

Rett Syndrome

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Rett Syndrome: Recognising the Communication Challenges, Needs and Potential of Individuals Living with a Rare Disease

Gillian Townend

Maastricht, 4th July 2019

1. Individuals with Rett syndrome appear to demonstrate an intact oculomotor system. This offers a promising base upon which to build the use of functional eye gaze for communication (*this thesis*).
2. Eye gaze controlled communication devices offer potential to individuals with Rett syndrome and their families, however, greater support from knowledgeable professionals is essential for individuals and families to gain maximum benefit (*this thesis*).
3. Developing international guidelines, and national and international support networks, collaborations and partnerships, is crucial if we are to spread knowledge, build expertise and increase communication services for people with Rett syndrome (*this thesis*).
4. Rett Expertise Centres have a central role to play in providing 'care for today' while seeking a 'cure for tomorrow' (*this thesis*).
5. Many argue that 'belief' has no place in academic or scientific pursuit yet 'belief' is an attitude, a state of mind that should allow you to be open to possibilities.
6. If I cannot use my own voice to speak, it does not mean I have nothing to say.
7. Autonomy in communication means being able to say what I want, when I want, to whom I want, in a way I want.
8. The fight for recognition of the needs of individuals with rare diseases is not yet over; rare disease communities can gain political strength by lobbying together for change.
9. Be the change that you wish to see in the world (*Mahatma Gandhi*).
10. It always seems impossible until it's done (*Nelson Mandela*).