Dependence

Most individuals with Rett syndrome (RTT) are dependent on others to assist them with the activities of daily life. However, that is not to say that some independent skills associated with eating, drinking, toileting and/or dressing, movement, recreation and communication, cannot be learnt or regained.

Communication

Communication is particularly important as there is strong desire by persons with Rett syndrome to interact with those around them, despite their lack of expressive language and impaired hand use. This desire is evident by their eye gaze, facial expressions, and/or body gestures. Rett syndrome individuals have greater receptive language (i.e., what they hear and understand) than expressive language (speech). It is important for them that the activity and/or content of a conversation, involves something that they find very stimulating.

Communication methods vary considerably among the Rett syndrome population. Methods can include one or more of the following, eye pointing and blinking, use of yes/no, flash cards, pictures, switches, facilitation, communication boards, head pointers, voice output devices, computers with touch windows, Intellikeys keyboard, switch activated mouse or eye gaze technology such as Tobii, and more recently, the IPad. Abilities can also be influenced by such things as the extent of hand use, degree of mobility and/or stiffness, state of posture, level of intelligence and the listener's appreciation of what communication techniques to use, to name just a few.

Education and learning

"Some girls with RTT get a bigger dose (of it) than others and will likely be more severely affected. Some may not make much progress but some will. But how do we know? …… In the absence of evidence to the contrary, what if we assume that they can and will make progress rather than assuming progress does not occur? And if we never tried to teach them, how could they ever learn?……" (source: Kathy Hunter, The Rett Syndrome Handbook, 2007, page 316).

FACT SHEET 5
Living with Rett Syndrome

www.rettaustralia.org.au

Life expectancy

Survival data has to be treated with caution as statistics on those actually affected by the condition and the number who die, do not include all such cases from around the world. The Australian Rett Syndrome Study* has reported that the likelihood of survival of Australian Rett syndrome girls born from 1976 onwards, would be 77.6% at 20 years of age, 71.5% at 25 years and 59.8% at 37 years.

*Twenty years of surveillance in Rett syndrome: What does it tell us? (Alison Anderson et al) Orphanet Journal of Rare Diseases 2014 Volume 9 No. 87, page 1.

Source: RSAA, 30 December 2020