

## **Helping children with Rett through depression and anxiety**

Jennie Simmons

My daughter has many health professionals involved in her care. At different points in time, sometimes all together, we have had GP's, social workers, school nurses, speech therapists, occupational therapists, physiotherapists, paediatricians, neurologists, cardiologists, geneticists... the list goes on. And yet, never a psychologist!

How can this be right? Surely her mental wellbeing is important too?

In our society, around 1 in 10 children aged 5-16 suffer from a diagnosable mental health disorder<sup>1</sup>. This means that, if our children were to suffer from a loss of mental wellbeing at the same rate as the general population, 10% would be suffering from a diagnosable disorder. However this estimate would certainly be too low, we know that people with learning disabilities suffer from mental health problems at a much higher rate – around 30 to 50%<sup>2</sup> and can expect that this would be true for children with Rett syndrome too.

Because our children struggle to communicate, it is very difficult for them to complete the assessments required to diagnose depression or anxiety, however we can estimate, based on general prevalence, that around at least 1 in 3 girls with Rett syndrome is very likely to be suffering from depression and/or anxiety. The reality is that it is likely to be even higher than this. Studies have shown that girls with Rett syndrome generally show high levels of stress hormones like cortisol<sup>3</sup> indicating that they may all have raised levels of anxiety. In fact many of the behaviours we see such as hand biting, social withdrawal and teeth grinding are strongly related to anxiety and depression. I also think that many of us, parents and carers, would say that we suspect our child is or has been depressed or anxious.

Can you remember the last time you were very frightened? Do you remember your heart racing, your palms sweating? The flood of adrenalin and cortisol through your body that shuts down anything unnecessary to immediate survival. In that moment of panic, the world closes in around a single point, it is difficult to breathe and difficult to think. Short term, it is a horrible sensation which can also lead to seizures, in the long term, high levels of anxiety lead to difficulties with digestion and often constipation and stomach pain, terrible teeth grinding, increased back and neck pain. Chronic stress is also associated with disrupted immune systems and more illness, raised risk of heart attack, difficulty concentrating and generally poor health. Children with Rett syndrome have so much to deal with already, it seems especially brutal that they have this to deal with in addition. It is appalling that it is often not even being considered as part of their standard professional care.

There is valuable work being done to try and create assessment tools that professionals can use for diagnosis of depression and anxiety for women with Rett syndrome. However, these

studies are not yet looking at what can be done to help. As a mother, I would like to hear about what we can do to make a difference, starting now.

As a psychologist, I am aware of well proven ways to improve mental health in the general population. It would be good to help our children to cope better, ideally before they are so depressed or immersed in their anxiety that drugs are the only option. The side effects of antidepressants and anti-anxiety medication can be awful (including feeling sick, headaches, constipation, insomnia and drowsiness) and they can also interact with other medication.

The following steps have been shown to make a real difference<sup>4</sup> to anxiety and depression (without the need for drugs) and there are ways we can adapt these ideas to the challenges our children face.

### **1. Socialising**

It is so essential for our children to spend time socialising, particularly with other children and not just with adult carers. Of course, this is really difficult when you can't talk! By teaching simple communication strategies (like a yes/no by looking at you or away, making choices on a choice board) we can give our children the tools they need to take part in group activities. Taking them to the cinema with friends, having a playdate, inclusion in local groups such as Girl Guides or setting up a local chit-chat group could make all the difference. It would be valuable to have "time chatting with peers" included on their EHCP or statement. Of course, these activities need support, a carer to manage and facilitate where Rett syndrome makes things impossible, but even once a month could potentially make a large difference.

### **2. Be active**

This is so very difficult when your body has let you down. However, we know that exercise is nature's great mood booster – through releasing feel-good chemicals and reducing immune system overload, it reduces anxiety and relieves depression<sup>5</sup>. Aerobic exercise is best, so walking for girls that are mobile or otherwise swimming are both great. Horse riding, for those children that can manage, is particularly good as it includes animal therapy and is great for core strength. Again, it is worth trying to have these included on an EHCP or statement. Outside of school, setting up a weekly riding lesson and regular swims would both be very beneficial, and hopefully something the whole family can enjoy.

I know that exercise is such a particular challenge for girls in a wheelchair – perhaps they could go out in their chair for a daily brisk walk in the fresh air (also great for their carers!) so that they can enjoy the movement and excitement. Perhaps they would enjoy a wheelchair dance to their favourite (upbeat!) music? In particularly difficult weeks, a reasonably firm massage all over the body, particularly incorporating stretches, can help with boosting circulation and generally improved wellbeing. When massaging, use a little oil (I like cold pressed sunflower oil which you can get from a health food shop), only expose the part of the body that you're

massaging (e.g. just one arm) so that the person stays warm, massage toward the heart and keep checking that the person is enjoying themselves.

### **3. Keep learning**

We all feel better when we feel like we are moving forwards in our life. Helping our children to keep learning is essential for them to feel control. Whether it is learning to say yes and no, learning to read using a flip book or learning to control an eye gaze computer, they are gaining life skills and building resilience.

### **4. Mindfulness**

Mindfulness is about paying attention in the moment to whatever is truly happening. A programme of mindfulness can make a big difference to everyone, and is accessible whatever physical challenges a person faces. It has been shown to be especially helpful to chronically ill people suffering with pain as well as for managing anxiety and depression<sup>6</sup>. Jon Kabat-Zinn is a great author for anyone wanting to find out more.

To this I would add general **emotional intelligence**, particularly from carers. It is so important to recognise the real emotions that a person with Rett syndrome might be experiencing. We all want to be heard. When we cry out in fear, pain, sadness or loneliness we want those that love us to tell us that they understand. This means avoiding anything dismissive (for example “it is not that bad,” “give me a smile,” or “don’t be sad”) and accepting the person’s emotions as they truly are (“I can see that you are feeling sad” “you look frustrated, I know that this is really hard”).

As a therapist myself, I would also add:

### **5. Giving our children control in their lives (avoiding helplessness)**

It is so important to enable our children to be active drivers of their own lives that I have written a whole piece on this before. This is about giving them genuine choices (what to wear, what to eat for breakfast, what to watch on TV, what their room looks like) all day, every day, and providing the tools to enable them to share these opinions. It is vital to mental wellbeing that people with Rett syndrome are not passive recipients in their own lives, but rather given the tools to take active control as much (and as age appropriately) as possible.

### **6. Gratitude**

Helping our sons and daughters to identify those parts of their life, even amongst all their struggles, that they feel genuinely grateful for. Perhaps a loved sibling, a favourite aunt or a wheelchair walk in the sunshine. This can be done using pictures or telling stories – in our house we have a lovely time making gratitude boards which we fill with pictures of things we feel grateful for (my daughter recently chose “music”, “chocolate cake” and “friends” to put on hers!) We put the board up around the house and it makes us all feel happy even days later.

## 7. Treating the body kindly

I believe that it is especially difficult for people with Rett syndrome to have a positive relationship with their body. Their body is so often in pain, out of control and letting them down. Their body is the subject of discussion with so many professionals, many of whom discuss their physical difficulties freely in front of them or try to make them do things they cannot or don't want to do. How can we bring some gentleness back? Perhaps a shoulder rub or a foot massage if that is something they would like? Some girls really love the feeling of a foot spa. Sometimes something simple like allowing the child to choose (from a pre-set selection) which physiotherapy exercise they will do today, or which music to listen to while they do their stretches, can bring both control and empathy back. I would also really recommend looking into getting a daylight lamp (SAD light) for the mornings as this can be very effective in supporting melatonin production and relieving some symptoms of depression, particularly in the dark winter months. We also find that taking our daughter to a chiropractor and a cranio-sacral therapist regularly makes a huge difference to her feelings of balance and stability (it makes such a difference that I re-trained as a cranio-sacral therapist myself).

Finally, and this is the toughest, we are our children's best role model. They will learn coping strategies from what we do and how we deal with our own fear and grief. It is difficult to find the time, and sometimes the energy, to **take care of ourselves**, but we must try our best to do so. This is how our daughters (and sons) will learn. It is also important to remember that a child cannot feel safe if her parents and primary caregivers are lost in their own grief – she will feel their anxiety and it will make hers worse. This means doing all of these things for ourselves as well.

The reality of Rett syndrome is that everything is difficult. Adding to our to-do list can feel impossible. However, by choosing those activities that work best for your child and your family and making a habit of doing them as often as is sensible, we can make a genuine difference to our children's mental wellbeing. I really believe that their minds are as important as their bodies and should be shown as much compassion.

## About me

I live in a small village in Buckinghamshire with my husband Mark and our two young children, Alethea who is 8 and Michael who is 3. Alethea has Rett Syndrome which was diagnosed in 2012 when she was 3½.

I worked in marketing and marketing research for 19 years as well as studying to become a psychologist with an MSc in Applied Positive Psychology and a Complementary Therapist (massage, sports massage and infant massage). I recently left the corporate world to re-train as a Cranio-sacral therapist which is now my focus. My passion is child development and especially well-being for little people and what we can do to help our children grow up into flourishing adults.

[www.jenniesimmons.co.uk](http://www.jenniesimmons.co.uk)



## References

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