



1. First Symptoms

Regression (9-30 months)

Some difficulty feeding
 Floppy and poor coordination of limbs, trunk and stereotypic hand movements,
 Walking, if achieved at all becomes unsteady,
 Head circumference if normal at birth slows.
 Onset of epileptic seizures
 Abnormal breathing patterns emerge; breath holding, hyperventilation, air swallowing
 Eating, chewing and swallowing problems
 Heart rhythm abnormalities
 Social withdrawal, confused (not autism).
 Partial or complete loss of spoken language
 Gastro intestinal problems

Note: Detailed care plan needs to be put in place to address the health needs of the specific comorbidities!

Rett [Health Checklist](http://www.rettuk.org) available to download from www.rettuk.org ("Resources for families")

Ideally: Support for the family can be accessed from the experienced and professional national Rett organizations. Contact www.rettsyndrome.eu. Access to knowledgeable and supportive GP.

2. Post Diagnosis

Need for involvement of multi-disciplinary team and co-ordination of care to manage symptoms with a care plan.
 Referral to paediatric (child) or neurological consultant (adult)

Ideally: Care plan to involve physiotherapy, occupational therapy, SaLT, hydrotherapy and music therapy - can help a person with RTT lead a happy and full life.
 Have an up to date [Health Passport](#) for use in hospital consultations or emergency

3. Surgery

Scoliosis
 Removal of stones (gall bladder or kidney)
 Other orthopaedic interventions, e.g. hip, feet
 Gastro-intestinal surgery when symptoms become severe
 Dental surgery often needed under anaesthetic

Ideally: Regular checks including X ray or scans where appropriate to check on progression of any identified problems.

4. Follow-Up...

Problems may exist when passing from paediatric to adult health care services
 Illnesses may be wrongly attributed to "having Rett syndrome," when in reality the condition is found in a neurotypical person of the same age and should therefore be treated in the same way.

Ideally: Annual health check with GP; include long QT check, blood tests, full body examination
 Any symptoms identified should be promptly referred for further investigation and escalated up the care pathway where necessary
 Use [Rett Disorders Alliance UK Health Checklist](#) to guide parents/carers and professionals through the complex symptoms and problems of the disorder.
 Download from Rett UK website, www.rettuk.org

