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Role of Occupational Therapy in Rett Syndrome

a) Occupational Therapy and Rett Syndrome in the literature

Articles of interest to Occupational therapists working with Rett Syndrome can be divided into two broad categories:

- Articles including information on therapy in general for Rett Syndrome. Eg:
    - Cass H, Reilly S, Owen L, Wisbeach A, Weekes L, Slonims V, Wigram T, Charman T (2003). Findings from a multidisciplinary clinical case series of females with Rett syndrome. Journal of Developmental Medicine and Child Neurology (45); 325 – 337.
    - Van Ackler R (1991). Rett Syndrome: A review of current knowledge. Journal of Autism and Developmental Disorders (21); 4: 381 – 406
    - The Rett Syndrome Handbook: In Words You Can Understand from Those Who Understand. Hunter, K (1999). International Rett Syndrome Association.
- Articles on approaches to hand function, including management of hand stereotypies. Eg:
    - Berryman D and Barrett L. (2002). Hand management in Rett Syndrome. Rett Syndrome Association of Australia (RSAA) Newsletter July 2002.
    - Kubas E (1992). Use of splints to develop hand skills in a woman with Rett Syndrome. The American Journal of Occupational Therapy 46(4); 364 – 368.
    - Naganuma G and Billingsley F (1988). Effect of hand splints on stereotypic hand behaviours of three girls with Rett Syndrome. Physical Therapy 68 (5), 664-671
    - Tuten H and Miednaer J (1989). Effect of hand splints on stereotypic behaviour of girls with Rett Syndrome: A replication study. Physical Therapy 69 (12), 1099 – 1103.
    - Woodyatt, G., & Sigafoos, J. (2000). Effects of amount and type of social interaction/activity on stereotyped hand mannerisms in individuals with Rett syndrome. Australasian Journal of Special Education, 23, 15-24.

b) Occupational Therapy and Rett Syndrome in the Rett Syndrome Multidisciplinary Management Clinic (CHW)

- Consultative approach
- Focus is on review and input regarding:
    - Generic Occupational Therapy issues
    - Rett Syndrome specific issues
- Frequently provided information listed
- Common interventions listed
- Support to community therapists

c) Occupational Therapy and Rett Syndrome in the Community

- Liaison and support to community therapists
- Provision of information to community therapists
- Provision of information to community groups

- Presentations at meetings, inservices and conferences when needed

Therapy ideas:

General principles

- Look for potential – for example use of eye gaze, or initiation of movement towards a desired object
- Keep in mind the affect of dyspraxia. Often times there is a marked delay between a prompt and reaction. Video-recording a session may help identify patterns
- Progress is often very slow. Rett Syndrome is not a neurodegenerative disorder, and improvements in functional self care and hand skills can be achieved throughout the lifespan *(Cass et al, 2003)*

Examples of goals *(from Rett Syndrome Handbook)*:

- *Identify and encourage use of head, elbows, or other body parts over which she may have better control*
- *Maximise hand use for functional activities*
- *Develop ability to access communication devices*
- *Develop ability to access a variety of assistive technology*
- *Improve ability to assist with dressing*
- *Improve ability to perform independent feeding skills*
- *Improve ability to assist with grooming activities*
- *Improve ability to tolerate sensory input in school setting*

Hints: *(from Rett Syndrome Handbook)*

- Focus on enjoyable hand activities during the regression phase (rather than on fine-motor skills)
- Provide physical assistance

Orthoses and assistive devices to consider: *(from Rett Syndrome Handbook)*

- Splints can position thumb for grasp
- Adapt materials to make easier to grasp
- Consider cuffs and loops to assist with grasp, cut-out cups
- Switches for independence and leisure / pleasure

Other therapy ideas: *(Based on Van Ackler (1991))*

- Ideas to encourage functional hand use:
    - Sensory input for hands (eg massage, exposure to a variety of textures)
- For apraxia and ataxia
    - Weighted vests can be calming and decrease ataxia in some girls
    - Use of a therapy ball
    - Rotation and weight-shift activities
    - Vestibular movement activities (if tolerated)
- Spasticity
    - Positioning for safety (eg during mealtimes) and tone reduction
    - Tone reduction activities such as rotation, weight-shift, vibration can temporarily reduce spasticity
- Scoliosis
    - Positioning to ensure a symmetrical and erect posture in sitting (as far as possible)