

Cystic Fibrosis

Cystic Fibrosis is a genetic disorder which affects many organs in the body predominantly the lungs, pancreas and sweat glands. Recent advances have found that the genetic mutation results in a lack of protein (CFTR) which transports salt that causes abnormal secretions, leading to respiratory problems, digestive problems and increased loss of salt from the sweat glands.

In most Australian states, new born babies are tested for Cystic Fibrosis within the first few days of birth. This is done by a heel prick test where small blood sample is drawn and sent to a laboratory for analysis.

There is no cure for Cystic Fibrosis. Current treatment aims to decrease the severity of the symptoms and prevent the development of complications.

Key treatment aims are to maintain a healthy weight gain in children and to minimise the severity of chest infections. Treatment begins in infancy to clear the lung secretions by means of daily physiotherapy and exercise. Treatment needs to be continued for life to limit lung damage and infection.

Developmental Areas

Children may display some of the following characteristics

Social and Emotional Development

- Health impacts on a child's social and emotional development due to time away from child care or school
- Impacts on opportunities for child to engage in social interactions
- Health issues may impact on emotional development—feelings of over dependence etc.

Physical Development

- Delays in developing skills due to fewer opportunities for the child to engage in physical activities
- Unable to participate in excessive physical activity

Cognitive Development

- Cognitive development may vary depending on child's experiences

Language Development/Communication

- Language development may be affected in the social setting should the child have had a limited social experience

CYSTIC FIBROSIS **Inclusion Strategies**

Each child diagnosed with **CYSTIC FIBROSIS** will be different and individual. It is important to gain information from the parents as to what characteristics of **CYSTIC FIBROSIS** their child displays. It is important to work closely with the parents as well as any additional support specialists e.g. therapists who may be involved with the child. It is also important to gain an understanding from the parent as to what is the most important aspect of their child attending your service. What is it that parents hope to gain from using your service? The following inclusion strategies are just some examples which may be applied to support the inclusion process. This list is only the start and it is dependant on a variety of factors such as environment, length of time child is in care, child's interest, likes, dislikes and skills already achieved. The strategies are divided into developmental areas however some strategies overlap and assist in a variety of developmental areas.

Social and Emotional Development

- Be aware of children's experiences in participating in social interactions with peers.
- Provide opportunities for children to engage in small group social interaction.
- Encourage and facilitate friendships with other children.
- Support emotional development.
- Encourage a positive self identity and self concept.
- Encourage children to make choices about their day.
- Support the parent/child teaching partnership through sharing with parents or caregivers information about the child's day.

Physical Development

- Modify the program of physical activities to include all children.
- Be aware of activities that may inappropriately over exert children.
- Encourage children to take a break or rest when they are tired and provide an alternative activity for them to engage in.

Cognitive Development

- Provide opportunities for children to explore tasks that require thinking.
- Support children's cognitive development through providing appropriately challenging experiences.

Language/Communication Development

- Support language development through the provision of language experiences e.g. word games, songs, finger plays, show and tell.
- Be aware of the child's ability to use and grasp language concepts.

Reference

Deiner, P.L. (1993) **Resources for Teaching Children with Diverse Abilities - Birth through Eight.** Harcourt Brace:

Umansky, W. and Hooper, S. (1998) **Young Children with Special Needs** Third Edition New Jersey, USA:Prentice-Hall

Gilbert, P.(1996) **"The A-Z Reference Book of Syndromes and inherited disorders—2nd Edition.** " Stanley Thornes (Publishers) Ltd: United Kingdom

Kozma,C. & Stock, J. (1993) **Caring for every child—Ideas to meet diverse needs in Child Care.** Funded by the Commonwealth department of Human Services and Health : Sydney

Disclaimer

Inclusion Works! provides information to Children's Services upon request. The information provided is obtained from a number of sources e.g. library, other services, resource books and Internet. The information provided is not intended to, nor does it, constitute medical or other advice. Persons access this information assume full responsibility for its usage. Acknowledgement of source of information is required if passed onto a third person.