



Key Actions for Keeping Healthy

In Rett Syndrome, focusing on prevention rather than waiting for problems to occur can be key.

- If they haven't had one before, all children and adults with Rett Syndrome need to have a **baseline ECG**, which is a non-invasive way of checking their heart. This is because some people with Rett Syndrome have a problem with their heart rhythm called Long QT Syndrome.¹ This is something that can develop at any age so it must be checked regularly or when there are particular changes in their condition.
- Start giving **Vitamin D supplements** - over the counter are fine, (unless you want respite or care home to give in which case you need a prescription). [Here are NICE guidelines](#) that specify how much should be given. Everyone with Rett Syndrome needs this because this patient group often have low levels of Vitamin D and can develop osteoporosis.² In some studies, Vitamin D has been shown to be protective against chest infections, which are also common in Rett Syndrome.*³

Due to the risk of osteoporosis a [Dexa scan](#) can be considered. Your child's GP or pediatrician can refer for a Dexa scan.

- Consider giving **probiotics**. Tests on viability of bacteria in these products are obviously important in enabling people to determine which products are most likely to be useful. There is some evidence to show that liquid products such as [Symprove](#) are more effective than freeze dried/capsule form.⁴ These products are aimed at improving gut health, tummy issues etc.* There are less expensive alternatives available but do your research and always speak to your GP about starting any new supplements.
- Ask for routine blood tests - annual tests for [electrolytes](#) and [nutritional](#)⁵ bloods are very helpful in identifying any deficiencies which can cause further problems in Rett Syndrome.
- Ask GP/pediatrician/consultant to advise about the **side effects** of any medications prescribed and ask about **drug-to-drug interactions**. EG. Some epilepsy drugs can cause a decrease in Vitamin D levels, therefore supplements may need to be adjusted.

- All children and adults with Rett Syndrome are at risk of **aspiration**; inhaling food, drink or saliva into their lungs. This can cause chest infections which are dangerous in Rett Syndrome. To help avoid aspiration, your child should always be sat upright (minimum 45 degree angle) when eating or drinking and for 30 mins afterwards.⁶ See the aspiration fact sheet [here](#) for more information.
- **Some medications can also cause changes in QT intervals.** If your child has had an ECG at diagnosis which does not show Long QT, this does not mean that they are not at risk of developing the problem later. A number of commonly used medications can affect the QT interval.

You can check newly prescribed medications yourself and raise issues with your doctor by going to the [Credible Meds website](#) and entering the name of the medication.

- Register your child on the [Rett Registry UK](#). This is confidential and secure and enables us to contact you quickly with clinical trial opportunities.
- Sign up for monitoring through the CIPP Rett Database, an online system which enables the specialist CIPP Rett team to monitor individuals with Rett Syndrome at a distance, flagging up any issues and gathering information which can lead to better outcomes for anyone living with Rett Syndrome. Email us for more info: cipp_rett@reverserett.org.uk
- For family support, advice and information, contact fellow UK Rett Syndrome charity, Rett UK support@rettuk.org

Please note that Reverse Rett does not endorse any particular commercial products. You should always speak to your doctor before starting any new supplements for your child/adult family member with Rett Syndrome.

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1. *The UK Rett Disorders Health Checklist recommends ECG; at baseline (diagnosis, on suspicion of ECG abnormalities from clinical/reported history, when there are changes in the health status of a patient, when there is desire to prescribe medication which is known to cause changes in QT status and as part of pre-surgical assessment when anaesthetic is being given. (UK Rett Disorders Health Checklist <https://www.reverserett.org.uk/healthchecklist/> p.7, DOA: 09.06.21)*
 2. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0146824> DOA 05.02.16
 3. <https://www.reverserett.org.uk/core/media/Vitamin-D-PDF.pdf> DOA: 09.06.21
 4. *Fredua-agyeman, Mansa & Gaisford, Simon. (2014). Comparative survival of commercial probiotic formulations: Tests in biorelevant gastric fluids and real-time measurements using microcalorimetry. Beneficial microbes. 6. 1-11. 10.3920/BM2014.0051.*
 5. *NICE Guidance: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition; Clinical guideline [CG32] Published: 22 February 2006 Last updated: 04 August 2017 section 1.5 Table 2 Protocol for laboratory monitoring of nutrition support*
 6. *UK Rett Disorders Health Checklist, <https://www.reverserett.org.uk/healthchecklist/> p2, DOA 09.06.21)*