s level of activity. Occasionally however issues around his gag reflex can arise.

Greg’s late grandfather was one of his greatest fans. His words “that boy is going to surprise you” are often repeated amongst us. They sustain us in the hard times and seek to remind us how far Greg has come.“

*— Anne and Julian, Greg’s parents*

# Support for Families at Every Age

## Adults (25+ Years)

As adults with RTS get older, their lives can continue to be active, social, and fulfilling. Many enjoy hobbies, friendships, and community activities. However, their care needs and health priorities may change over time.

Medical knowledge about ageing in RTS is still developing, and many adult healthcare professionals may not be familiar with the condition. Regular check-ups and proactive planning help maintain health, comfort, and independence through adulthood.

### Healthcare

Some of the same health challenges seen in childhood can continue into adulthood (weight management, spine curvature, vision/hearing issues, keloids, ingrown nails, constipation, sleep difficulties etc.)[9,16].

### Tips

- Continue regular reviews with specialists such as cardiology, orthopaedics, gastroenterology, neurology, endocrinology, and ophthalmology.
- Keep a care notebook or digital health passport that summarises medical history, current medications, and contact details for healthcare professionals.
- If possible, remain under the care of or in contact with a clinical geneticist who understands RTS.

### Common Health Issues

#### Behaviour

Adults may show more repetitive or rigid behaviours, or experience anxiety, impulsivity, or low mood.

#### Gastrointestinal

Constipation remains common. A balanced diet, plenty of fluids, and prescribed laxatives if needed can help.

#### Skin

Keloids and nail infections can increase with age. Regular skin checks help prevent complications.

#### Sensory Changes

Gradual loss of vision or hearing may occur; annual eye and hearing tests are recommended.

#### Sleep

Sleep apnoea and increased need for rest are common; discuss these with your GP or a sleep clinic.

***(Please see Appendix C for Sleep Tips)***

# Support for Families at Every Age

## Adults (25+ Years)

### Mental Health

**Behavioural changes** can sometimes become more noticeable in adulthood[16,28]. These might include frustration, impulsivity, strong adherence to routines, or difficulty with attention. Such behaviours can sometimes mask underlying physical discomfort (e.g. pain, constipation, infection, or anxiety). Many people with RTS have a high pain threshold; behavioural changes such as irritability or withdrawal may be early signs of discomfort or illness.

**Tips**

- Rule out medical causes first with your GP.
- Consider a referral to a psychiatrist, psychologist, or behaviour specialist familiar with learning disabilities.
- Encourage daily routines, physical activity, and meaningful social contact to promote wellbeing.

### Communication

Many adults with RTS continue to use speech, sign language, or a combination of both. Even if speech is limited, understanding is often much greater than expression.

**Makaton** remains a popular and effective communication method in the UK. It combines speech, signs, and symbols and can be used throughout life to support understanding and self-expression.

### Community Living

Many adults with RTS enjoy social and occupational activities, including supported work, volunteering, or day services. Staying engaged helps maintain mental and physical wellbeing.

Ideas for community inclusion:

- Attend local day centres, adult learning classes, or arts and sports programmes.
- Explore volunteering or supported employment schemes through organisations like Scope, Mencap, or Leonard Cheshire.
- Stay connected with both peers with disabilities and typically developing friends to encourage social balance.

# Support for Families at Every Age

## Adults (25+ Years)

### Future Planning

As your loved one and your family age, it's important to plan for long-term support and stability. Conversations about future living arrangements, finances, and care responsibilities can feel difficult but are best started early.

Key areas to think about:

- Who will help your loved one make decisions in the future?
- Where will they live if you can no longer provide daily care?
- Have you written a will or appointed a Lasting Power of Attorney (LPA) or Deputy through the Court of Protection?
- Have you discussed advance care planning (e.g. medical wishes or end-of-life care preferences)?
- Have you explored financial options such as a trust or appointeeship to safeguard their benefits and assets?

### Supporting Parents and Carers

Caring for an adult with RTS can bring great joy but also new challenges. It's important to look after your own wellbeing, maintain social connections, and plan for times when you may need rest or extra help.

You are not alone. Many UK charities offer carer support, advice, and funding for breaks:

**Carers Trust** • **Family Fund** • **Contact UK**

# Support for Families at Every Age

## Checklist for Families (Adults)

Use this checklist to guide annual reviews, health checks, and ongoing planning across all areas of care:

### Medical and Physical Health

- [ ] Annual health check with GP
- [ ] Vision and hearing checked yearly
- [ ] Weight, diet, and constipation monitored
- [ ] Skin, wound healing, and nail health reviewed
- [ ] Sleep and behaviour discussed regularly with GP or specialist nurse
- [ ] Regular reviews with key specialists (e.g. cardiology, gastroenterology, neurology, ophthalmology)

### Mental and Emotional Health

- [ ] Assessment for anxiety, mood, or behavioural changes
- [ ] Access to psychologist or psychiatrist through Community Learning Disability Team or GP referral
- [ ] Daily routines and social engagement maintained

### Communication and Therapy

- [ ] Speech therapy or Makaton support reviewed
- [ ] Feeding or swallowing needs monitored
- [ ] Communication plan shared with all carers and professionals

### Living and Long-Term Planning

- [ ] Review of housing or supported living arrangements
- [ ] Care plan updated regularly with Adult Social Care
- [ ] Financial supports (PIP, Universal Credit, Carer's Allowance) confirmed
- [ ] Will, LPA, and future care plans discussed and documented

### Family and Carer Wellbeing

- [ ] Carer's assessment completed with local authority
- [ ] Access to respite or short breaks
- [ ] Emotional support and peer connections maintained

# Support for Families at Every Age

## Practical Tips from Families (Adults)

***(These tips are shared from other parents of children with RTS. Always consult with your child's paediatrician or specialist prior to implementing these tips)***

- Where a family member wishes to benefit someone with RTS, ensure that their will is drafted appropriately and consider the use of trusts
- Explore grants available through www.gov.uk/access-to-work for the cost of travel and necessary equipment
- Liaise with your local pharmacy to arrange for prescriptions to be ordered automatically and delivered to the individual's home
- Look at accessible travel providers to explore going on holiday

**Recommended Resources**

RTS UK • NHS • Genetic Alliance UK • Mind • Scope • GOV.UK • Carers UK

Mencap (Health) • Mencap (Work) • Mencap (Wills) • The Makaton Charity

Royal College of Speech and Language Therapists

Your local Community Learning Disability Team • Your local Learning Disability Nurse Directory

*For more information on* ***scoliosis, keloids, ingrown nails, constipation, sleep apnoea*** *and* ***vision or hearing loss****, please see the International Guidelines and plain English document.*

***Please also seek medical attention.***

# Family Information and Support

## Siblings: What is it Like to Have a Brother or Sister with RTS?[29-34]

**(By Dr Karen Aldred D. Clin. Psychol., BSc)**

What is it like to have a sibling with RTS? Well, my sister Sue has RTS so I should know! Or should I? The thing is, just as every person with RTS is different so is every sibling's experience. How it is for me isn't necessarily how it is for everybody. Sue was born when I was three, so I can't remember much before she came along. The things you grow up with tend to feel typical even if they might not seem so to others. So, for me having a sibling with RTS seems typical and having a sibling without RTS would seem quite strange!

As well as having a sister with RTS I also happen to be a clinical psychologist by profession. I have learned something from my professional training and my day-to-day job about how people are affected by having someone with a disability in the family. In this article I am going to tell you what I have learned from speaking to siblings of people with learning disabilities and from looking at the research that has been done about siblings. I will also tell you about Sue, as I can't resist!

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### Pride and Joy

I remember how excited I was when my sister was born, and the anticipation I felt on the way to the hospital to meet her; a little bundle of joy with loads of jet black hair. I was very proud, and that feeling of pride has never left me as I have watched my sister grow, learn to walk, talk, swim, learn to read and do all sorts of things that might be easy to others but have been a real challenge for Sue.

I am proud to be her sister. There is never a dull moment with Sue. She has the most wonderful sense of humour and is great fun to be around. Watch out you if you try to tease her because she will always have a witty comeback, even if it is only putting her thumb to her nose and wiggling her fingers!

For siblings of children with learning disabilities this feeling of pride is common. Watching at close quarters as their siblings struggle to master things that others find easy gives us a real sense of how important and hard fought these small achievements are.

Researchers have interviewed children who are siblings of people with learning disabilities and found that they tend to have heightened empathy skills compared to other children. In other words they are very good at being able to put themselves into other people's shoes. This gives them a greater understanding of people in adverse circumstances. It is also a very useful life skill and helps people make good relationships in their work and social life.

# Family Information and Support

## Siblings: What is it Like to Have a Brother or Sister with RTS?

**(By Dr Karen Aldred D. Clin. Psychol., BSc)**

### Younger Siblings

The experience of having a sibling with RTS will be different depending upon their position in the family. For younger siblings, they are at first unlikely to understand that there is anything different about their siblings. Their understanding will increase as they grow older. Younger siblings have the rather unique experience of catching up with and overtaking the sibling.

### Older Siblings

For older siblings the birth of a younger brother or sister is usually a major change to their life, whether or not the sibling turns out to have a disability. Excitement, a feeling of responsibility, being the 'big girl' or 'big boy', sharing your parents' affection and attention and your toys; these are common experiences for children when a younger brother or sister comes along. When the older child finds out there is something different about their sibling this can have an impact. The younger sibling is likely to grow up always knowing about the disability whereas the older child may find out more suddenly.

### What is Typical Behaviour Towards a Brother or Sister with RTS?

All siblings fight, squabble, tease and are jealous of each other. They try to pass the blame to one another for things going wrong. This is still true for siblings where one of them has RTS. The non-RTS child may be given more responsibility for these events just as usually older siblings are.

But when you have a sibling with RTS you may feel more guilty after fighting or squabbling with your sibling. You may berate yourself feeling that it is not right to do this with someone with a disability (and if you don't chances are your parents will!)

*Karen with her sister Sue*

# Family Information and Support

## Siblings: What is it Like to Have a Brother or Sister with RTS?

**(By Dr Karen Aldred D. Clin. Psychol., BSc)**

### Wishes and Sadness

Psychologists and other researchers have become very aware of the emotional reactions that parents have when they realise their child has a disability. They recognise that parents can be shocked, worried and go through a grieving process for the more able child they perhaps hoped for.

More recently their attentions have focused upon the feelings of siblings. In fact, siblings may go through a similar series of emotions to their parents. In essence they are grieving for the 'lost' abilities of the child. This is in terms of:

- What the child is not able to do at the current time (and all the repercussions this then has on giving time and support, hospital visits etc)
- Change in expectations and hopes for their future (work, marriage, children etc).

These feelings of grief are quite typical emotions and are described elsewhere in this guide.

I myself remember having daydreams as a child that one day they would find a 'cure' for Susan and that she would be able to play board games with me or come for a bike ride. Even as an adult it is hard not to occasionally think, 'wouldn't it be nice' if she was more able to do this or that.

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### In The Shadows

Because children with RTS need so much care and support, the other children in the family will often inevitably have to take a back seat. Their parents may have less time and energy for them than they would like. Often in families where there is a disability, money may be tight; either because of a parent needing to stop work to look after the RTS child, or because of saving and planning for the RTS child's future. This can put a strain on the whole family, including siblings who may have to make do with less.

Because of the needs of the RTS child sometimes it may not be as convenient for children to have their friends round or it may be that parents are not as able to ferry their other children to their friend's house or to other social activities. Sometimes a sibling may be the RTS child's main companion and parents may want them to stay at home and play with their brother and sister. All of this means that sometimes it can be harder for the sibling to make and keep friends and they may become a little bit isolated from their peers.

Sometimes children who have RTS siblings may experience people knowing them only because of their sibling and may get fed up with being known as, Tom's Brother or Mary's sister rather than by their own name.

## Siblings: What is it Like to Have a Brother or Sister with RTS?

**(By Dr Karen Aldred D. Clin. Psychol., BSc)**

### Being Different

Children may feel embarrassed by how their sibling acts or looks and worry about going out and about with them. They may not be sure about how to explain RTS to their friends. Sometimes children may get teased or bullied as a result of having the sibling. On the other hand, some children enjoy the feeling of being different or special by having an RTS sibling.

For me Susan was often a great ice-breaker when meeting new friends. She was much less shy than I was then and could be guaranteed to do or say something that would make us all laugh or get us all talking.

### Responsibility and Pressures

For siblings there is often a feeling of needing to look after and protect the person with RTS. Children may worry about their RTS sibling being picked on or teased by other children. They may worry about how their brother or sister is going to cope with life. Sometimes children may have misunderstandings about what it means to have RTS. They may feel worried about asking their parents about what RTS means.

Children may also worry about how their parents are coping. Sometimes children end up in the role of an extra parent as there is so much to be done for their sibling. Sometimes they might feel that they cannot tell their parents about their own problems for fear of overburdening them.

Some children become the target of all the wishes and hopes that the parent had for the other sibling. The pressure to achieve at school and at sport or other activities can be heightened as all the expectations are upon them rather than shared. The parents' thwarted hopes and ambitions for the RTS child become directed into their other children.

Adult siblings may worry about what is to happen when parents are not around to care for their brother and sister or may already be providing some of the care. This responsibility can affect life in all sorts of ways from deciding where to live to choice of husband or wife. My husband passed the RTS compatibility test early on in our relationship. Luckily for me he has welcomed Sue with open arms, and they have lovely banter together.

Some siblings can feel pressurised by their parents' expectations of them caring for their sibling when they are no longer able. The sibling may feel guilty for example about not wanting to look after their RTS brother and sister in their own home. For myself, I have great respect for how my parents have given so much of their lives to caring for Susan and have done such a fantastic job of taking care of us both. I feel I have a lot to live up to.

# Family Information and Support

## Siblings: What is it Like to Have a Brother or Sister with RTS?

**(By Dr Karen Aldred D. Clin. Psychol., BSc)**

### Does Having an RTS Sibling Affect People Psychologically?

In 2024, researchers reviewed sixty different research studies on siblings of people with learning disabilities. They found siblings were more susceptible to negative behaviour/emotions, such as guilt, and were more likely to experience depression. This does not mean that every sibling of someone with learning disabilities gets depressed, but just that the risk of depression is slightly higher than the average person.

There is evidence that having a sibling with a learning disability can have some psychological benefits. Children learn to empathise quicker and can build up coping skills which help them to deal with life's ups and downs. Kindness, patience, acceptance of other people and being aware of the needs of others have all been reported.

The ways in which parents support, and help their children can make being a sibling of someone with a disability a more positive experience.

I know for sure that I would have been very different if I hadn't had my sister Sue. For a start I would know far less about Knight Rider and Karen Carpenter (some of my sister's favourite conversation topics.) Who knows, perhaps I wouldn't have become a Clinical Psychologist. At the end of the day, I wouldn't trade my little sister for any other.

*Karen with her sister Sue*

*Karen with her sister Sue*

# Family Information and Support

## Siblings: Experiences of the Brothers and Sisters of Children with RTS

**(By Jane Waite, Laurie Powis, and Professor Chris Oliver)**

The quotes included in this section come from informal interviews and discussions with siblings of children with RTS that were collated by Dr Jane Waite and Prof Chris Oliver at a Rubinstein–Taybi syndrome family conference. Siblings were keen to share their experiences, memories, and reflections, offering valuable insight into what it is like to grow up alongside a brother or sister with RTS.

The voices of siblings themselves highlight both the joys and the challenges of growing up with someone with RTS.

### What Siblings Value and Enjoy

"He can make you smile even when you are feeling really rubbish. He gives you the most amazing hugs."

***Charlotte speaking about her brother Steven***

"He makes me proud because he's learnt how to use the computer and play games by himself."

***Brody speaking about his brother Karl***

"I think it's because of him that I'm the person I am. You don't really notice it until someone else points it out."

***Charlotte speaking about her brother Steven***

### How Siblings Connect and Bond

Shared activities that are enjoyable and accessible to both siblings often help strengthen relationships and build confidence for both children.

"It made me happy because I taught him how to ride a tricycle."

***Daisy speaking about her brother Henry***

"I help her with drawing, putting her shoes on, and choosing DVDs."

***Isabel speaking about her sister Olivia***

# Family Information and Support

## Siblings: Experiences of the Brothers and Sisters of Children with RTS

**(By Jane Waite, Laurie Powis, and Professor Chris Oliver)**

### Challenges Siblings May Face

Some siblings describe challenges, particularly in childhood, or difficulties when others do not understand RTS.

"When I was younger, he needed a lot of attention, and that was hard at times."

***Charlotte speaking about her brother Steven***

"Some people don't understand and can be unkind, but that doesn't change how I feel about them."

***David speaking about his two adopted brothers James and Ben***

### Advice from Siblings

"Have patience, help them learn new things, and remember they're still your brother or sister."

***David speaking about his two adopted brothers James and Ben***

"Keep teaching them life skills and help them grow."

***Matthew speaking about his cousins Ben and James***

### In Summary

Siblings of children with RTS often describe relationships that are loving and influential. While challenges are part of the experience, many siblings report personal growth, strong family bonds, and a sense of pride in their brother or sister. With understanding, reassurance, and appropriate support, siblings can thrive alongside their family member with RTS.

## Tips from Siblings

- Remember that the sibling bond is close and very precious - sibling first, carer second.
- Don't be over-protective, give them space to be their own person.
- Don't be jealous of the extra attention that your sibling may get. You're loved just as much.
- Your RTS sibling may ask you difficult/personal questions. Answer honestly. You are their best source of information.

# Family Information and Support

## Support for Siblings

It's important for brothers and sisters to know that support is available for **them**, too.

There are several organisations and charities that offer help, advice, and fun opportunities for siblings of children with disabilities or additional needs:

- **RTS UK:** We know how important it is for the whole family to feel connected and supported. RTS UK holds family get-togethers and events where everyone is welcome: parents, siblings, grandparents and friends. These gatherings are a lovely way for siblings to meet others who understand what life is like in an RTS family.
- **Sibs UK:** A national charity that supports brothers and sisters of disabled children and adults. They offer tips, stories, online groups, and advice for siblings of all ages.
- **Contact UK:** A charity for families with disabled children. They have information and advice for the whole family, including ways to help siblings feel included.
- **Young Carers Services:** In some areas, local councils or charities run "young carers" groups. These give siblings the chance to meet others in similar situations, have fun, and get extra support if they help care for their brother or sister.

*Phoenix with her sister Elektra*

*Greg with his brother Mark*

# Family Information and Support

## Caregiving and Respite

Caring for a child with RTS can bring both great joy and real challenges. Parents and carers often describe the experience as deeply rewarding, but it can also be emotionally demanding. Balancing care, work, and family life sometimes leaves little space for rest or personal time.

Research shows that parents and carers of children with additional needs can experience **higher levels of stress**, financial strain, and social isolation[35]. Taking **regular breaks**, even short ones, and having trusted support networks in place can make a big difference to your wellbeing and your family's overall quality of life[35,36].

### Why Respite and Self-Care Matter

Looking after yourself is not selfish, it's **essential**. Taking time for small breaks such as a walk, coffee with a friend, or time alone helps you recharge and return to caregiving with more patience and energy.

If you have a partner, family member, or friend who can step in to help for short periods, this can be a valuable way to share the responsibility of care. Building a circle of support, both formal and informal, can help your child become more confident with others and support their growing independence.

### Finding Respite and Support in the UK

Formal respite and short break services vary across the UK, but most local councils provide some form of support for families caring for a child with additional needs. You can start by asking for a **Carer's Assessment** from your local authority; this looks at your needs as a parent or carer and can lead to access to short breaks, respite care, or financial help. Other sources of help include:

- **Local council short breaks services:** Many councils run holiday clubs, activity schemes, or supported play sessions for disabled children.
- **Social services:** Families can request an assessment under the Children Act 1989 (for the child) or the Care Act 2014 (for adult carers).
- **Health visitors or GPs:** Can make referrals to social care, community paediatrics, or specialist disability teams.
- **Parent carer forums:** Provide opportunities to share experiences, influence local services, and find peer support.

# Family Information and Support

## Caregiving and Respite

When planning any **respite activity**, think about:

- Your child's strengths and interests
- How they communicate their needs
- What situations make them anxious or tired
- Which environments or activities help them thrive

Preparing new caregivers with this knowledge will help ensure your child's experience is positive and that you can relax knowing they are well supported.

### Building Community and Informal Supports

Alongside formal services, many families find informal networks just as valuable[37]. This could include trusted relatives, family friends, school staff, or community volunteers who know your child well.

**Local activities**, such as inclusive sports, music, or art sessions can provide social interaction for your child and time for you to rest. Faith communities, charities, and museums may also offer inclusive events or family sessions at low or no cost.

As your child grows, helping them build independence in these community activities can make respite time easier and more enjoyable for everyone.

*Summer Fun Day Windsor Parallel Event 2025*

*Summer Fun Day Windsor Parallel Event 2025*

**Recommended Resources**

Carers UK • Contact UK • Family Fund • The National Autistic Society • NHS

# Family Information and Support

## Finances and Benefits

**A person with RTS and their carers may be entitled to a number of social security benefits.**

In England and Wales, these are administered by the Department for Work and Pensions (DWP), in Scotland by Social Security Scotland, and in Northern Ireland by the Department for Communities (DfC). Benefits are subject to change from time to time and so applicants are advised to contact the relevant department for the latest information on eligibility and how to make a claim.

Disability and carer benefits that people commonly claim include:

- **Child Disability Living Allowance (DLA):** For children under 16 with disability-related needs.
- **Personal Independent Payment (PIP):** For adults (between 16 and state pension age) with a long-term disability.
- **Carer's Allowance:** For people providing significant care.
- **Employment and Support Allowance:** For those with limited capability for work.
- **Universal Credit:** For those who are on low income or unable to work.
- **Attendance Allowance:** For disabled people over pension age.

Making a claim can sometimes seem daunting, but there are people that can help. Please see GOV.UK for their contact details. There are other organisations who can also offer advice and assistance, such as:

- The Social Care and Health department of your Local Authority
- Citizens Advice Bureau
- Welfare Rights Advisory Services
- Contact a Family
- Cerebra

**Note:** This information applies in the UK only, and different provisions will apply or may not exist at all in other countries.

# Conclusion

So much has changed and much has been learned since Dr Rubinstein and Dr Taybi met each other and shared their knowledge of RTS. Families now have a body of research, though small, to refer to and to share with their loved one's medical providers for optimal care. There are doctors and geneticists in the United States, Europe, and a handful of other countries, continuing to try to learn more about RTS and interventions that can support individuals with RTS to reach their full potential.

In addition, the advances in technology have improved families' ability to access the most up to date information and to connect with other families who have children or adults with RTS via Facebook, X (formerly Twitter), the internet, and other social media outlets. Given the rarity of RTS, the ability to reach beyond geographical areas and connect with each other is something that offers families new opportunities to avoid isolation. These connections offer support, information, and informal mentoring.

**Families of, and individuals with RTS, are living full lives in their communities. Individuals with RTS contribute to their communities by working, volunteering and spending time enhancing the lives of others who are part of their schools, religious institutions and neighbourhoods.**

*Disco event at the RTS Conference 2024*

With the appropriate supports from their families, community, and experts in the area of disability, the RTS community is thriving!

As family members and parents/guardians, you are encouraged to help your loved one with RTS create and attain their desired best life in their community. It is important to share your experience and knowledge about RTS with medical providers, service providers, other family members, and the general public. Through these efforts you will contribute to a more knowledgeable, accepting, and inclusive society for individuals who have RTS.

For free extra copies of this guide or further information, to become a member of the Support Group, make a donation or discuss possibly fundraising, please **contact**:

- **Rubinstein-Taybi Syndrome Support Group** (email: **info@rtsuk.org.uk**)
- Free extra copies of this guide can also be downloaded from **https://www.rtsuk.org.uk/info-bank/**

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Appendix A

# Education, Health and Care Plan Tips

The first thing to understand about EHCPs is that they are legally binding documents that should list your child's learning difficulties and the support that they require to help them with those difficulties. As the name suggests, the EHCP also includes related social care and health needs, but it is important to know that the EHCP does not place an obligation on statutory bodies in relation to these sections of the Plan. There is no entitlement to an EHCP if your child only has a social care or health need. It is the educational element of need that triggers an EHCP.

The EHCP can provide support from birth up to 25 years, so can continue to provide educational support beyond the end of secondary school and into further education or apprenticeships, provided the young person still has learning outcomes to be met and needs support. Beyond 18/19 years, the focus is often on developing independence skills.

'Education' is considered broadly and includes the following areas, all equally important:

- Cognition and learning
- Communication and interaction
- Social, emotional and mental health
- Sensory and/or physical needs

## Requesting an EHC Needs Assessment

Your child should already be receiving support at school but where it is felt that they require more support than the school can provide from within its own resources, then the school or parents can make a request for an EHC Needs Assessment to the home local authority. If the application goes through, the entire process ending in an EHCP should take no longer than 20 weeks. If the local authority has decided to issue an EHCP, a draft Plan for review must be sent to parents by week 16. The draft Plan will not name a school or type of placement – this is left blank for parents to put forward their own choice. It is important at this point to also check the sections of the draft Plan to ensure your child's difficulties are fully described in Section B, because this leads to provision required in Section F to meet those needs. The drafting in Section F is equally important so that anyone picking up the Plan is very clear about what support is to be provided, when, how often, and by whom.

Should the local authority refuse to carry out an EHC Needs Assessment, or decide to assess but not issue an EHCP, or you do not agree with the content of the final EHCP (for example, the level of support or the named school/college), there will be the opportunity to appeal to the SEND Tribunal, an independent national body.

# Education, Health and Care Plan Tips

## Annual Reviews

Once the EHCP is finalised, it must be reviewed at least annually to make sure the content is still correct, whether provision needs changing, to look at outcomes, whether the school/college is still able to meet needs, and to look forward. Planning for the future starts in Year 9 when discussions should be had around what your child and you would like to achieve. Parents should be prepared to consider preparation for adulthood and independent living; what is going to be needed beyond secondary school in relation to education, social care and health?

Again, strict timelines are to be followed to conclude an Annual Review. If the local authority is amending the Plan, it must issue the draft amended Plan within 4 weeks of the Annual Review meeting and issue the final amended Plan within a further 8 weeks i.e. a maximum of 12 weeks from the Annual Review meeting. If the local authority is not amending the EHCP, they must issue their decision within 4 weeks of the Annual Review. Parents will have the right to appeal to the SEND Tribunal if they do not agree with any decisions of the local authority after the Annual Review.

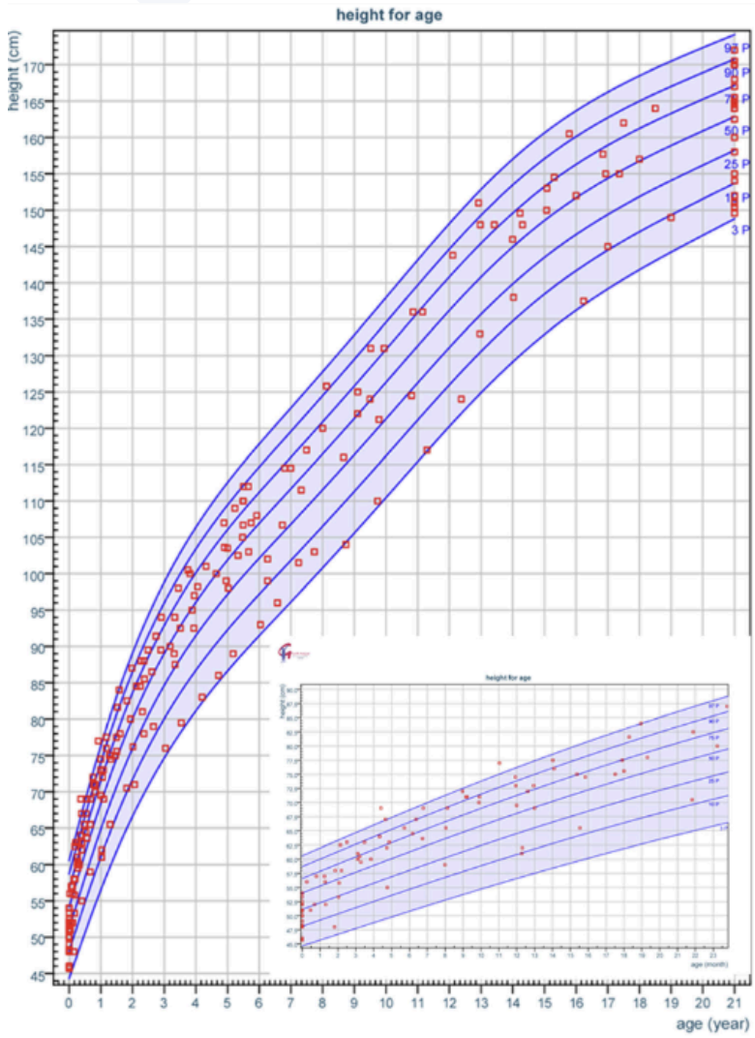
## Ending EHCPs

There is a legal process to be followed when ending/ceasing to maintain an EHCP which usually starts at the 'last' Annual Review. If the local authority sends a notice of its decision to end the Plan for an unlawful reason, the decision is invalid and the EHCP must remain in place until the deadline to appeal the decision has passed or if you appeal, the appeal is heard and a decision reached.

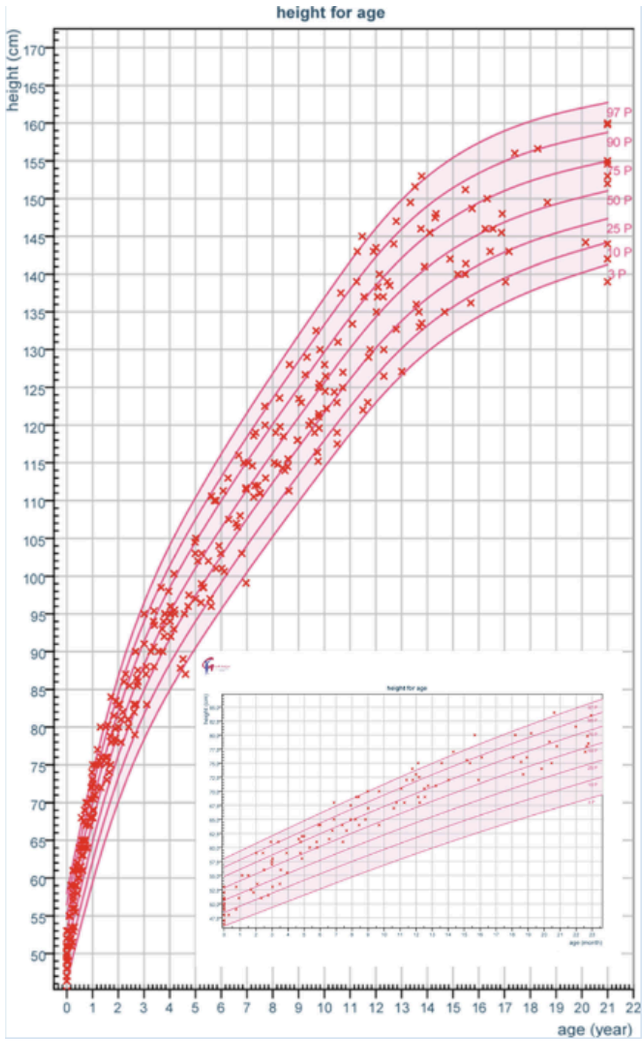
Appendix B

# Growth Charts

The following growth charts were published in "Growth Charts for Individuals with Rubinstein-Taybi syndrome", Beets et al, (2014) and were formulated with individuals from a variety of countries. They included only individuals with confirmed diagnosis by genetic evaluation (clinical and/or molecular).



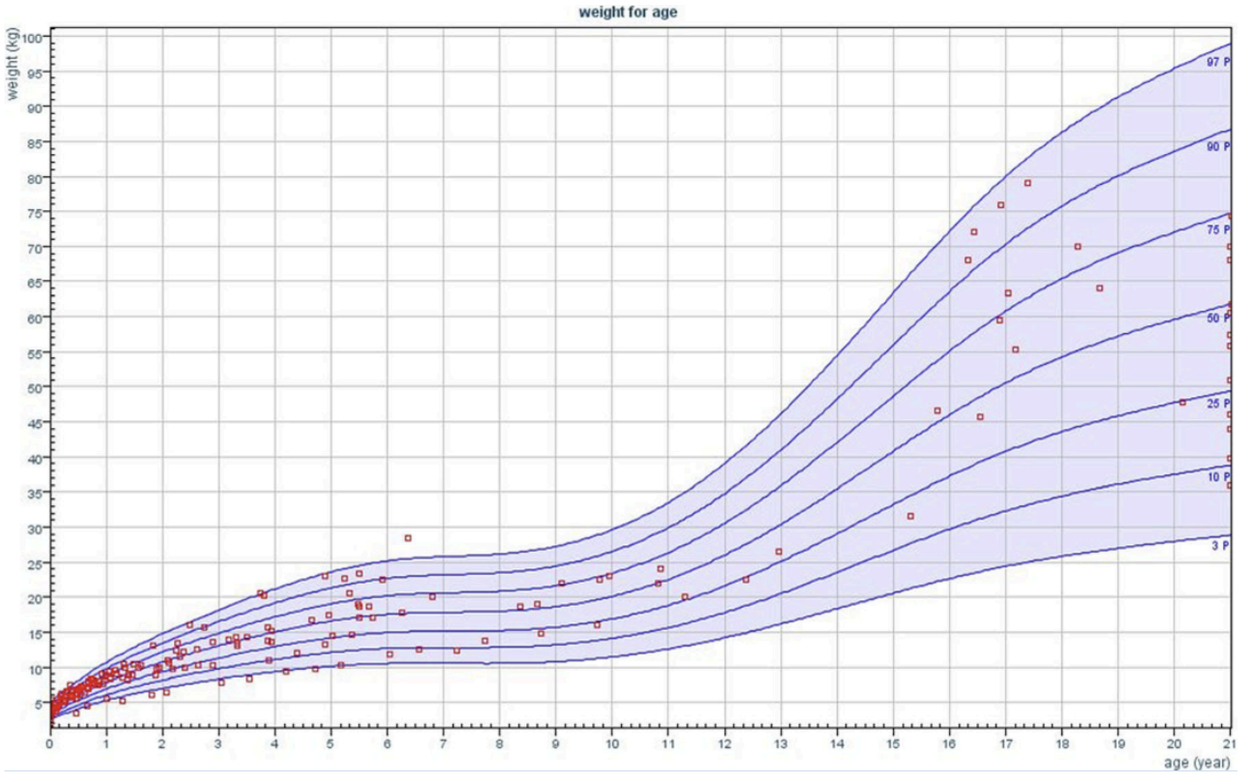

*Growth in height for boys with RTS, ages 0–21 years, showing individual data points. The inset shows an enlarged graph of length/height for boys 0–24 months of age.*



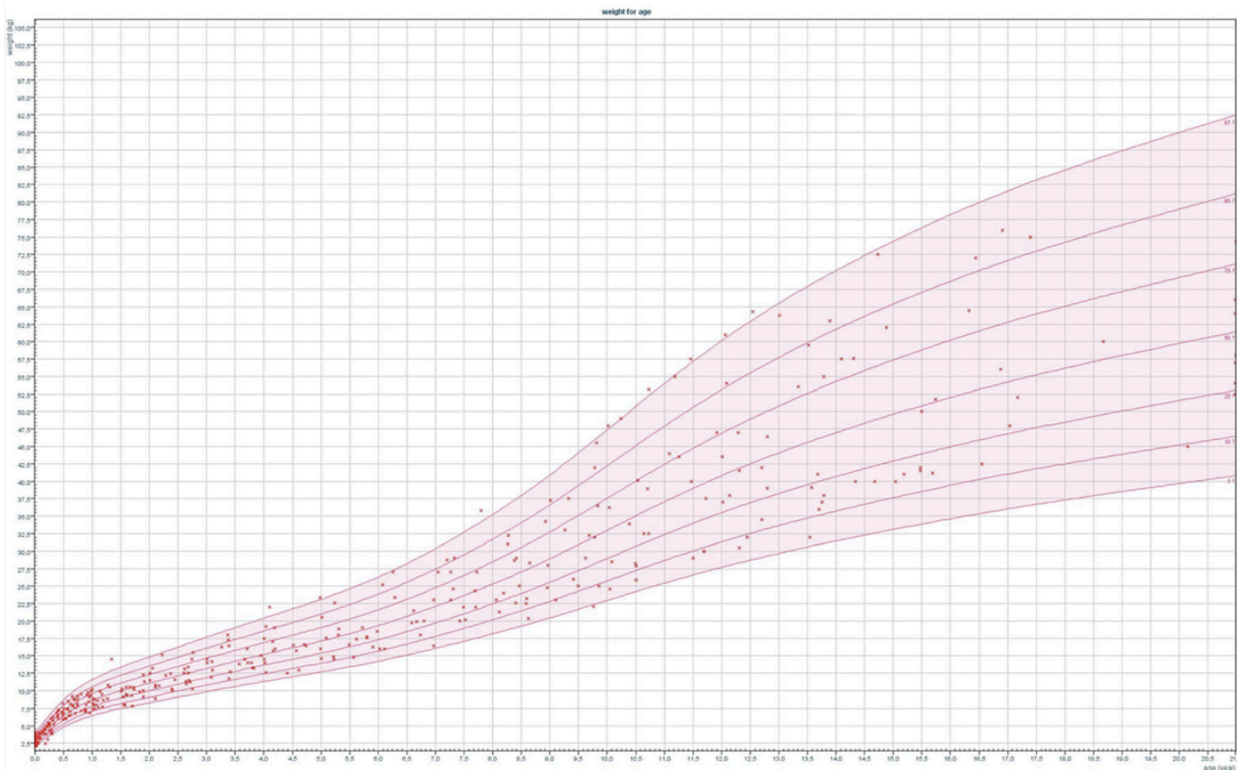

*Growth in height for girls with RTS, ages 0–21 years, showing individual data points. The inset shows an enlarged graph of length/height for girls 0–24 months of age.*

Appendix B

# Growth Charts



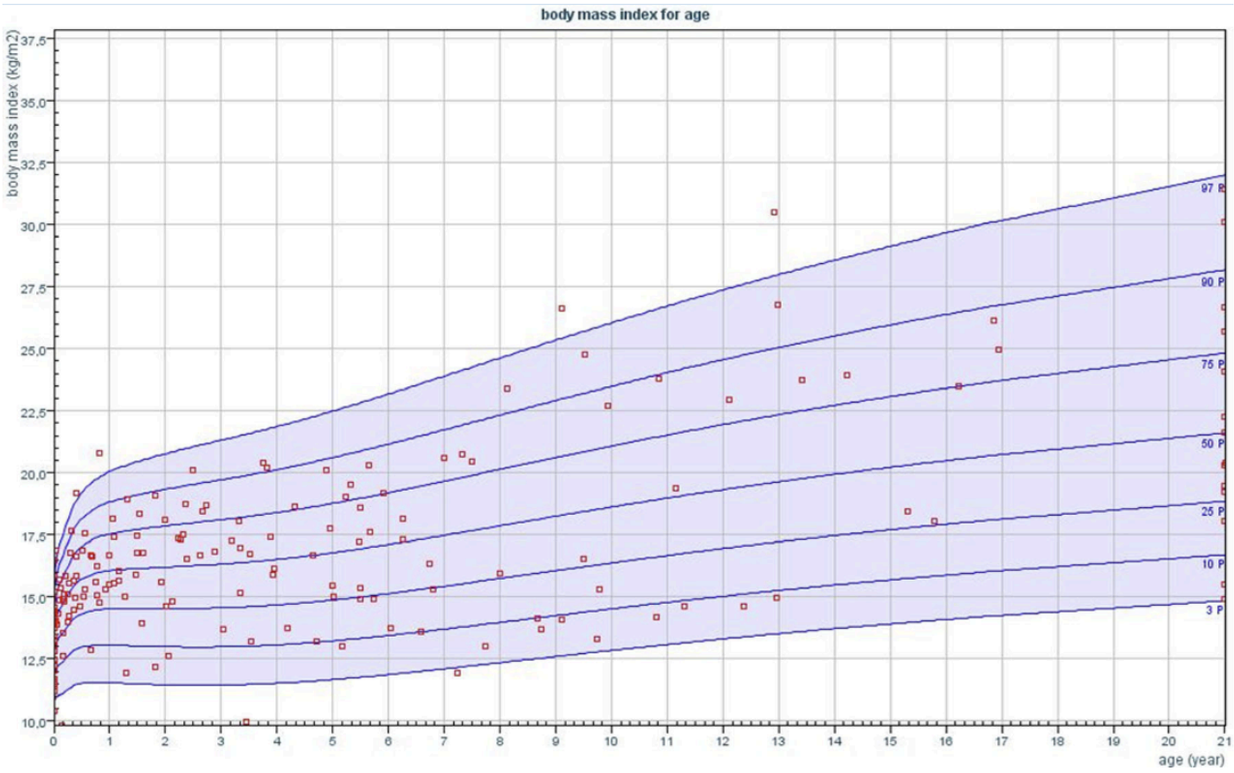

*Weight in boys with RTS, ages 0–21 years, showing individual data points.*



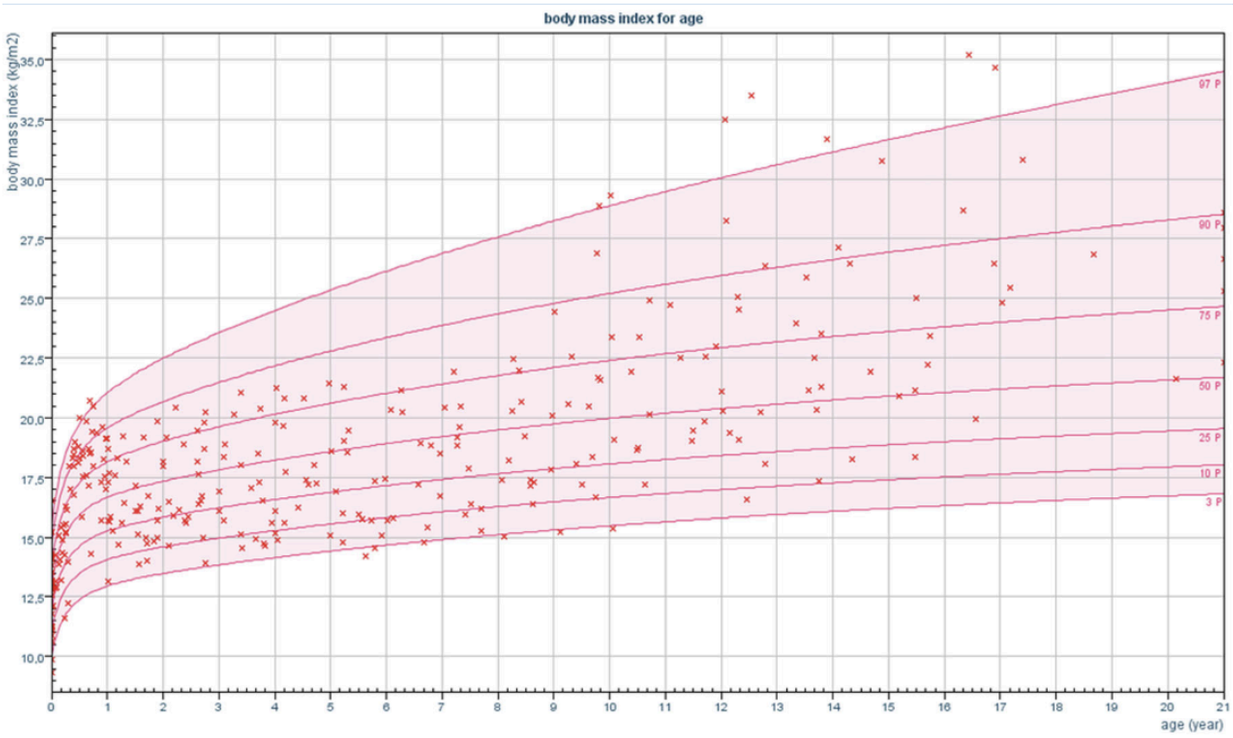

*Weight in girls with RTS, ages 0–21 years, showing individual data points.*

Appendix B

# Growth Charts



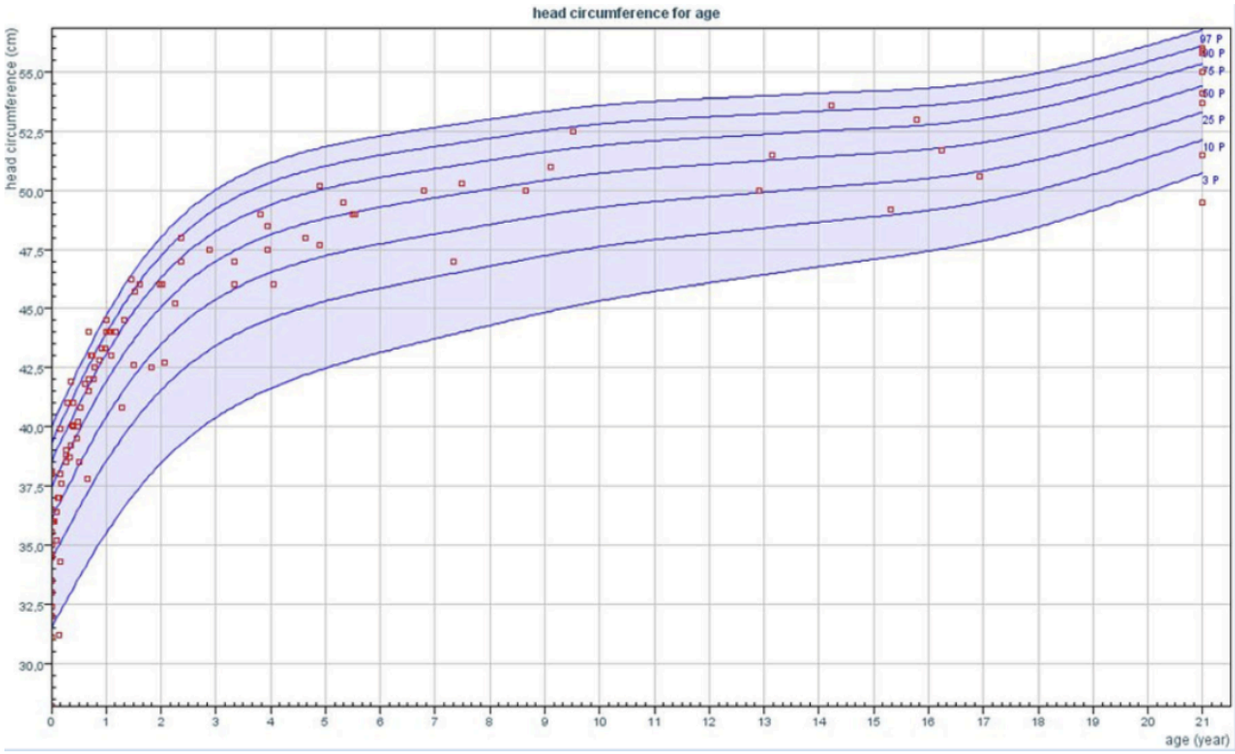

*BMI in boys with RTS, ages 0–21 years, showing individual data points.*



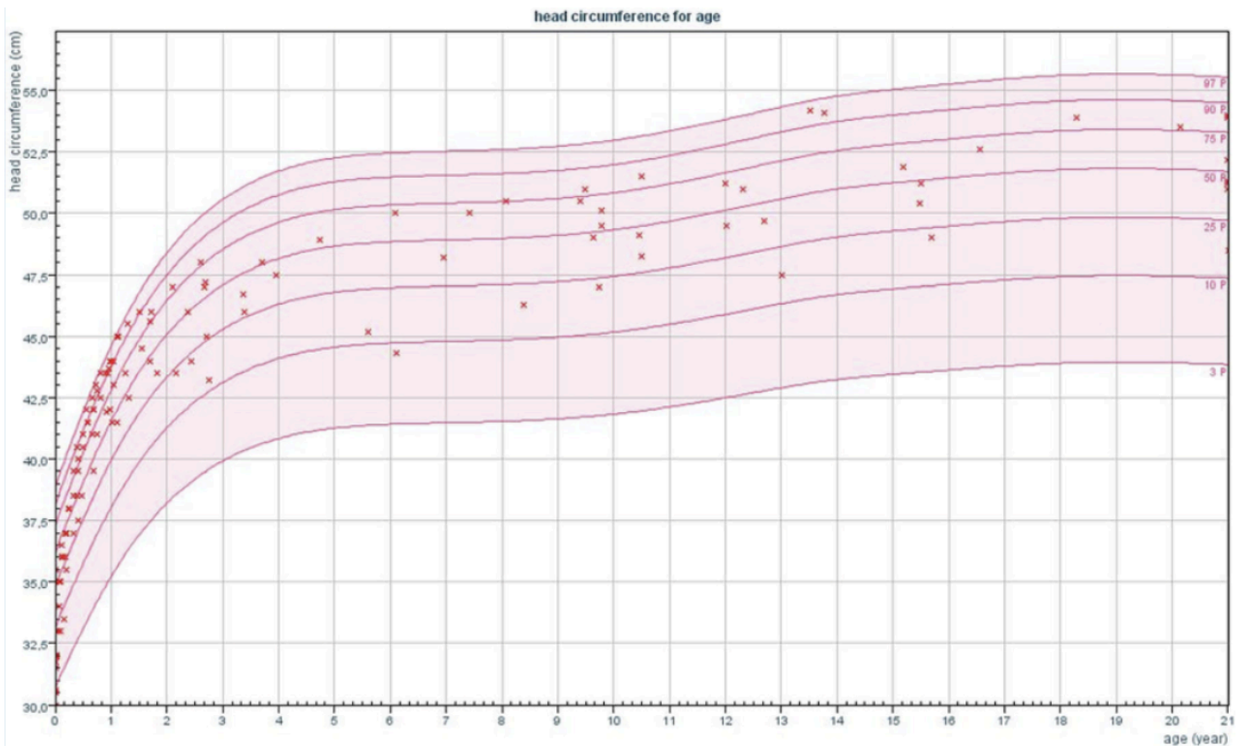

*BMI in girls with RTS, ages 0–21 years, showing individual data points.*

Appendix B

# Growth Charts




*Head circumference in boys with RTS, ages 0–21 years, showing individual data points.*




*Head circumference in girls with RTS, ages 0–21 years, showing individual data points.*

Appendix C

# Sleep Tips

Getting enough rest can be one of the biggest challenges for families, both for children and parents. Many children with RTS experience differences in sleep patterns, such as difficulty settling, waking often, or snoring due to airway structure. A consistent bedtime routine, comfortable sleep environment, and the right professional support can make a big difference.

The following **tips** are designed to help caregivers, families, and individuals with RTS promote healthy sleep through practical daily routines and supportive bedtime practices:

## 1 Create a calm bedtime routine

- Keep bedtime and wake-up times consistent, even on weekends.
- Follow a gentle, predictable routine: bath, pyjamas, story, soft music, and dim lights.
- Avoid screen time for at least an hour before bed.

## 2 Make the bedroom sleep-friendly

- Keep the room cool, dark, and quiet (blackout blinds can help).
- Use a night-light if your child prefers low light.
- Weighted blankets or soft, sensory bedding can provide comfort (check with your occupational therapist or paediatrician first).

## 3 Encourage daytime activity

- Gentle exercise such as swimming, walking, or soft play can improve sleep quality.
- Exposure to daylight helps regulate your child's natural sleep–wake rhythm.

## 4 Watch for breathing difficulties

- If your child snores loudly, gasps, or seems to stop breathing briefly, speak to your GP. These may be signs of sleep apnoea, which can often be treated.

## 5 Build positive sleep associations

- Encourage your child to fall asleep in their own bed so they can resettle more easily when they wake.
- Use a favourite soft toy or blanket for reassurance.

# Sleep Tips

## 6 Manage reflux and constipation

- Reflux and tummy pain can interrupt sleep. Try smaller, more frequent meals and keep your child upright for a short while after eating.
- Constipation is very common in children with RTS and can also cause bedwetting or night-time accidents.
- Encourage plenty of fluids, high-fibre foods, and, if needed, speak to your GP about suitable medication.
- Addressing constipation often improves both comfort and continence overnight.

## 7 Keep a simple sleep diary

- Note bedtime, night wakings, naps, and daytime behaviour.
- Share this with your GP or health visitor to help identify patterns or triggers.

## 8 Remember to look after yourself

- Night-time challenges can be exhausting. Share care if possible, and take rest when you can.
- If sleep issues persist, ask your GP about Short Breaks Services or carer support through your local council.

### Speak to your GP, paediatrician, or specialist nurse if:

- Snoring, gasping, or restless sleep continues.
- Your child often wakes or seems tired during the day.
- You notice changes in breathing or feeding at night.
- Bedwetting continues after addressing constipation or toileting routines.

### Your GP may refer you to:

- A paediatric sleep clinic
- An ENT specialist
- A community paediatrician for assessment and care coordination
- An occupational therapist
- A sleep practitioner for sensory or behavioural support

### Recommended Resources

The Sleep Charity • Contact UK • ERIC • Cerebra (Sleep Service)

Cerebra (Sleep Guide) • Scope • NHS

Appendix D

# Dental Tips

Maintaining good oral health is especially important for individuals with RTS, as certain features associated with the condition, such as high-arched palate, dental crowding, and delayed tooth eruption can increase the risk of dental challenges. With the right strategies and preventive care, these issues can be managed effectively, promoting comfort, confidence, and overall well-being.

The following **tips** are designed to help caregivers, families, and individuals with RTS support healthy teeth and gums through practical daily routines and professional care:

**1**

Use a child-friendly **electric toothbrush** to make brushing easier and more thorough

**2**

Parents or carers should brush or supervise toothbrushing **twice per day** (last thing at night + one other time)

**3**

**Spit** after toothbrushing, don't rinse

**4**

Arrange **regular check-ups** with an NHS community dentist familiar with additional needs

**5**

See your dentist for **fluoride varnish applications**

**6**

Always use a **fluoride** toothpaste:

- 0-3 years old smear of toothpaste labelled no less than 1000ppm F
- 3-6 years old pea-sized toothpaste labelled 1000-1500ppm F
- Over 6 years old pea-sized toothpaste labelled at least 1350ppm F

**7**

Look for **sugar free medicines**

**8**

Your dentist can also check for any signs of **jaw tightness** or discomfort, especially as your child grows

**9**

Reduce the frequency and amount of **sugary food and drinks**