There are lots of ways we can help you and professional working with you by:

- Telephone and electronic support
- Proactive support for all families
- Self-help support groups
- A network of family support contacts
- Family weekend
- A wide and comprehensive range of accessible information
- Working closely with multi-disciplinary team of experts
- Developing professional knowledge and expertise
- Supporting and funding UK based research
- Working in partnership internationally
- Establishing best practice in care and management with local professionals
- Regular updates through email and newsletter
- Regional family days

What our families say

> *"We contacted Rett UK just after we received our daughter's diagnosis, and they were brilliant – so helpful and reassuring. Since then we've attended a wonderful Rett UK Family Day and a Rett Syndrome Clinic, which gave us vital medical advice. We regularly use their website for information for ourselves, family and health professionals. It's great to know they will be on the end of a phone if we have a problem. We really appreciate everything they do."*

Contact information

Enquiries
01582 798910
info@rettuk.org

Follow us on Twitter
@RettUK

Like us on Facebook
facebook.com/RettUK

Rett UK, Langham House West, Mill Street,
Luton, LU1 2NA
info@rettuk.org 01582 798 910
www.rettuk.org

Registered charity 1137820
Registered Company in England and Wales: 07339522

Rett Syndrome

- What is it?
- What it means to families
- How we can help

Rett UK
Support today, hope for tomorrow

Rett syndrome is a complex neurological disorder. Genetic in origin, it affects one in 12,000 females and a few males. Although signs of Rett syndrome may not be initially obvious, it is present at birth and becomes more evident during the second year.

Being told the toddler you thought was healthy, but perhaps a little slow to progress, in fact has a rare and complex disability called Rett syndrome, is devastating for the whole family.

At this point in time, you may not know anything about Rett syndrome. You may have just received a letter of a phone call confirming the diagnosis, but no more information than that. Alternatively, you may have been on the internet to find out as much as you can, and feel frightened about what you have read.

Receiving a diagnosis is a profoundly painful experience, yet knowing your child has Rett syndrome also means that the involvement of professionals can be focussed in this context. This will give your daughter or son the maximum chance of developing and maintaining his or her skills.

The Family Support Team at Rett UK is proactive in providing structured support during difficult periods. They can enable families and carers to have personal contact with others who have been in a similar situation.

Who we are

Established in 1985, Rett UK is a parent led charity dedicated to making a real, positive and lasting difference to people living with Rett syndrome. We provide professional support services for families, carers and professionals.

Our aims are:

- To support families and carers and ensure that all people with Rett syndrome have access to best practice in diagnosis, treatment and care.
- To promote, support and encourage research into the genetic, therapeutic and social aspects of Rett syndrome – and towards an eventual cure.
- To increase the awareness of Rett syndrome and the issues facing all people with Rett syndrome, their families and their carers.

Making a difference

Our Family Support Team provides empathetic support to each and every family who contacts us for help.

The team have a wealth of knowledge, experience and skills, to support you with any requests for help. This could be support through your initial diagnosis, through the early years helping you get the best support from your local team, offering guidance and advice during transitions to adulthood and by helping adults meet their full potential and aspirations for a long and full-filling life.

> *“When we had our diagnosis within about a week I picked up the telephone and spoke to one of the Family Support Workers. Even though this was a very distressing call to make, it was pivotal in helping us come to terms with everything. It’s great to know someone is there to help”*

Rett UK makes the lives of those affected by this devastating disorder more bearable and gives hope for the future. A cure is a possibility but for over 3,000 families in the UK affected by Rett syndrome access to the right information, therapies and treatments is not just helpful, but in the case of Rett syndrome it can be a life saver.