RTS support group

Welcome to the family conference

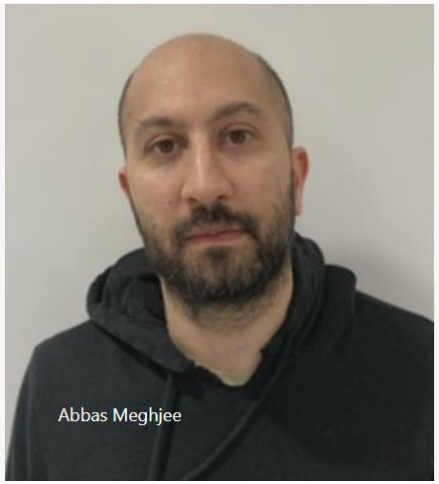
Saturday 6 June 2026

The creche is open for drop-off. Conference will start at 9.30

Welcome!

- Welcome, introductions & agenda
- Housekeeping
- Check in
- Theme park tickets for tomorrow

Meet the committee team



Jo

Chair

Abbas

Treasurer

Ann

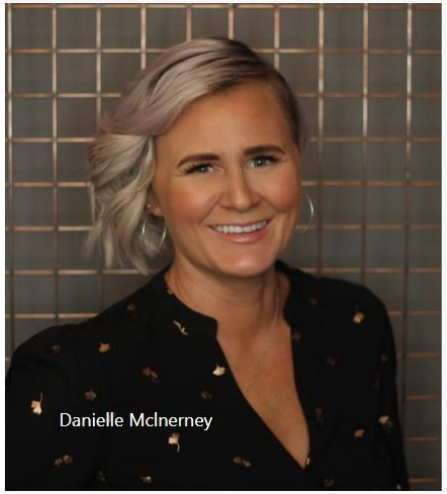
Super-organiser

Julian

Rich

--- Fundraising ---

Meet the committee team



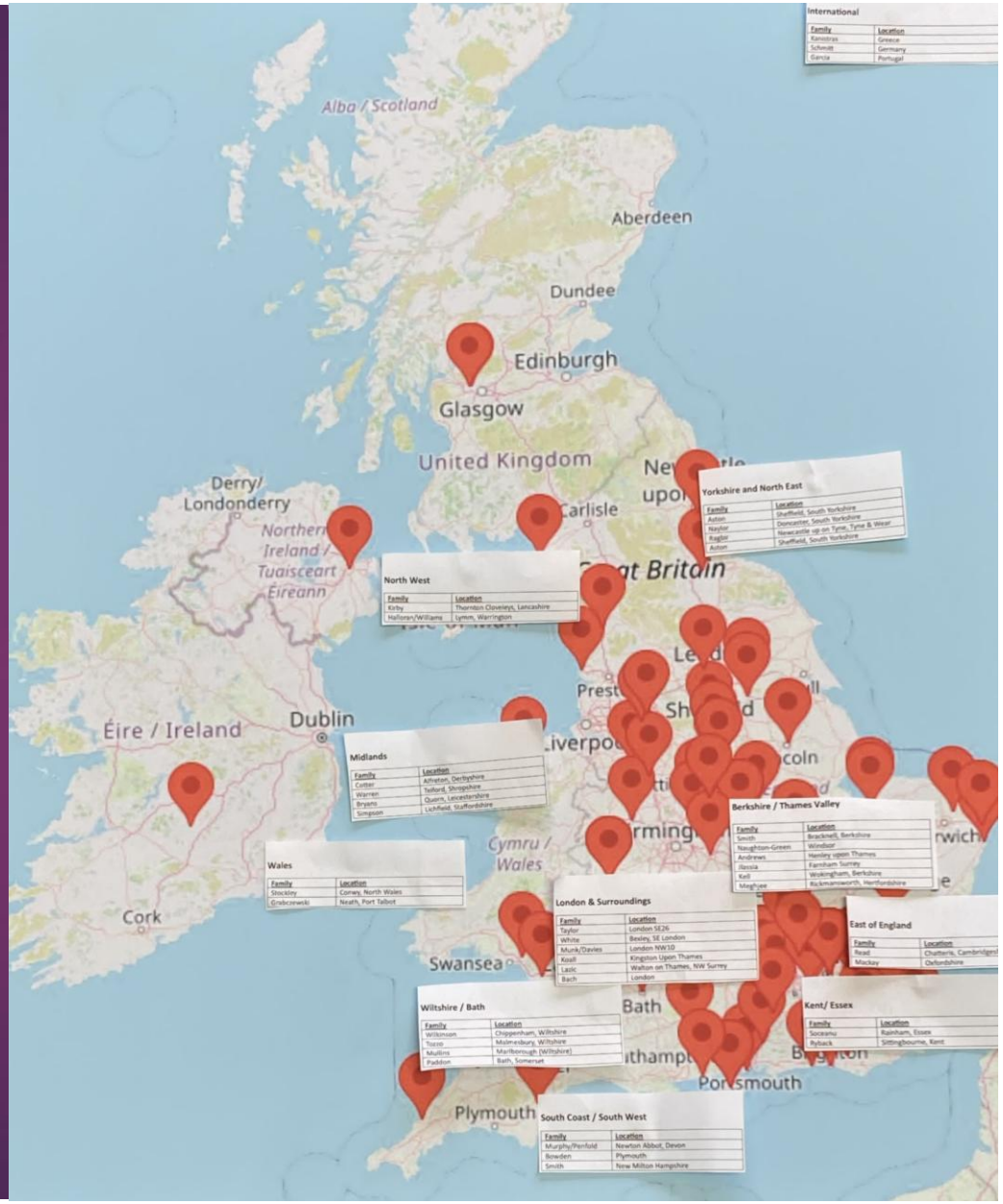
Zohra **Danielle** **Rosie** **Elisa** **Delphine**

--- Family Network ---

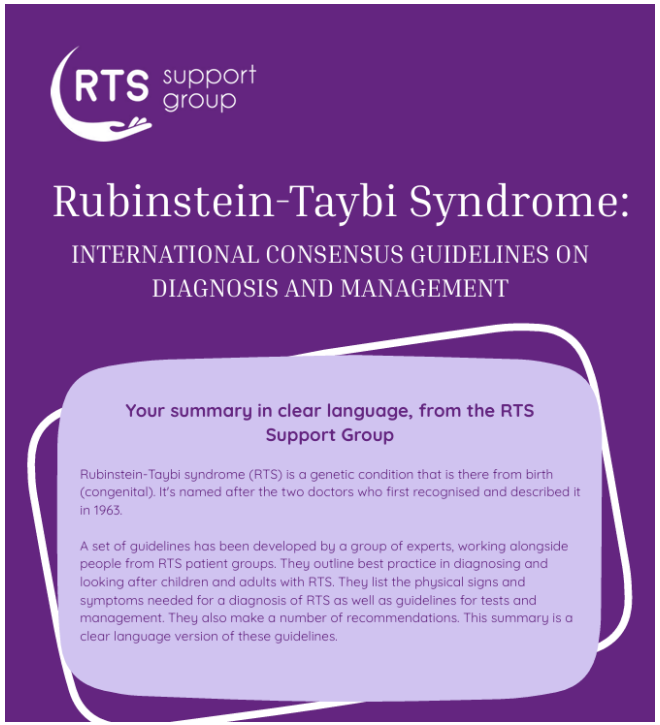
--- Communication ---

RTS support group

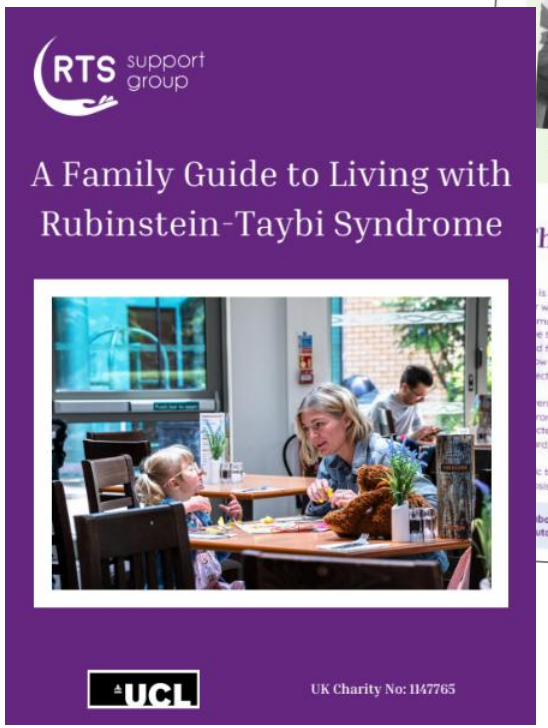
Are you part of the Family Network?



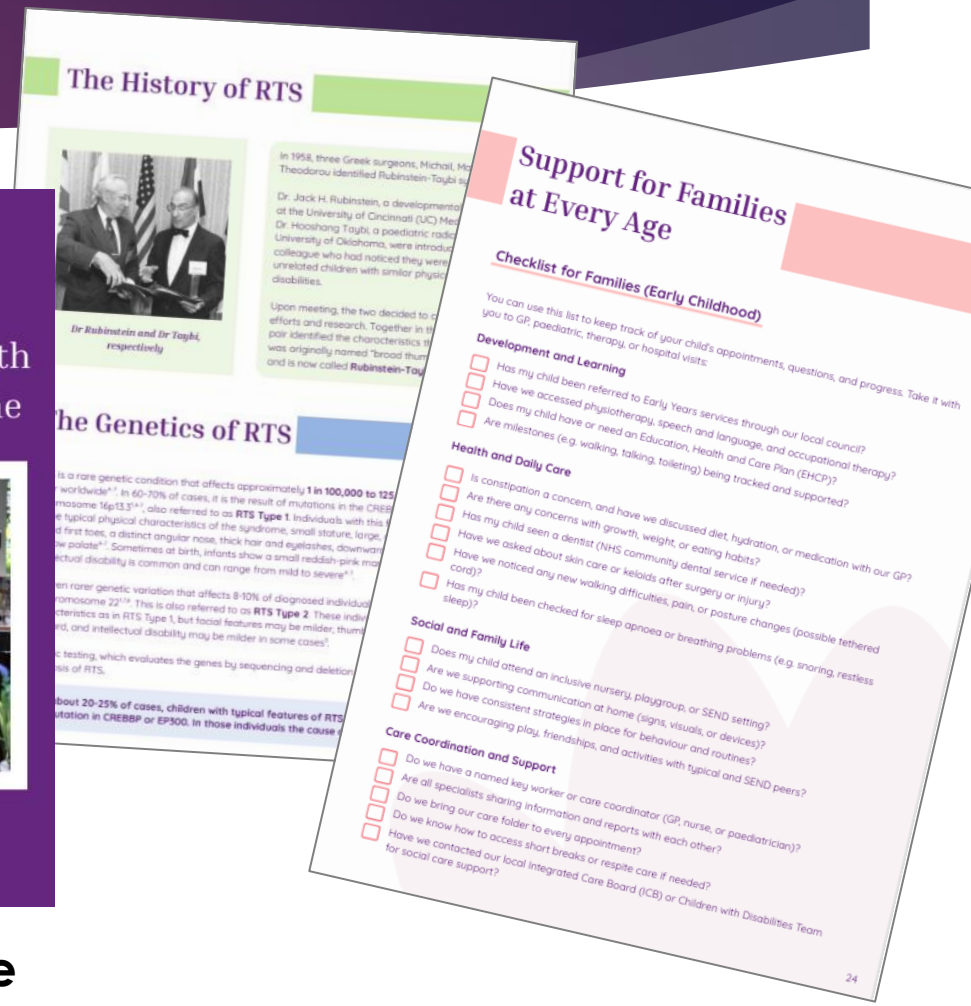
New resources at rtsuk.org.uk Info Bank page



NEW plain English version of the International Consensus Guidelines on RTS

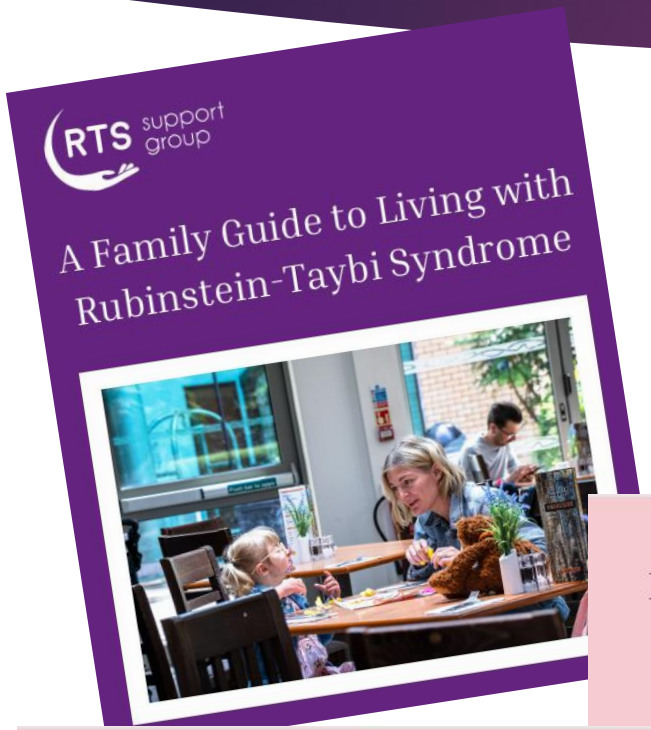


NEW Family Guide



RTS support group

THANK YOU



Meet Phoenix

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

Phoenix

Meet Willow

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

Willow

Phoenix with her sister Elektra

Greg with his brother Mark

Meet Anna

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

Anna

Anna

Meet Greg

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

Greg at his apprenticeship

Meet Morgan

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

Morgan with a skip lorry

Meet Aara

Aara was diagnosed with RTS at 6 months old.

Aara

Expert speakers

Dr. Susan Wiley

Dr. Jane Waite

Courtney Greenhill

Laxmi Patel

1:1 appointments are available

Today's agenda - morning

Our speakers and sessions this morning:

10.00 **Family connection carousel**
Meet other RTS families

10.45 **Education, Health & Care Plans (EHCPs)**
Laxmi Patel, Special Educational Needs Solicitor, Boyes Turner

11.05 **Coffee break**

11.20 **Emotional experiences and wellbeing in RTS**
Courtney Greenhill

11.40 **A Shared Perspective on RTS: Medical and Psychological Insights**
Dr. Susan Wiley and Dr. Jane Waite

12.50 **Collect children from the creche and LUNCH**

Today's agenda - afternoon

14.00 **Removing Barriers**
Jane & Jimmy James

14.45 **Rotating break out groups 4 x 30 minutes**

Teens & young adults – Meet in the foyer
Crazy golf and social time

16.45 **AGM and final words**

17.00 **Close. Day attendees depart / Overnight attendees check in**

18.15 **Pre-dinner drinks in the Tower Suite Foyer**

18.45 **Dinner. Celebration Awards and Disco**

Making sense of behaviours that challenge

The Nitty Gritty of EHCPs and the Law

Managing your emotional journey as a parent carer

International Guidelines

Meet other RTS families

Family Connection Carousel

Speed dating format!

Explanation of cards

7 minutes to chat, then those with ‘green/rotate’ move on

Ice breakers…

- **Introduce your family**
- **What are you looking forward to most about the conference?**

SEND, EHCPs and the Law

Laxmi Patel, Partner and Head of Education, Boyes Turner LLP

SEND: Special Educational Needs and Disabilities

EHCPs: Education Health and Care Plans (EHCPs)

Boyes Turner

SEND, EHCPs and the Law

June 2026

Laxmi Patel, Partner and Head of Education

Boyes Turner LLP

SEND, EHCPs and the Law

Laxmi Patel

- Laxmi is an experienced solicitor in the niche area of SEND law. She is listed in the Legal 500 and Chambers directories as a leading SEN solicitor.
- She represents clients at the SEND Tribunal, including Health and Social Care extended appeals, and often works collaboratively with schools and local authorities. She has experience of complex appeals and case manages them from beginning to end, securing significant packages of education and social care support.
- Laxmi is recognised as a SEND expert and is invited regularly to share her knowledge on changes to SEND legislation, government guidance and changes to practice and procedure for external organisations.
- She is a committee member of the Education Law Association, which organises talks and discussion groups for educationalists, lawyers and advice workers concerned with the law of education.

Content

1. The law
2. School based support
3. How to get an EHCP - EHC needs assessment (EHCNA)
4. Evidence / therapy reports
5. EHCP - what kind of support can you get?
6. Placement options
7. Annual Reviews
8. Key transitions
9. Appeals to the SEND Tribunal
10. What's on the horizon? The SEND White Paper

1. The law

- Children & Families Act 2014 (CFA) – Part 3
- The SEND Regulations 2014
- SEN (Personal Budgets) Regulations 2014
- SEND (First-tier Recommendations Power) Regulations 2017 - but note: Health and/or social care that educates or trains is education provision. Under the extended appeal, non-binding recommendations can be made for health and social care.
- SEND Code of Practice (CoP) – 0-25 years (Jan 2015)(CoP)

Chapter 9 CoP sets out information about assessments & content of EHCPs

S77 CFA – Must '*have regard*' to CoP

NB. Local Authority (LA) may have its own local policies but CoP will always carry greater weight and CFA and Regulations will have the last say.

2. School based support

SEN support in schools – para 6.44+ SEND CoP

- Schools to remove barriers to learning and put effective special educational provision (SEP) in place.
- A 4-part graduated approach cycle: **assess, plan, do, review**. Earlier decisions and actions are revisited, refined and revised with a growing understanding of the pupil's needs and what supports the pupil in making good progress and securing good outcomes.
- **Assess** – class teacher working with the SENCo, views of parents, pupil's own views and, if relevant, advice from external support services eg health or social services who should liaise wit the school to help inform assessments. Where professionals are not already working with school staff, the SENCo should contact them if the parents agree.
- **Plan** - parents must be formally notified if pupil is placed on SEN Support. The teacher and SENCo should agree, in consultation with the parent and the pupil the adjustments, interventions and support to be put in place, with a clear date for review. The support and intervention provided should be chosen to meet the outcomes identified for the pupil, based on reliable evidence of effectiveness, and should be provided by staff with sufficient skills and knowledge.

2. School based support

- **Do – t**he class/subject teacher should remain responsible for working with the child on a daily basis, even where interventions involve group or 1:1 teaching away from the main class.
- **Review –** the effectiveness of the support and interventions and their impact on the pupil's progress should be reviewed in line with the agreed date. Consider the views of the pupil and parents and enable them to be involved in planning next steps.
- **Involving specialists** – eg Educational Psychologists, CAMHS, specialist teachers or support services (Autism Outreach, VI or HI specialists), therapists (OT, SLT, PT) - where a pupil continues to make less than expected progress, despite evidence-based support matched to the pupil's area of need, the school should consider involving specialists, including those secured by the school itself or from outside agencies. Schools can involve specialists at any point to advise them on early identification of SEN and effective interventions and should always involve a specialist where a pupil continues to make little progress despite SEN support. Parents should always be involved in any decision to involve specialists.
- **Requesting an EHCNA –** where despite the school having taken relevant and purposeful action to identify, assess and meet the SEN of the child or young person (C/YP), the C/YP has not make expected progress, the school or parents should consider requesting an EHCNA. Note that the LA will expect to see evidence of the action taken by the school as part of SEN support.

3. EHC needs assessment

- SEN support – assess, plan, do, review.
- Exceptions – significant change in circumstances; transfer into the LA and no information received.
- S36 (8) CFA – LA must secure assessment if:
  a) CYP has or may have SEN and
  b) It may be necessary for SEP to be made in accordance with an EHCP.
- For 18+ years – also need to consider if additional time is needed to complete education or training compared to majority of others of same age with no SEN.

3. EHC needs assessment

- Get the school's support, if possible.
- Write to Director/Head of Children's Services/ LA may want parents to complete an online form.
- LA must respond within 6 weeks.
- List the CYP's difficulties and evidence eg school reports, Individual Education Plans (IEPs), exclusions, therapists' reports.
- Where CYP has made progress, evidence to show it has only been as a result of much additional support at a sustained level over and above that which is normally provided.
- List why an EHCP may be needed eg. therapies, specialist teaching, additional support 1:1 or small group work, specialist equipment.

4. Evidence - therapy reports

SEND Tribunal advice is that your report should:

- Meet the standards of the professional's code of conduct
- Include their qualifications and experience
- State the purpose of the report and explain written or oral instructions
- List any other reports they have referred to
- Describe their assessment, observations and diagnosis – highlight factual assumptions, deductions from those assumptions and any unusual, contradictory or inconsistent features of the case
- Say if and when other experts were consulted, what information was shared and how this informed views
- Include all relevant information
- Identify, narrow and agree any issues where possible
- Make it clear if there is not enough information to reach a conclusion on a particular issue or point

5. EHCPs

The EHCP is made up of Sections A – K. Amendments can be made to all Sections at Annual Review but only **Sections B, F and I can be fully challenged at the SEND Tribunal**.

- A - Views, interests and aspirations of the child, parents and YP
- **B - Description of the child/young person's (CYP) learning difficulties i.e. their SEN**
- C - Health needs that relate to the CYP's SEN
- D - Social care needs that relate to the CYP's SEN
- E - Outcomes sought
- **F - Provision required to meet educational needs**
- G - Health care provision
- H1 - Social care provision (under 18 years) (s2 of Chronically Sick and Disabled Persons Act 1970)
- H2 - Other social care provision
- **I - Type and name of school/college**
- J - Details of Personal Budget (if requested and agreed)
- K - List of advice

5. EHCPs

- Detail the child/young person's (CYP) fully in Section B (not just in Section A).
- Match needs in Section B to provision to meet those needs in Section F.
- Outcomes: SEND CoP 9.66 – 'An outcome can be defined as the benefit or difference made to an individual as a result of an intervention. It should be personal and not expressed from a service perspective; it should be something that those involved have control and influence over, and while it does not always have to be formal or accredited, it should be SMART.'
- Provision must be very clear - quantified and specified.
- L v Clarke and Somerset CC 1998 – Provision in Section F of an EHCP must be so specific and clear as to leave no room for doubt as to what has been decided.
- B-M and B-M v Oxfordshire CC 2018 – a high level of specificity is required, even in a special school or special resource base.

5. EHCPs

What can be achieved with a good Plan?

- Appropriate level of support for education and training up to 25 years with ‘some’ certainty of delivery – judicial review/personal budget if provision is not being delivered.
- Personal budget - at LA and HT’s discretion
- Broad meaning of training and what may be included – independence living, wheelchair practice, eye gaze, CBT, physiotherapy, music therapy
- Placement named on the EHCP required to take the child
- Possibility of bespoke package of support
- Ability to specify hours of support from professional, reviews, staff training etc.
- Some flexibility around types of placements (and provision in school holidays).

5. EHCPs

Some examples:

- Hydrotherapy - LA can be required to provide it offsite with transport
- Provision in school holidays if there's a risk that the child requires continuity over the period to avoid regression
- Residential placements – up to 52 weeks, if required
- Bespoke EOTAS package with: tutors, TA support, specialist equipment, weekly input from therapists – OT, SLT, PT, music therapist, provision for weekly trips or social/leisure activities, provision for software to be purchased and updated; EP to provide advice and training to new staff; admin and meeting time for all staff; time for private therapists to liaise with NHS equal
- Through the appeal - social care almost 24/7, throughout the year, 2:1 with a nurse + one other – shared funding by health and social care

6. Placement options

- Is it the right school?
- Have you identified the next school/college?
- Is the peer group right?
- Can the school/college meet needs?
- Mainstream or special school or a split placement?
- Maintained or independent/non-maintained?
- Day or residential placement?
- Are you looking for a residential placement?
- Home education? Education Other Than At School (EOTAS) v elective home education
- Remember EHCP can provide support for education up to 25 years.

7. Annual Reviews

Preparation for the AR:

Change to level/type of support?

- Consider requesting an earlier interim review if necessary
- Discuss with the SENCO and therapists – make sure they write a report or attend the AR
- Prepare your evidence

Change of school/type of school? Deadlines for LA to re-issue Plan:

- By 15 February if key transition stage eg moving to secondary school
- By 31 March if post-16 transition

7. Annual Reviews

- Gather evidence for changes being put forward.
- Make sure the review is called within a year of the last review.
- Go through the EHCP and mark up areas that need changing or that you want to discuss.
- Are any assessments required in preparation for the AR?
- Make sure everyone involved is invited to attend the AR and asked to prepare a report.
- Gather your evidence and prepare your requested amendments / parental contribution in writing if substantial.
- Make sure reports are circulated to everyone at least 2 weeks before the AR meeting.
- Follow up the AR meeting.

7. Annual Reviews

- School to send AR report to LA within 2 weeks of meeting
- LA to decide to:
  - (1) end the Plan
  - (2) make no amendments or
  - (3) make changes to the Plan

  and must let parents know of decision within 4 weeks.
- If LA is amending the Plan, keep an eye on the timetable.
- 8 weeks from issue of proposed amendments to a final EHCP (High Court case - *R (on the application of L and others) v Devon CC [2022] EWHC 493 (Admin))*- but there is an imminent Govt consultation response to be published shortly.
- Parents will be given 15 days to respond to the draft Plan.

9. Appeals to the SEND Tribunal

Decisions re content of B, F, I of the EHCP (and social care and/or health) & decisions to end the EHCP.

- Mediation - where the appeal is not just about the name or type of school/placement and where no school/placement is named
- An appeal can generally only be made where a mediation advisor issues a certificate.
- Consider an extension appeal – Tribunal will consider recommendations to Health and Social Care elements of Plan alongside Education appeal.
- Appeal to Special Educational Needs and Disability Tribunal – 2 + 1 month to appeal.
- Appeal process – 12-15 months unless it's a transition appeal or child is out of education.
- Cease to maintain an EHCP appeal – 'no longer necessary' – no longer requires SEP specified.

9. Appeals to the SEND Tribunal

Other options:

- Discuss concerns with the school SENCO, therapists etc.
- Revisit at next Annual Review – collate evidence in meantime
- Consider requesting interim / emergency review
- Complain to the Local Government Ombudsman.

10. The SEND White Paper

- Overall message is that SEND provision is too expensive, too many appeals, costs are unsustainable for LAs, schools and the Tribunal.
- Introduction of a more inclusive system, replacing most EHCPs with Individual Support Plans, introducing a tiered support model and investment of nearly £4 billion.

Key changes:

- Aim to streamline - introduction of a new 3-tiered system of educational support and likely to be 7 packages that are nationally defined, not tailored to individual children. A national team of independent experts will decide these and make recommendations every 5 years.
- Expand ‘inclusion bases’ – expectation is that every secondary school will have one.

10. The SEND White Paper

- SLT, OT and other experts being available to mainstream schools directly – 'Experts at Hand'.
- Special schools to support mainstream schools in identifying and supporting needs.
- New duty on schools to create an ISP for every child with SEN – reviewed annually.
- EHCPs for the most complex needs – will set out provision but the detail will be in the relevant selected specialist provision packages (SSP). LA responsible for funding.
- LA will review the EHCP only at key stage transitions – i.e. reducing right of appeal.
- Placement options to be limited to what is assigned under different SSPs/levels. Not everyone will be able to ask for a special school.
- Limitations to Tribunal's powers – to consider if a different SSP is required i.e. not to decide on specifics. Placement - decision limited to consideration of LA's decision for reasonableness. If unreasonable – can direct the LA to reconsider but not that a particular placement is named. Ultimate decision lies with the LA.

10. The SEND White Paper

- School challenges: to identify and deliver SEND provision; to hear complaints about ISPs.
- Govt will issue guidance on what they consider to be reasonable adjustments.
- Very little about health and social care in the White Paper.
- Those with EHCP will keep them until transition time.

Timings:

- Feb 2026 – SEND White Paper: Every Child Achieving and Thriving Children and Young People First – Govt Consultation; closed on 18 May 2026.
- Several stages before law is passed – First Reading in Parliament, Committee Stage, Report Stage, Second Reading, House of Lords, Royal Assent, roll out and implementation.
- New legislation not expected to come into effect until 2028/29. In the meantime, the current system remains.
- First cohort to transition to the new system will be those at the end of primary, secondary, and post-16 in 2029/30.

Boyes Turner

Thank you! Any questions?

Please contact us if you have any questions.

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Boyes Turner LLP

RTS support group

COFFEE BREAK

PLEASE RETURN AT 11.20

Emotional experiences and wellbeing in RTS

Courtney Greenhill

Summary of PhD Findings

Emotional Experiences and Wellbeing in RTS

Courtney Greenhill, Dr Jane Waite, Dr Georgie Agar & Dr Jo Tarver

What did the PhD include?

- An interview study with parent/carers
- A self-report interview study with individuals with RTS
- A large-scale questionnaire study
- A direct assessment study

1) People With RTS Experience Emotional Difficulties

Families reported anxiety and emotional outbursts (i.e., angry and frustrated emotions) to have an impact on daily life.

Anxiety

Parents and individuals described:

- Increased repetitive movement or restlessness
- Repetitive or ‘checking’ questions
- Becoming overwhelmed in noisy or unpredictable situations
- Worry linked to unfamiliar places or changes in routine

Some of these signs of anxiety may not be included in typical diagnostic descriptions of anxiety, meaning they may be missed in clinical settings.

Emotional Outbursts

Parents and individuals described:

- Emotional outbursts as sudden and intense
- Behaviours reported included emotional vocalisation, physical aggression to objects, and physical aggression to others.
- Common triggers included:
  - Not being able to do a preferred activity
  - Finding a task too difficult
  - Misunderstandings or disagreements with others
  - Being told “no”

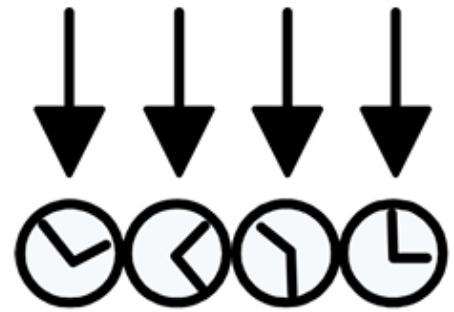
2) Adapted interviews enabled individuals with RTS to share their emotional experiences

- A small group of individuals with RTS took part in adapted interviews to talk about their own emotional experiences.
- They were able to:
  - Name situations that made them feel anxious, sad or frustrated
  - Explain what triggers these feelings
  - Describe how their body feels when emotions build
  - Share what helps them calm down
- Parent/carer reports closely matched the experiences described by individuals with RTS.

Birthday party

School

Not enough sleep



Change in routine

3) Comparison to Typically Developing Peers

Individuals with RTS had higher anxiety scores than a group of typically developing children

Compared to typically developing peers, people with RTS may be more vulnerable to anxiety

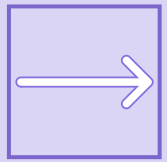
This does not mean everyone with RTS will develop an anxiety disorder, but it suggests:

- Anxiety may be more common
- Support for anxiety should be considered earlier
- Clinicians should be aware of RTS specific signs of anxiety

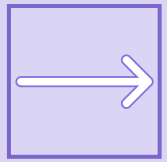
4) Factors Associated with Anxiety

- Certain factors seem to make anxiety more likely in RTS
- Across the studies, two factors stood out as being especially important:
  - Intolerance of uncertainty
  - Impulsivity

Intolerance of Uncertainty



Finding it hard to cope when things are unknown, unpredictable, or different from usual. This was the strongest and most consistent predictor of anxiety.



Intolerance of uncertainty emerged as the clearest area that may be helpful to target in future support.

Impulsivity

- Higher impulsivity levels were associated with higher anxiety levels
- One possible explanation for this is difficulties with the executive function process known as ‘inhibition’
- Inhibition helps us pause, think, and stop ourselves from reacting automatically
- If inhibition is more challenging, as it may be for some individuals with RTS, situations can feel overwhelming or harder to manage in the moment

Other factors also played a role, including:

Sensory sensitivities (especially to sound)

Difficulties with emotional regulation

Autistic characteristics

5) Factors Associated with Emotional Outbursts

Emotional outbursts were more unpredictable and potentially vary between individuals.

Outbursts were linked to:

- Sensory sensitivities
- Difficulties with emotional regulation
  - Within this, struggling to tolerate frustration
- Executive function difficulties (e.g., shifting from one activity to another, impulsivity)
- Day-to-day triggers, such as not being able to do a task or activity, and being tired/ hungry, or pre-menstrual.

6) Emotional Difficulties in RTS Type 1 and Type 2

People with RTS Type 1 and Type 2 showed similar levels of emotional difficulties, but the causes may differ.

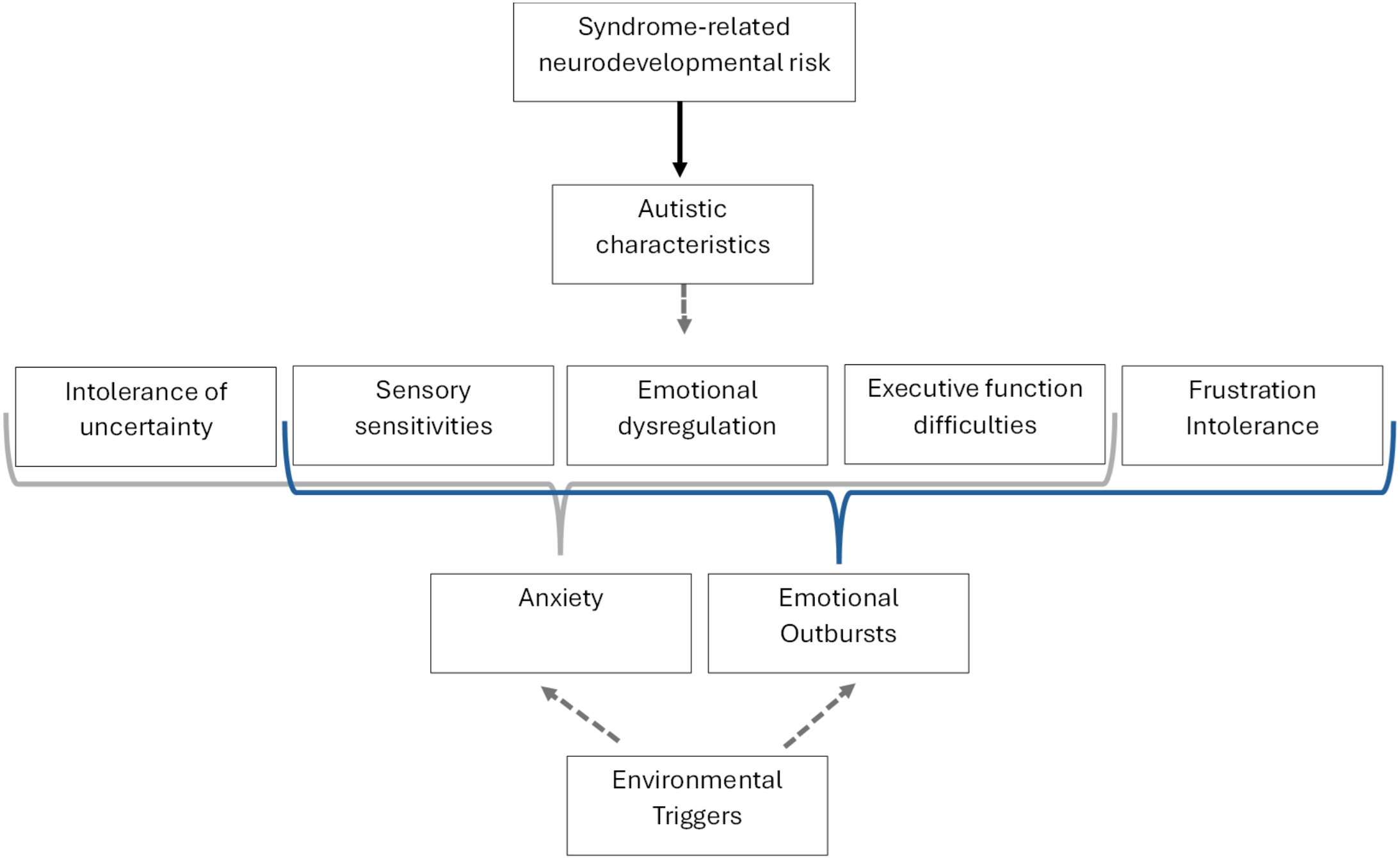
Overall levels of anxiety and emotional outbursts were similar across RTS subtypes, but the pathways contributing to these difficulties may not be the same.

This highlights the need for individualised approaches, as what helps one person may not help another.

7) People with RTS are Happy

Important to recognise that many parents/carers reported their child as generally happy.

91% of parent/carers indicated that their child experiences strong positive emotions, such as happiness and excitement.


Syndrome-related neurodevelopmental risk
Autistic characteristics
Intolerance of uncertainty
Sensory sensitivities
Emotional dysregulation
Executive function difficulties
Frustration Intolerance
Anxiety
Emotional Outbursts
Environmental Triggers

What does all this mean for families?

Individuals with RTS may experience anxiety and emotional outbursts.

Knowing this can help families feel less alone and less confused about what they're seeing.

Understanding triggers can help families anticipate and reduce distress.

Certain emotional behaviours may not fit standard clinical checklists. It is important to consider whether behaviours such as increased motor activity and perseverative requests may be a sign of anxiety in people with RTS.

Supporting emotional regulation and intolerance of uncertainty may be particularly helpful.

Thank you to all the parents that took part and continue to support the research!

RTS support group

Aston University
BIRMINGHAM UK

Current Research Projects

Understanding the origins of repetitive behaviours in babies aged 6–12 months using brain scans

Rachel Martlew

Talking to families to develop a syndrome sensitive intervention for anxiety for children aged 4–15 years

Lily Waller

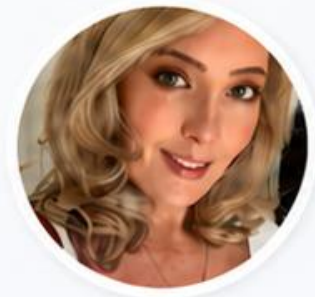
Collecting questionnaire data over the lifespan to understand the psychological and support needs of people with RTS

Dr Rory O'Sullivan

Questionnaire study to help improve annual health checks for people with learning disabilities

Dr Benjamin Costello

Talking to parents of children whose children have more subtle indicators of learning disability to learn about how parents make sense of their child's condition



Jessica Bodfish

A Shared Perspective on RTS: Medical and Psychological Insights

Dr. Susan Wiley and
Dr. Jane Waite

Expert panel discussion

- Facilitated Q&A with Dr. Susan Wiley and Dr. Jane Waite
- Led by Courtney Greenhill
- The following slides were not presented at the conference – but contain much of the information discussed and are useful for reference

Rubinstein Taybi Syndrome Family Conference

June 2026

Cincinnati Children's
changing the outcome together

Top Family Priorities to discuss

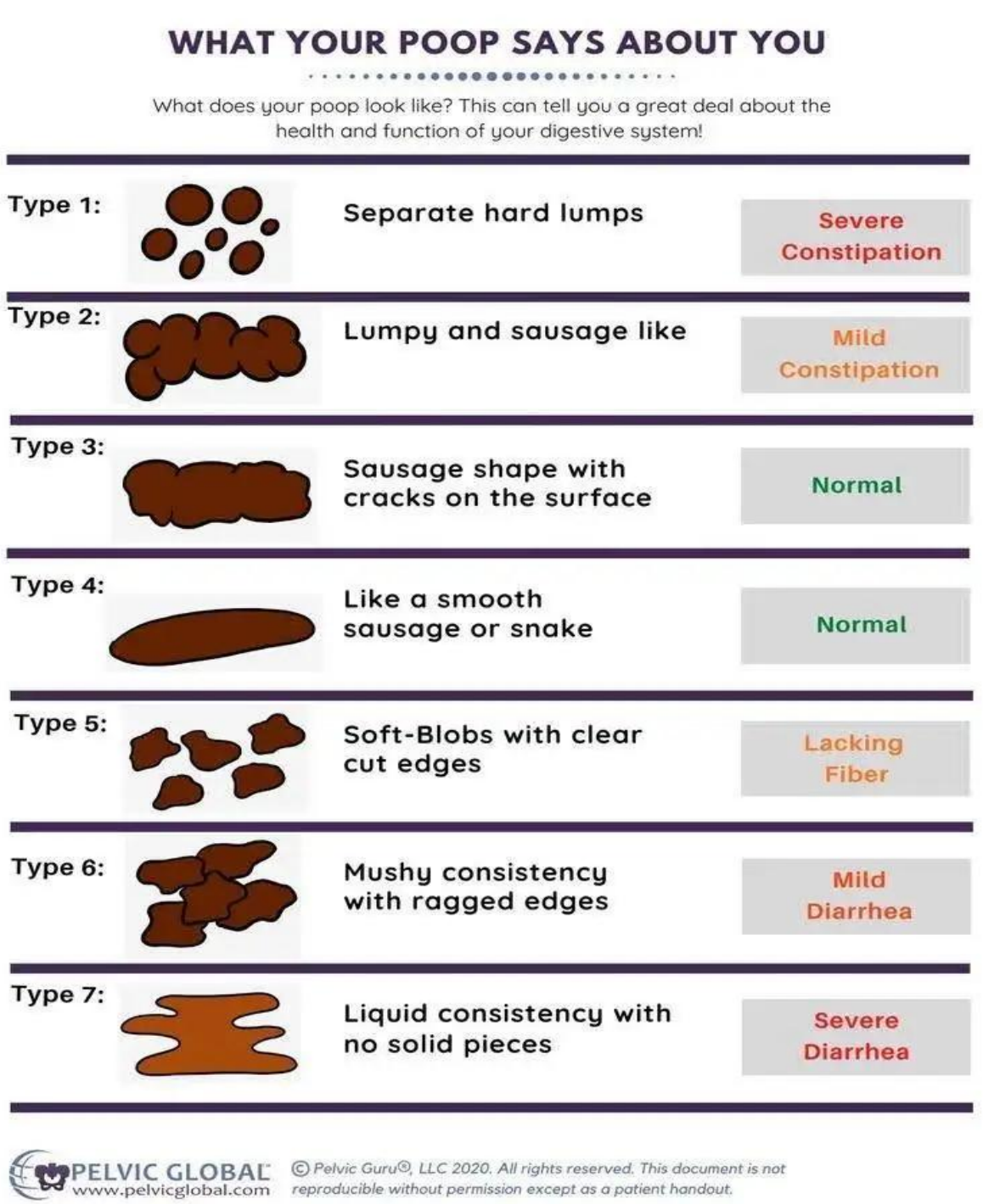
- Toileting, constipation and nutrition
- Sleep issues
- Puberty

- *If a family is struggling with toileting, constipation or diet, it can feel overwhelming—where should they start?*

Cincinnati Children's
changing the outcome together

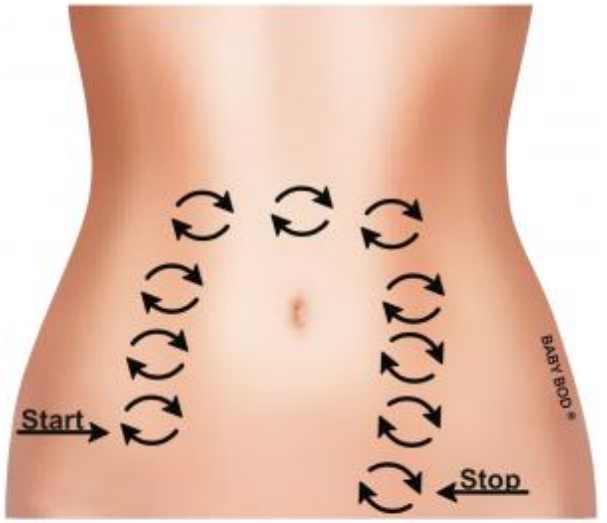
Toileting

- Medical considerations:
  - Role of acute constipation
  - Role of chronic constipation
  - Consideration of tethered cord (when do we worry?)



Constipation

- Role of mobility and tone
  - Movement helps with bowel motility
  - Low tone can impact movement through the bowels
  - Pelvic floor PT, massage
  - Reflux (spitting up) may be a sign that a child is constipated (if it can't move forward, it will come back the other direction)



Constipation Massage Path

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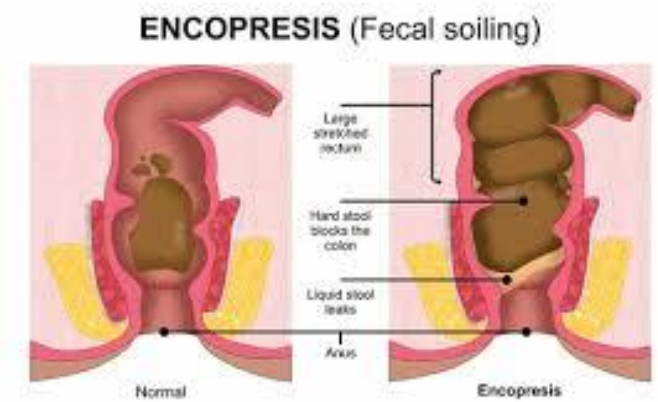
changing the outcome together

Constipation

- Acute constipation
  - Some children will with-hold when trying to toilet training because it hurts
  - You will sometimes see a child standing at a table, grunting and a red face but they may actually be trying to hold it back in rather than push it out
- Chronic constipation
  - Can prompt the bowels to get stretched, impacting the awareness of what is happening and then more issues with accidents around a hard stool ball or because they don't recognize they have something coming out.



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The FLACC Pain Scale

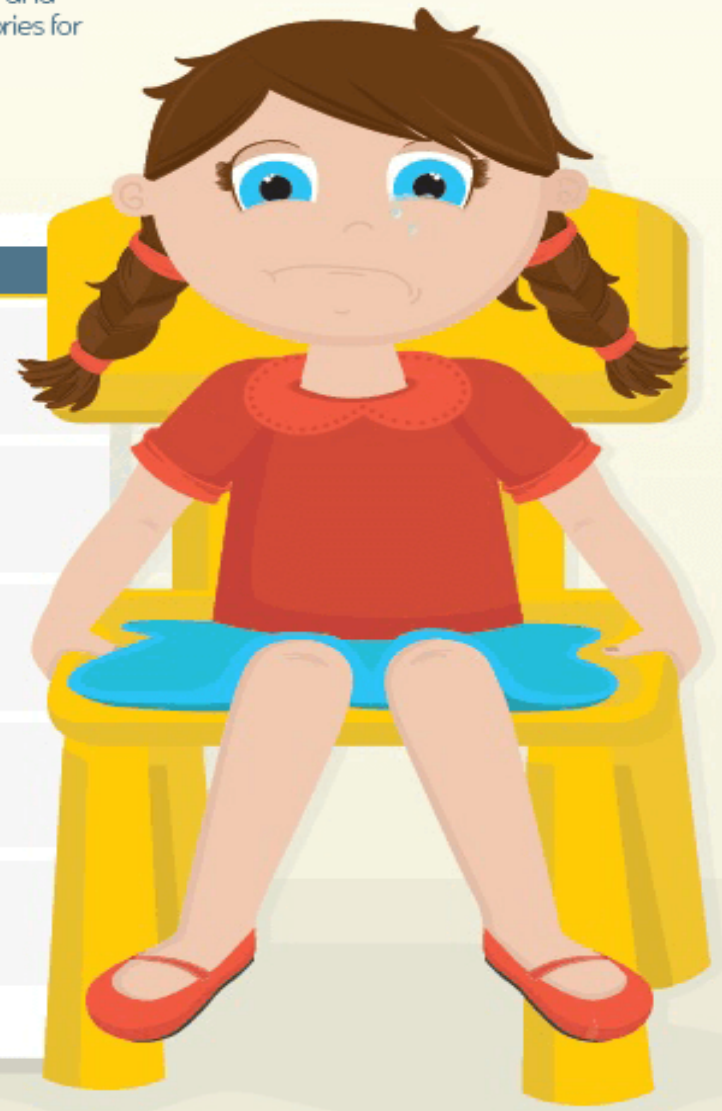
Sometimes it is difficult to assess pain in children who are non-verbal. The FLACC Pain Scale is a system that can help parents and professionals assess pain levels in children who have limited or no expressive communication. The diagram shows the categories for scoring. Zero, one or two points are given to each of the five categories: Face, Legs, Activity, Cry and Consolability.

Interpreting the Behaviour Score
Each category is scored on the 0-2 scale, which results in a total score of 0-10

0	relaxed and comfortable	4-6	moderate pain
1-3	mild discomfort	7-10	severe discomfort of pain or both

Categories	Score Zero	Score One	Score Two
Face F	No particular expression or smile	Ocasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs L	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity A	Lying quietly, normal position moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry C	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability C	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distactable	Difficult to console or comfort

If a child is showing these behaviours, it doesn't necessarily mean that they are in pain, as some of the behaviours measured by the FLACC scale can happen for other reasons. However, parents are advised to follow up high scores with a professional.



CEREBRA
Working wonders for children with brain conditions

REFERENCE Merkel, S.I., Voepel-Lewis, T. Shayevitz, J.R., and Malviya, S. (1997). The FLACC: A behavioural scale for scoring postoperative pain in young children. *Pediatric Nursing, 23(3), 293-297.*

Constipation

- Acute constipation
  - Short-term laxatives/stool softeners
- Chronic constipation
  - Need a comprehensive approach of behavioral timed sitting along with keeping the bowel movements soft (smushers) and motility medication (pushers)
  - Sometimes a “clean-out” is needed
  - General rule of thumb is that we need to treat for as long as the constipation has been there and then very slowly weaning from the medications

- *Parents often wonder if the issues are behavioural or if something is going on physically, how can they tell?*

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In reality it may be both physical and behavioural:

- Painful bowel movements can lead to fear and avoidance
- What looks like refusal is often anxiety
- Confidence may take longer to recover than constipation
- Reduce pressure and focus on small successes
- Progress is often gradual

- *“How closely linked are diet, constipation and toileting—and what should parents focus on first?”*

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Constipation

- Role of diet
  - Sufficient fluid is key! (but not just milk)
  - Fiber sources: fruits (strawberries), juices that start with P help you poop (papaya, pineapple, prune), graham crackers, popcorn (if safe at a skillset that is safe to chew and swallow)
    - Beware dry fiber without fluid, you can make concrete
  - Monitor foods that could constipate (cheese, milk)

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Tethered Cord

- What are the clues of a possible tethered cord?
  - Sacral dimple, hair over the spine
  - **Changes** in gait or bowel and bladder patterns (often with growth spurt)
  - Neurological exam can point to a lower cord issue
- How do we decide if there is a “symptomatic” tethered cord
  - A combination of imaging and function (low lying conus is common but might not cause tethered cord)
  - In infancy can do an ultrasound of the spine
  - In older children an MRI of the lumbar spine with cinematography is needed (looking at cord movement and pulsation)
  - Also often look at other systems that could be impacted, like bladder functioning with urodynamics, neurological exam, and gait changes.
- Treatment
  - Neurosurgery will determine if surgery is indicated
  - They try to avoid recurrent surgeries, but re-tethering can occur due to adhesions from surgery

- *“Many parents worry about very limited diets. How concerned should they be, and what’s a realistic approach?”*

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changing the outcome together

Limited Diets

Many neurodivergent children have strong preferences around food.

Selective eating may be influenced by:

- Sensory sensitivities (taste, texture, smell, appearance)
- Anxiety about unfamiliar foods
- A preference for predictability and routine
- Previous difficult experiences with eating

Limited Diets

What tends to help?

- ✓ Introducing new foods gradually (15-20 exposures before a child can be willing to put something in their mouth!)
- ✓ Repeated, low-pressure exposure
- ✓ Foods in different forms
- ✓ Celebrating small steps (looking, touching, smelling, tasting)
- ✓ Building familiarity over time (think outside the plate)

- *A very common concern is toilet refusal—especially when a child will use a nappy but not the toilet. What might be going on here?*

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Toileting

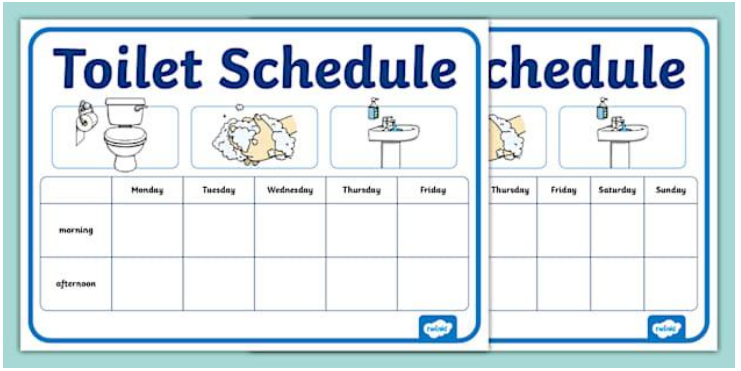
- Developmental skills:
  - Ability to recognize that you are having a bowel movement
    - Initially recognizing **after** having a bowel movement
    - Child readiness clues: hiding to have a bowel movement
    - Recognizing **before** I have a bowel movement that I have to go (and can or cannot wait)
  - Ability to do the steps of going to the bathroom (getting onto the toilet, pulling up and down clothing)
  - Desire to please others (motivation), communication to indicate I need to go
  - Limited concerns with sensory experience, fear of sitting on the toilet
  - Responding to schedule/cues and timed toileting (including willingness)
  - Initiating or requesting may come second and impacted by communication skills (it's okay to use a timed schedule and prompts, that is still successful!)

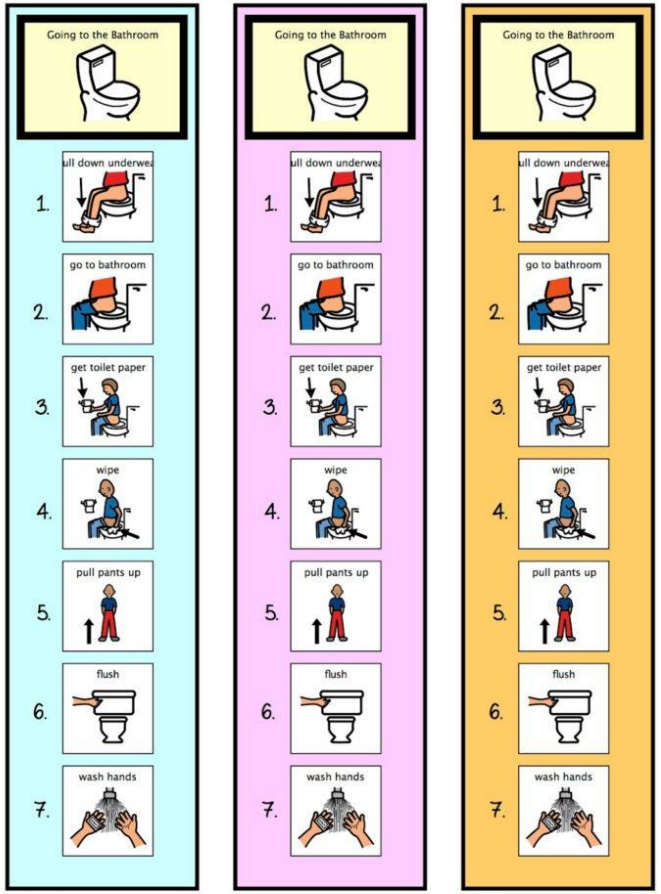
Toileting

- What does it take to go to the bathroom independently?
- Medical considerations:
  - Soft enough bowel movements (but not too soft) to come out without pain
  - Ability to recognize that you are having a bowel movement or needing to urinate
    - Initially recognizing **after** having a bowel movement/wet
    - Child readiness clues: hiding to have a bowel movement
    - Recognizing **before** I have a bowel movement/wet that I have to go (and I can or cannot wait)
    - Dry after a nap
  - Ability to “squeeze” the stool out (internal and external sphincter)

Toileting

- Behaviors and motivation that helps
  - Getting the data on bowel and bladder patterns
  - Building the skills, “Reverse chaining”
  - Using schedules, timers
  - Incentive strategies and how to spread out the incentives when appropriate





Reduce Pressure

When toileting becomes stressful, children can become more anxious and resistant.

What helps?

- Keep prompts calm and predictable
- Use routines rather than repeated reminders
- Avoid punishment, criticism, or showing frustration
- Focus on creating positive experiences around toileting
- **The goal is for the toilet to feel safe, not stressful.**

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Build Confidence

Children often need to develop confidence in small steps.

Think about:

- Breaking the task into manageable stages (consider sensory experiences)
- Practising skills without pressure
- Supporting success at each step
- Moving at your child's pace
- Confidence grows through repeated positive experiences

SENSORY CHALLENGES IN THE BATHROOM

Celebrate Progress

Celebrate Progress

- Progress is often gradual.
- Success is not just using the toilet independently.

- **Celebrate:**
- Sitting on the toilet
- Communicating a need to go
- Reduced distress or avoidance
- Increased awareness of bodily signals
- Small steps towards independence
- **Small gains can lead to big changes over time.**

Sleep

- Sleep cycles by age (and consolidation over time)
- Disruptions to sleep
  - Medical and behavioral contributors
- Building sleep patterns that support a good night's sleep

- *Sleep can be one of the most challenging areas for families—impacting not just the child, but the whole household.*

- *For children with additional needs, sleep difficulties are particularly common, and often complex. So let's start with this, sleep issues seem to be very common in children with additional needs—why is that?*

How much sleep do typically developing children need?

- Age-dependent and to some degree individually variable

Age	Hours
0-2 months	12-19 hours
3-11 months	14-15 hours
1-3 years	12-14 hours
3-5 years	10-13 hours
5-10 years	10-11 hours
11-17 years	8.5-9.5 hours

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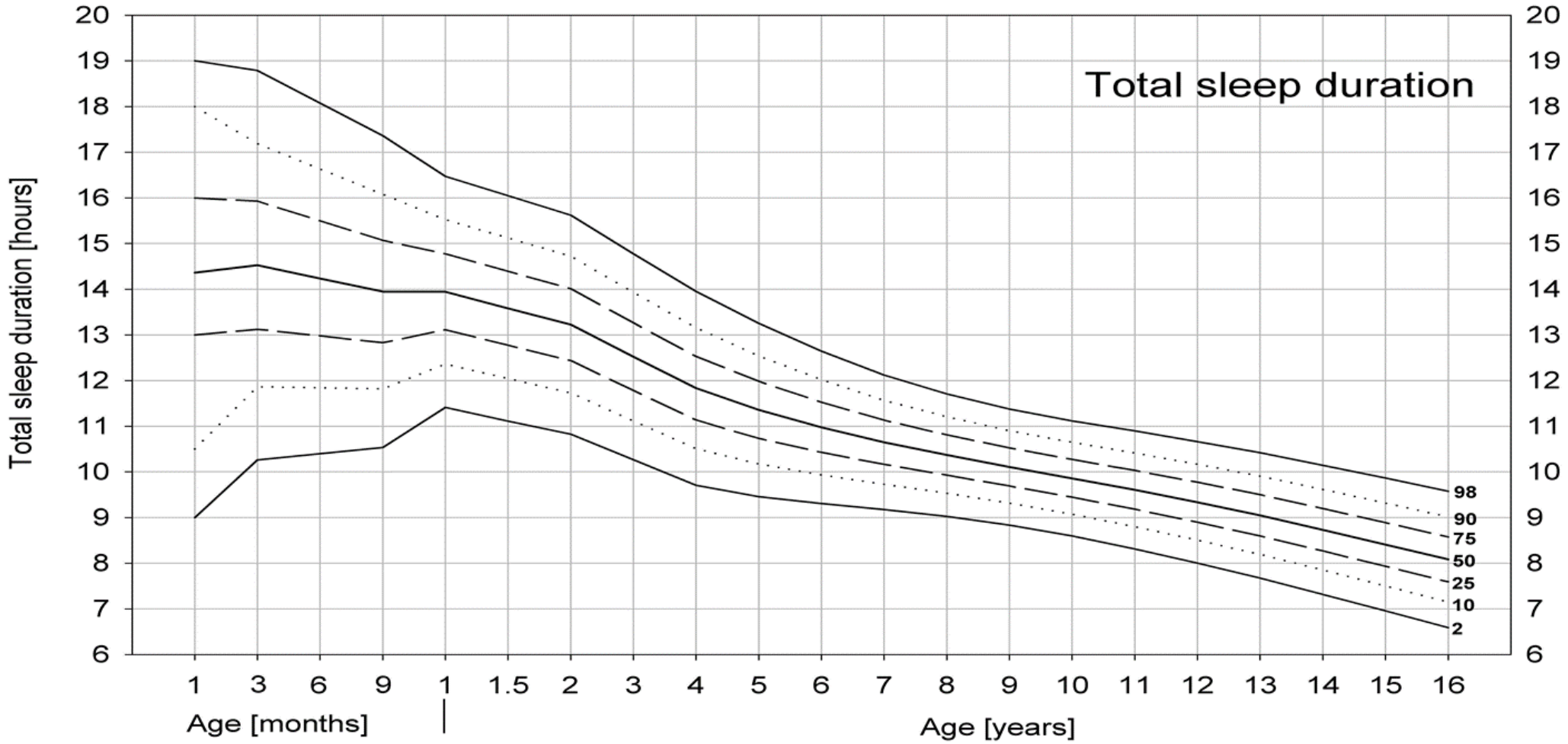

Iglowstein et al., 2003, p. 304

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What happens beyond our control that interferes with good sleep

- Frequent hospitalization/NICU stays (we aren't good at letting children get into an appropriate sleep cycle)
- Illnesses (ear infections, respiratory illnesses, etc)
- Reflux, feeding difficulties when young (is my provider telling me to wake my child up to feed due to slow growth?
- Small airways which can cause a higher rate of sleep apnea
- Selective appetite can contribute to low iron stores which can be linked to restless leg syndrome

What happens beyond our control that interferes with good sleep

- Differences in body clock – change in release of sleep hormone (in some people with neurodevelopmental conditions)
- Fear of the dark and separation anxiety (may be entirely developmentally appropriate)

What happens within our control that interferes with good sleep

- For older children, “fear of missing out”, difficulty stopping electronics, the usual behavioral issues (prolonging bed time, getting up frequently after being in bed)
- When children are a little older, long naps in the afternoon
- Eating right before going to bed (second wind)
- Exercise (trying to wear children out late in the day)
- Safety considerations with night-time awakenings

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- *So it seems that sleep challenges can have multiple factors, and aren't purely 'behavioural'.*

- *If a family is struggling with sleep—bedtime battles, night waking—what should they prioritise first?"*

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What can we do to improve sleep habits

- Working towards good sleep hygiene
  - Regular bedtime routine (and consider timing that is age appropriate)
  - Wind-down time
  - Build a good sleep environment (lighting, avoiding screens, abrupt loud sounds)
- Building self-calming strategies when developmentally appropriate
- Work towards falling asleep on their own when developmentally appropriate (can be a gradual de-sensitization approach or the “cry it out method”)
- Sleep diaries can help identify patterns of sleep

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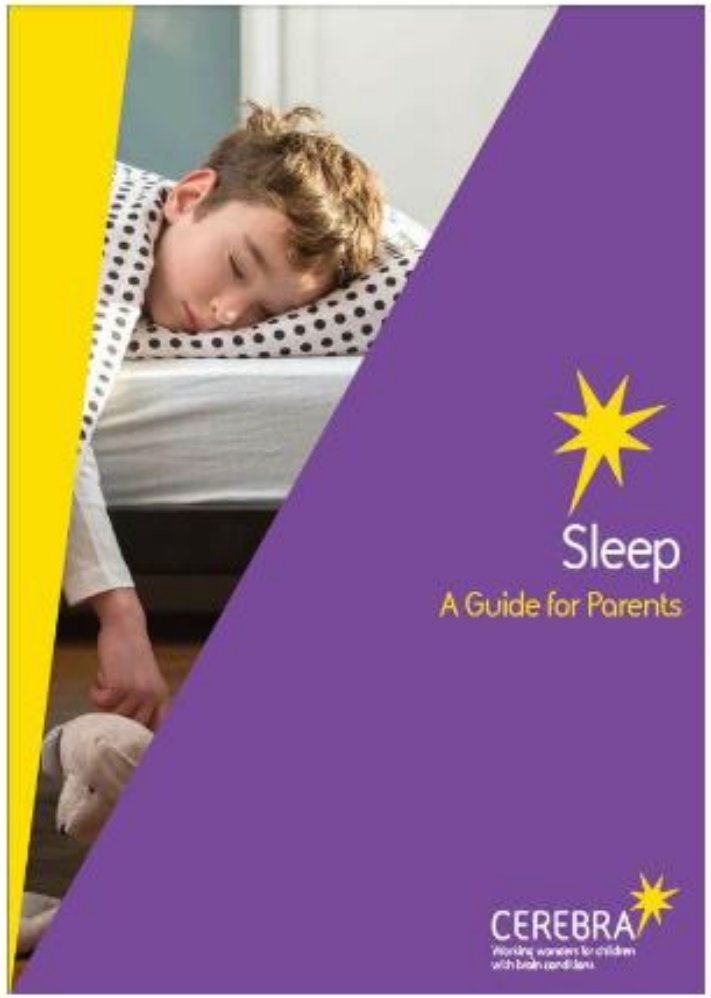
- *Waking in the night and needing a parent is something many families struggle with. How can this be managed in a realistic and supportive way?*

Night-waking

- We all naturally wake up through the night
- For children who need help to fall asleep, they will need this again to fall back asleep
- Working towards helping children fall asleep on their own can help
- The time you have done all of the right behavioral strategies, the next day, you might recognize a medical issue that disrupted a child's sleep
- Other medical needs can also cause sleep disruptions like reflux, ear infections)

Cerebra Sleep Guide

- **Cry it out** – Gradually reducing parental responses so the child learns to settle independently.
- **Bedtime fading** – Temporarily moving bedtime later to match when the child naturally falls asleep, then gradually bringing it earlier.
- **Faded withdrawal** – Gradually reducing parental presence and support at bedtime over time.



Sleep Advice Service

We understand that if you have one child that doesn't sleep, the whole family suffers. Our range of sleep services will help your child – and everyone in your family – get a good night's sleep.

Sleep Advice Service

Guides

Webinars

How well did you sleep last night?

Seminars

Research partner

Sleep Training for Professionals

- *And finally—what should parents expect in terms of sleep progress, and how do they know they're on the right track?*

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- *Families may feel that sleep challenges can feel relentless, but with the right understanding of both the physical and behavioural factors, and a consistent approach over time, meaningful progress is possible.*

- **Other follow on questions if there is time…**
- *"When should families seek specialist help?"*
- *"Is melatonin or medication ever appropriate?"*
- *"How can parents cope with their own sleep deprivation?"*

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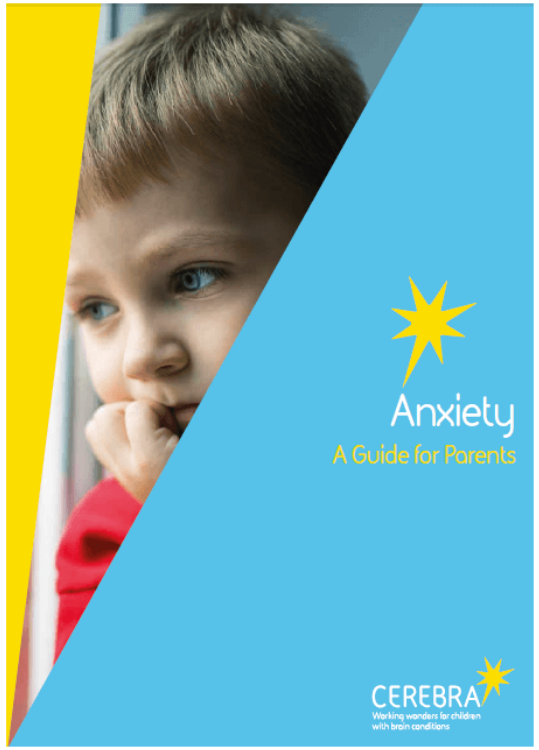
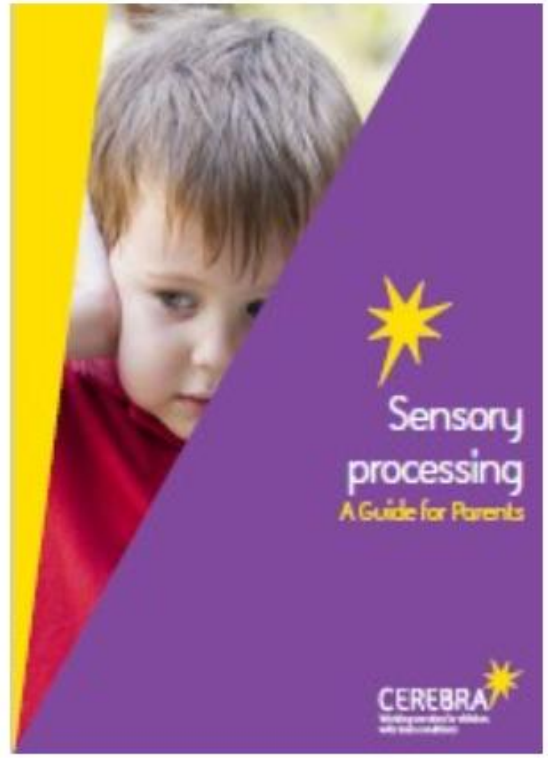
Sleep supports

- When a child isn't sleeping, parents aren't sleeping!
- Meeting with a psychologist who works with sleep problems can be very helpful
- They can guide you and fine tune your approaches
- Sometimes we consider sleep aides such as melatonin (what our body naturally makes to establish sleep cycles) or other sleep medications
- Most medications are more helpful at getting children to fall asleep rather than stay asleep
- If a child has really delayed sleep onset or disrupted sleep cycles, sometimes we also use light to re-establish the body's natural sleep wake cycle

Download the Cerebra Sleep, Pain, Anxiety and Sensory Processing Guides





- *Puberty can be a challenging and uncertain time for any family—but for children with additional needs, it can raise additional questions around readiness, understanding, behaviour and independence. We've pulled together some of the most common questions parents ask to put to our experts.*
- *Firstly, when is the right time to start talking about puberty—and how should parents approach this with children who have different communication or learning needs?*

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Puberty

- Every parent fears puberty
- Bigger concerns with developmental levels

- Menstrual cycles
- Building appropriate behaviors
  - Social interactions, things that feel good
- Managing behaviors that have been around a long time but now my child is bigger and stronger

Strategies to support understanding

- Start early, build a vocabulary and understanding of our bodies (with the correct words)
- Build skills to understand how we interact with others in our lives (who we can hug, who we give a high five to, who we just greet).
- Build skills to recognize what are private parts (where bathing suit covers) and build capacity to say no to unwanted attention

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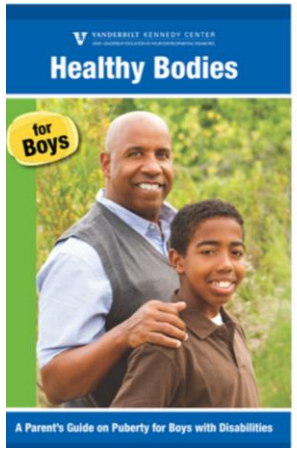
Clues that Puberty is on it's way

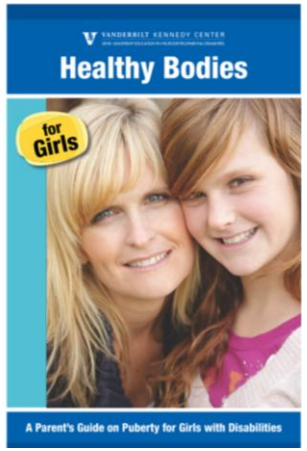
- For girls, breast development is the first true sign of puberty. Following this, there is typically 1-2 years before menstrual cycles start.
- Girls often don't have much height growth once they start menstruation
  - If true puberty is developing prior to 11 or 12, consider going to an endocrinologist and discussing prolonging the onset of puberty
- For boys, testicular growth is the first true sign of puberty.
- Growth spurt continues for some time after onset of puberty

Why we might use medications to start puberty if it is very delayed

- Bone health
  - Estrogen supports bone health in girls
  - Testosterone supports bone health in boys
- Health screening and care
  - Boys can have undescended testicles as infants and we seek to do surgery early enough to preserve testicular function as well as to ensure a way to screen for testicular cancer
  - Vaccinations to prevent HPV in boys and girls (virus that pre-disposes women to cervical cancer)
  - Fertility is possible

Understanding puberty





- Girls
  - Body hair, odor
  - Periods can be light and intermittent for the first year
  - Some teens can manage if already independent in toileting, other families seek medical management of menstrual cycles
- Boys
  - Body hair, odor
  - Changes in voice, facial hair
- Masturbation
  - Morning erections and masturbation

Good resource:

Vanderbilt Healthy Bodies Toolkit

The Healthy Bodies Toolkit

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Options for Medical Management of Periods

	Method	Administration	Expected Bleeding Pattern	Advantages	Disadvantages	Contraceptive Failure Rate
Combined Estrogen and Progesterone Medications	Pills	Daily	• Predictable periods (monthly or every several months)	• Many options • Easily reversible	• Possible nausea, upset stomach, irregular bleeding, breast pain • Increased blood pressure and blood clots are less common but serious possible side effects of estrogen • Estrogen generally is not recommended for patients with migraine headaches with aura, high blood pressure, personal or family history of blood clots, or limited mobility	6-9 pregnancies per 100 women in a year*
	Patch	Weekly		• Easily reversible		
	Vaginal ring	Monthly		• Easily reversible		
Progesterone Only Medications	Pills	Daily	• Limited bleeding at higher doses	• Many options • Easily reversible	• Possible increased acne, mood changes, and weight gain • Requires taking the medication at the same time daily	
	Injection	Every 3 months	• Irregular bleeding at the start • 80% rate of no bleeding with long term use	• Less frequent administration	• Possible increased acne, mood changes, and weight gain • Reversible bone loss • Not recommended for patients with low bone strength	
	Implant	Up to 4 years	• Lighter, sometimes irregular bleeding • 20% rate of no bleeding with long term use	• Ease of continued use	• Requires a procedure for placement (office) • Highest rate of unpredictable bleeding	Less than 1 pregnancy per 100 women in a year
	Intrauterine device	Up to 7 years	• Lighter bleeding • Up to 60% rate of no bleeding with long term use	• Ease of continued use • Limited hormone circulation	• Requires a pelvic exam and procedure for placement (office/operating room) • Irregular bleeding and cramping for several weeks to months after placement • Not recommended for patients with a small or differently shaped uterus	

*Not all progesterone only pills are approved as birth control.
**In our clinic, surgical methods of managing periods are not usually considered.

- *Parents often worry about new behaviours during puberty. How can they tell what's typical development, and what might need support?*

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Moods and feelings

- Are also part of growing up and becoming more independent
- No matter a teenagers cognitive processing, they have a life experience and may seek what siblings or peers have, including greater independence
- Puberty will shift sleep-wake cycles (natural changes in melatonin surges in teens)
- Physical changes can be exciting or concerning to the individual (sensory experiences of shaving, using deodorant)
- Like any behavior, if behaviors in teens impact day to day care, functioning, or mental health, seeking help is important to do

PUBERTY CHANGES:

WHAT'S TYPICAL AND WHEN TO SEEK SUPPORT

LIKELY TO BE PART OF TYPICAL PUBERTY

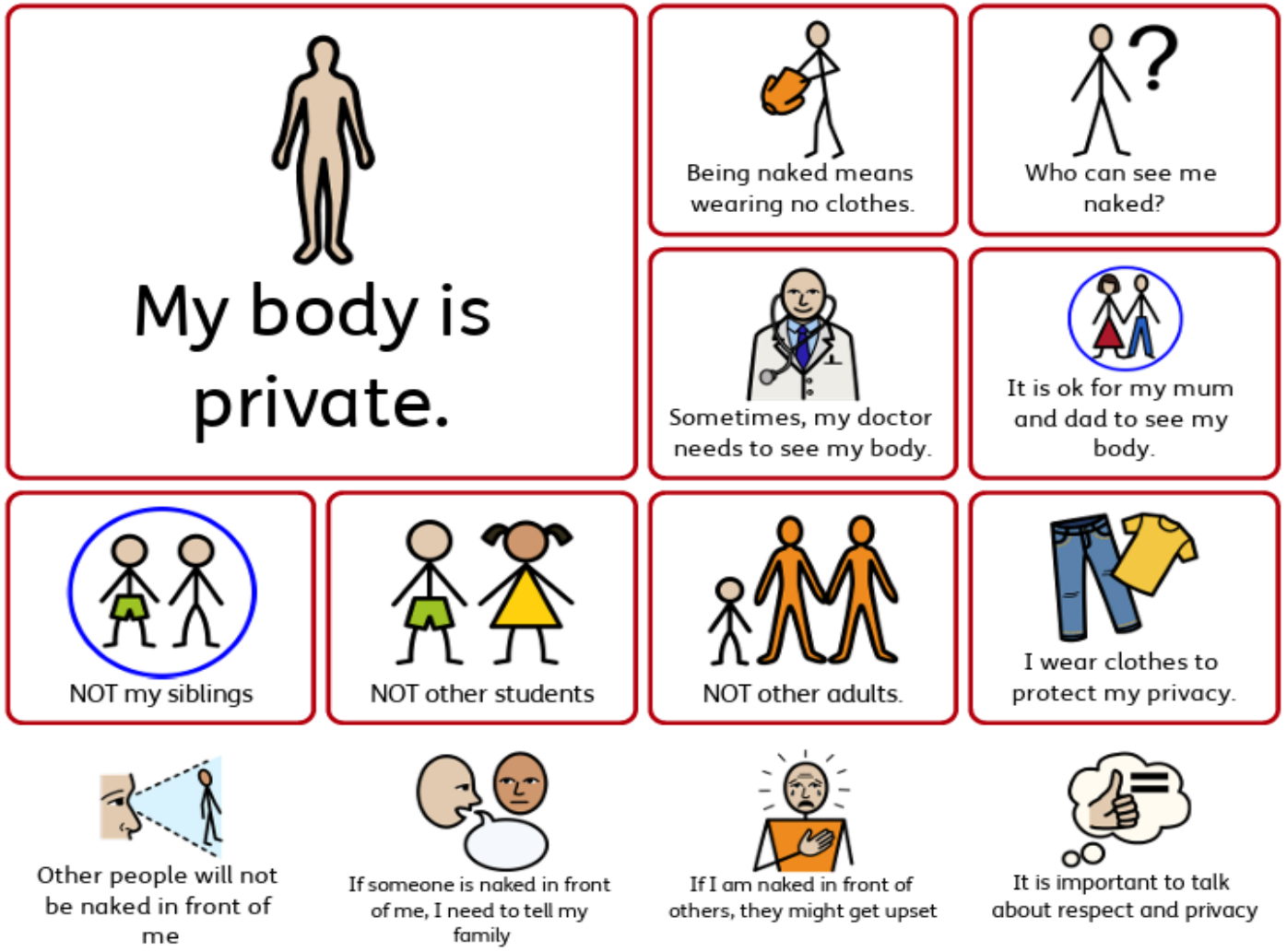
- Wanting more privacy
- Increased self-consciousness
- Mood fluctuations
- Greater independence
- Interest in relationships
- Masturbation in private settings
- Increased emotional reactions

CONSIDER SEEKING ADDITIONAL SUPPORT IF:

- Behaviour changes suddenly or dramatically
- Distress is persistent or severe
- There is a significant loss of skills or independence
- Aggression or self-injury increases substantially
- Sleep, eating, school attendance, or daily functioning are affected
- The young person seems overwhelmed by the changes they are experiencing
- Safety or vulnerability becomes a concern

- *A big concern for many families is how to teach privacy and appropriate behaviour—especially in a way their child understands and can apply in different settings.*

Teaching Privacy



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- *“Finally—how can parents support their child to become more independent and confident through puberty?”*

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Supporting independence

- At all ages, we can have expectations for children to contribute at their level of abilities (help out the family chores)
- Starting at young ages is foundational for skills needed in puberty
- Using social stories, hands-on support, moving to verbal prompts and/or visual schedules can build to greater independence

- *Puberty can feel daunting, but with early preparation, clear communication and the right support, it can also be a positive step towards independence.*

And finally, what is one key piece of advice you would give parents?

Cincinnati Children's
changing the outcome together

RTS support group

LUNCH

Collect children from the creche

See you back here at 14.00

Removing Barriers

Jane & Jimmy James

Sue Cochrane
Wrest Park
English Heritage

Removing barriers

- Presentation by Jimmy and Jane James, parents to Imogen, age 26 with RTS and voluntary work arranged with Wrest Park, an English Heritage site.


Nicholas Again
Family
THE BODY IN QUESTION
THE YES BRAIN
STRONG TO THE CORE
Your Name Is Today
NOW NOT TO WEAR BLACK
MUM'S HANDBOOK
Mindfulness
MARK WILLIAMS
DANNY PENMAN
INNER WELLIES
The Call for WOMEN BISHOPS
Beyond the Edge
CRITICAL CARE NURSING SECRETS
BREAKING MAD
Multicoloured Mayhem
CAROL VORDERMAN'S
PHYSICAL
HEALTH AND WELLBEING
Adam Kay
FINAL CUT STEVEN BACH
STEVEN PINKER
ZERO NEGATIVITY
ANT MIDDLETON
Is it me, or is it hot in here?
HAIR POWER
JANET STREET-PORTER
he's having a baby
DESMOND MORRIS MANWATCHING
what not to wear
THE BLACK ANGELS
THE EMPLOYER'S HANDBOOK
MICHAEL BIRDATH
FREE TO TRADE


WHAT'S ON TODAY
GET THE
COST OF YOUR
TICKET BACK!
ASK US
AT
ADMISSIONS
Step into England's story!
TRICKS
JUST TREAT

Teens and up session

Meet in the foyer for Crazy Golf

RTS support group

30-minute interactive workshops

Rotate through each session

Making sense of behaviours that challenge

The Nitty Gritty of EHCPs and the Law

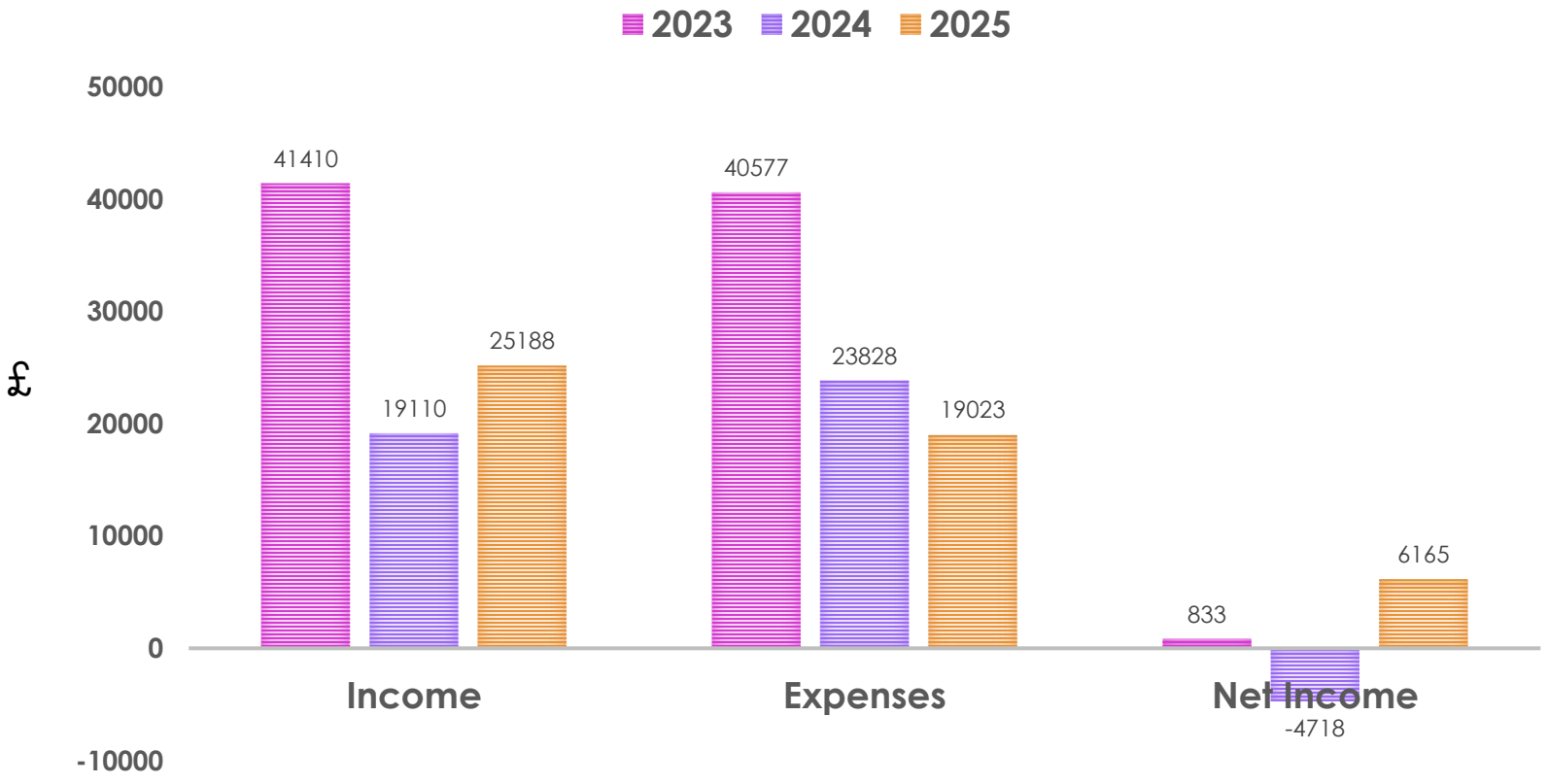
Managing your emotional journey as a parent carer

International Guidelines

RTS support group

2025 AGM

Financial report



The last financial year has seen us maintain our regular donations.

In addition, we generated funds from Parallel run and the Raffle.

Major Expense for the year was the cost

- 2024 Conference (outstanding invoices)
- Clinical Guidelines
- Summer Fun Day

Past fundraising events

2022 – GREAT SOUTH RUN

2023 – 3 PEAKS CHALLENGE

2025 – PARALLEL LIVING

RTS support group

Take part in the headline fundraiser for 2026!

WHAT IS IT?

ULTRA CHALLENGE

WHAT DO YOU DO?

EVENTS HELD ACROUND THE COUNTRY WHERE PARTICIPANTS CAN WALK, RUN OR JOG A DISTANCE OF THEIR CHOICE FROM 10KM TO 50KM AT A PACE WHICH SUITS THEM.

WHEN:

SATURDAY 26TH SEPTEMBER

WHERE:

HENLEY-ON-THAMES

We have a dedicated web page

CHILTERN 50 ULTRA CHALLENGE®

Sat 26 SEPT 2026

Chiltern Hills · 50 km Loop + 25 km & 10K · Walk, Jog, or Run
Henley Basecamp · Camping · Parking · Transfers

JOIN THE TEAM!

Join the Rubinstein-Taybi Syndrome Support Group Team with a superb 50km looped challenge through some of the Chilterns' finest countryside.

Expect historic trails, rolling hills, nature reserves, and fantastic views throughout. From our **Henley basecamp**, enjoy a **Saturday night celebration meal & bar**, plus extensive **on-site camping and parking**. The route offers real variety, wonderful scenery, and is **easily accessible from London**.

You'll receive **full support and hospitality**, and with a **25 km loop** and a **10 km loop** also available, there's a **Chiltern Ultra Challenge®** for every Team.

ULTRA CHALLENGE SERIES

JOIN THE TEAM!

FOLLOW THE STEPS BELOW TO SIGN UP, SET UP YOUR FUNDRAISING PAGE AND BOOK YOUR OPTIONAL EXTRAS

1. REGISTRATION & FEES

- Choose your distance and click sign up.
- Registration Fees are covered by RTS Support Group

2. FUNDRAISING

- As your place is sponsored, we hope that you will fundraise.
- There is no set minimum, but fundraise as much as you can!
- Set up your JustGiving page by clicking the button below.

3. BOOKABLE EXTRAS

- In the relevant section below you can view the extras available for the event.
- Click the 'Book Extras' button to find the extras form.
- You can pay at checkout and any discounts will be applied at checkout

OUR CHILTERN CHALLENGE!

Whether you're a walker and new to challenge events, an experienced trekker, a marathon enthusiast upping the distance, or a seasoned ultra runner. Our team can choose from all distance options, and you can choose which suits you best. Most will walk – but if you want to jog or even run – that's fine! The Chiltern 50 Ultra Challenge is fun, safe, & rewarding – with full support all the way, enabling you to push yourself further in wonderful scenery, and enjoy a great weekend away.

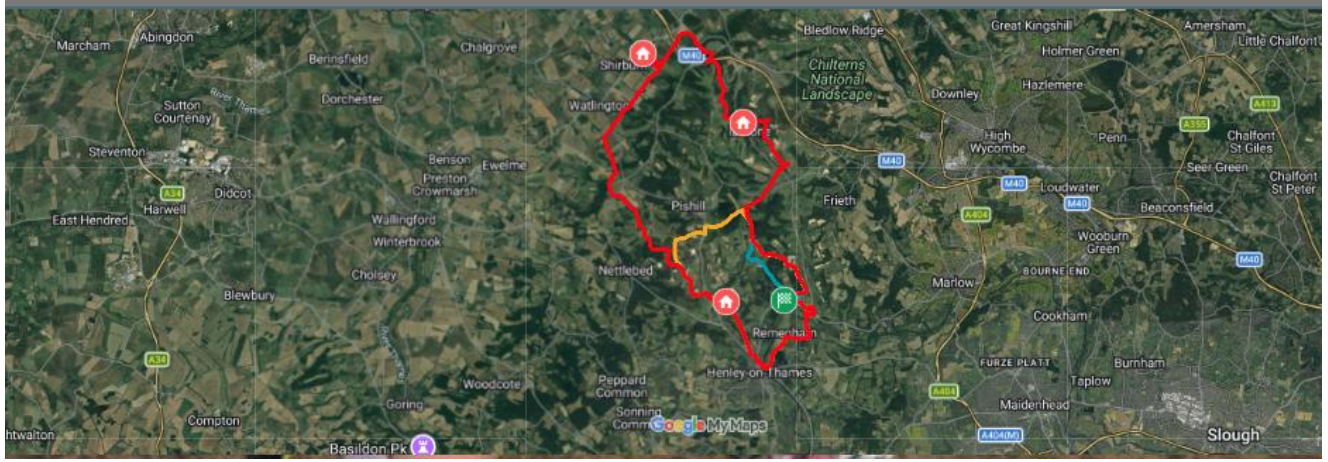
Check out which Challenge is for you....

FULL CHALLENGE 50 KM LOOP →

1/2 CHALLENGE 25 KM LOOP →

CHILTERN 10 KM LOOP →

EVENT FACTSHEET



Free to participate and easy to sign up

1. REGISTRATION & FEES

REGISTRATION DEADLINE – 1ST SEPTEMBER '26 AT 12:00PM

SIGN UP NOW

50km CHALLENGE
£0 (Adult place normally £139!) Fee paid by charity & fundraise **as much as possible!**

25km CHALLENGE
£0 (Adult place normally £89!) Fee paid by charity & fundraise **as much as possible!**

10km CHALLENGE
£0 (Adult place normally £49) Fee paid by charity & fundraise **as much as possible!**

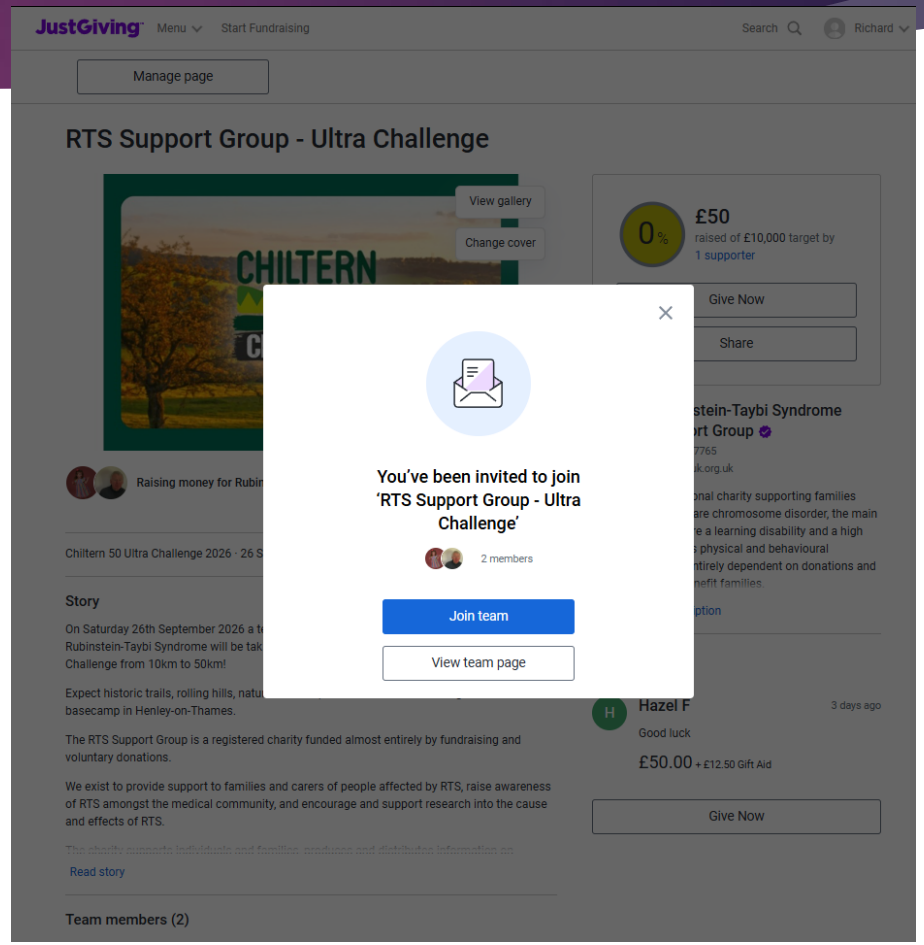
SIGN UP NOW

Link to the team fundraising page

2. FUNDRAISING

You are taking on the Chiltern 50 Ultra Challenge in support of RTS Support Group. Use the link below to visit your fundraising page. Make sure you direct any donations you receive go to this page!

VISIT YOUR FUNDRAISING PAGE



And there's merchandise to look the part!

3. BOOKABLE EXTRAS

We do have a range of additional optional extras designed to make the planning for, and joining your challenge easier. Sign-up to your chosen Challenge first – and you can then book any optional extras later / separately.

VIEW EXTRAS →

BOOK EXTRAS →

Merchandise

Purchase your t-shirt in support of RTS Support Group below.

BUY NOW ON THE RTS WEBSITE

For further information or any questions please contact info@rtsuk.org.uk

RTS UK Support Group Official Charity Tee

£15.00 GBP

FREE UK SHIPPING OVER £34

Size Chart

Color

Purple

Size

Age 3/4 | Age 5/6 | Age 7/8 | Age 9/11 | Age 12/13 | Adults S | Adults M | Adults L | Adults XL

Add to cart

30-Day Guarantee **Free Returns** **Free Shipping**

Description

Washing Instructions

Shipping & Returns

Scan the QR code to join in!

RTS support group

THANK YOU

SAFE TRAVELS

EVENING ATTENDEES MEET AT 18.15 IN THE TOWER SUITE FOYER