

## *Learning Through Experience: St Margaret's School Successfully Teaching Pupils with Rett Syndrome*

*Jan Cunningham*



Jan Cunningham has been Head Teacher at St Margaret's School since 1997, after joining the staff as Deputy Principal. She holds a Masters Degree in Educational Studies (SEN) and is an Associate to the New Era Academy. Jan was educated at stage school and started her career as a drama teacher before

moving into special needs teaching in 1980.

### **Summary**

St Margaret's School, part of national charity The Children's Trust, has pioneered its own curriculum especially for pupils with profound and multiple learning difficulties (PMLD) and complex health needs. Through the development of its multi-sensory Profound Education Curriculum (previously known as the Developmental Curriculum) the school has been able to support pupils with Rett syndrome, a rare neurological disorder that primarily affects females. In this article you will meet Hannah, a girl with Rett syndrome who attends St Margaret's, find out a parent's perspective of the importance of a specialised curriculum, and learn how the Profound Education Curriculum works.

### **Introduction**

The mission of St Margaret's School is to put pupils first and at the same time promote intellectual, emotional, physical and social development. As those attending the school cognitively function at the level of a three to 12-month child, the challenge has been how to provide a suitable and relevant education to this group. The National Curriculum is simply not suitable and does not allow pupils the opportunity to maximise their potential.

It was through our work in developing our own alternative, The Profound Education Curriculum, we discovered that the combination of education with different types of therapy (e.g. physiotherapy, speech and language therapy, occupational therapy and music therapy), and 24-hour nursing care was invaluable, especially for pupils with Rett syndrome. Since then St Margaret's has admitted a significant proportion of pupils with the condition.

### **So what is Rett syndrome?**

Rett syndrome is a complex neurological condition which affects one in every 100,000 girls and is generally diagnosed as a regression or deterioration in toddlerhood after one to two years of normal development. Rett syndrome shares some symptoms of autism and cerebral palsy and is associated with growth retardation, severe to profound learning disabilities, and significant communication impairment – often alongside additional social and behavioural difficulties. By adulthood only around 50 percent of those with the condition will walk. Epilepsy, chronic spinal curvature and breathing and feeding difficulties are also common features. According to the Rett Syndrome Association UK ([www.rettsyndrome.org.uk](http://www.rettsyndrome.org.uk)) there are more than 2,400 people in the UK with the condition. Hannah is one of eight students with Rett syndrome currently at the school. Here is her story...

### **Hannah and her curriculum**

Hannah's parents knew from a young age that their daughter was not developing and reacting as she should. After many years of uncertainty she was diagnosed with Rett syndrome. When she reached school age she attended a school for children with disabilities but, with the help of specialists including a paediatrician, she joined St Margaret's School aged eight as a residential pupil.

During the transition to her new surroundings her Rett syndrome manifested itself in the form of continual screaming. A set routine and specialist programmes devised for her in school and continued in her residential house helped to significantly reduce her screaming within the first 18 months. Becoming less agitated was a real achievement and also helped improve her quality of life and ability to participate in school.

Hannah's frustration at being unable to communicate verbally also contributed to her screaming and could lead to self-harm. She also actively disliked being involved in group activities and found it difficult to be included in school assemblies. Being on her own with her favourite stimulus – the television – was in the beginning one of the few ways that Hannah could be calmed. Watching her favourite DVD has now become a treat for the end of the day and something Hannah has learnt to anticipate.

The structure of the Curriculum and its 24/7 nature means that pupils like Hannah know what is happening and it allows them to anticipate what is next. The consistency of working with the same on-site multi-disciplinary team has also proven invaluable and has helped Hannah to tolerate new activities, something not possible before. The use of photo symbols has also helped with this.

The social aspect of St Margaret's Profound Education Curriculum promotes awareness of self and others and encourages the development of skills needed to interact with others. This is an area where Hannah has really started to come into her own. She has become an engaging and lively member of the school and has started to show a keen interest in her peers. Whilst increasingly interested in her surroundings, with encouragement and prompting she is starting to be able to return her attention independently to the task she is doing, an important part of her sensory and cognitive development.

Hannah is now able to go on outings and be involved in activities with her peers. If she begins to find a situation difficult to cope with, she can signal to her staff that she would like some 'time out' after which she can return to the activity. Returning to an activity was not possible before and could lead Hannah to become increasingly agitated.

The school's curriculum has really helped Hannah develop across her Individual Education Plan (IEP). In 2001 her aims for the year included being able to sit quietly in a classroom and to have an awareness of her peers. By 2009, her goals included demonstrating expectations of up to five unfamiliar events and being able to give distinct signals to request more of an activity. She achieved more than 70 percent of all of her aims across her IEP last year.

Music therapy, aromatherapy, hydrotherapy, horse-riding and rebound therapy (a type of physiotherapy using a trampoline) have all proven beneficial to Hannah and have helped her access more diverse activities. She also now walks from her on-site residential house to school on a daily basis, accompanied by a member of staff. The strength of Hannah's personality is now really shining through and although finding rigid routine important, she is able to cope with changes, a real sign of her progress.

### **Families and the Curriculum**

What does St Margaret's mean to a parent? Jake, whose daughter attends St Margaret's School, explains how the Curriculum has helped her achieve irrespective of her Rett syndrome:

*We can't image what life would be like without St Margaret's. We could not see our daughter attached to a mainstream education system – the combination of therapies and education here is definitely the right way forward for her. A child with Retts has a limit to their progression, for example our daughter will never speak. Since being at St Margaret's she has become much calmer and happier and she has had access to all kinds of activities such as hydrotherapy and horse-riding that she could not do at home.*

As a family we're still very involved in our daughter's education. We attend meetings twice a year to discuss her progress and provide input into how we think she's doing, and have contact with the school and her residential house. She loves coming home for the weekend and being with us and we help her to continue the programmes she has been working on at school if we can. St Margaret's is indispensable – we're indebted to the staff in so many ways.

### **St Margaret's Profound Education Curriculum**

Essentially The Profound Education Curriculum has allowed our pupils to make sense of the outside world so learning can take place. It is divided into five core areas:

- sensory/cognitive skills
- communication skills



covers the development and integration of all the senses. By stimulating and awakening the senses, those with Rett syndrome are able to make sense of the outside world so learning can take place.

St Margaret's works on the principle of the 24-hour curriculum which embraces all aspects of development, whether it is within the school building or the residential/family home. Each pupil has their own specialised Individual Education Plan and associated tasks are

completed in class groups, with school activities or one-to-one sessions. Activities are based on a multi-professional approach and timetabled to give structure and promote anticipation through repetition.

Each class has an on-site physiotherapist, occupational therapist and speech and language therapist. Pupils have individual therapy programmes designed to maximise their physical potential, independence, communication and purposeful hand use. Music therapy can also help children with Rett syndrome to develop their social interaction skills and is provided by our onsite music therapists.

The practicalities of how St Margaret's supports pupils with Rett syndrome is shown in the following table:

- social skills
- life skills
- motor skills

It also includes religious education, creative arts, leisure, topic work and extra-curricular activities to provide diversity in which learning can happen. Further Education is also provided for pupils aged up to 25, enabling them to prepare them for adult life.

Those with Rett syndrome are usually dependent on others throughout their lives. Regardless of ability, all pupils, including those with Rett syndrome, have access to a curriculum which is broad, balanced and designed to be relevant to their individual needs. The Profound Education Curriculum works with this particular group of children and young people because it

ASPECTS TO CONSIDER	OUR APPROACH IN THE 24-HOUR CURRICULUM
Hand skills	<ul style="list-style-type: none"> <li>• Educational, therapy and care programmes are developed to encourage purposeful hand function</li> <li>• Intervention programmes are developed where necessary to support pupils who may self-harm</li> </ul>
Balance, standing and walking skills	<p>Pupils are supported to maintain these skills by taking part in the following:</p> <ul style="list-style-type: none"> <li>• independent walking programmes</li> <li>• splinting programmes</li> <li>• individual physiotherapy programmes</li> <li>• horse-riding, cycling and hydrotherapy</li> <li>• independent sitting programmes</li> <li>• a wide range of aids are used as appropriate to individual needs ( e.g. handling belts, walking frames, Bambach chair, balance boards)</li> </ul>

Breathing issues	<ul style="list-style-type: none"> <li>Staff training ensures awareness of the patterns of breathing behaviour and strategies which will support pupils' individualised, interdisciplinary programmes</li> </ul>
Epilepsy	<ul style="list-style-type: none"> <li>This is monitored and controlled individually by our on-site medical team and specialist consultant clinic</li> </ul>
Increasing spasticity	<p>This is addressed by using:</p> <ul style="list-style-type: none"> <li>individual physiotherapy programmes</li> <li>occupational therapy programmes</li> <li>medical interventions</li> </ul>
Communication	<ul style="list-style-type: none"> <li>Assessment of communication skills</li> <li>Individual and group programmes designed to develop understanding and expression</li> </ul>
Eating and drinking	<ul style="list-style-type: none"> <li>Detailed assessment is made of oral skills</li> <li>Individual eating and drinking programmes are put in place</li> </ul>
Scoliosis	<ul style="list-style-type: none"> <li>This is monitored regularly by physiotherapists, doctors and consultants at the on-site clinics (Scoliosis is an abnormal lateral curvature of the spine.)</li> </ul>
Regular consultant clinics	<ul style="list-style-type: none"> <li>Orthopaedic specialists visit every three months</li> <li>A special seating clinic is held monthly</li> <li>There are also regular visits from a neurologist and a consultant child and adolescent psychiatrist</li> </ul>

Aspects covered within the 24-hour Curriculum

### Moving forward

Staff at St Margaret's are using their expertise developed through working with pupils with Rett syndrome to help improve the learning experience. One example is the use of light-weight, custom-made splints by our occupational therapists in reducing the stereotypical hand movements associated with Rett syndrome. These have been trialled successfully on three of our pupils. Our speech and language therapist has also been looking at the effects of a music-based auditory stimulation package, 'The Listening Programme', on pupils' ability to interact and concentrate in school activities. This Programme has so far given encouraging results with the girls with Rett syndrome.

### Conclusion

St Margaret's School and The Profound Education Curriculum have a lot to offer pupils with Rett syndrome. Currently more than 40 schools in the UK and worldwide are using the Curriculum and discovering the benefits it can have for pupils with PMLD.

### Contact

For further information about St Margaret's School or The Profound Education Curriculum visit: [www.thechildrenstrust.org.uk/stmargaretsschool](http://www.thechildrenstrust.org.uk/stmargaretsschool) or call 01737 365810.