

THE ROLE OF THE PHYSIOTHERAPIST IN THE TREATMENT OF THE TERMINALLY ILL OR DYING CHILD

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SUMMARY

The role of the physiotherapist in the treatment of the dying child is twofold: Firstly, treatment is directed towards developing the child to full potential, maintaining function, preventing deformities and relieving pain and discomfort. Secondly, she has a role in supporting the parents and family. The need for a domiciliary physiotherapist is indicated.

I am sure that most of us physiotherapists feel inadequate and unsure of ourselves when called upon to treat the terminally ill or dying child. The most common amongst these fatal diseases in paediatrics are cystic fibrosis, leukaemia, cancer, progressive muscular dystrophies and progressive genetic disorders.

"It is hard to imagine a more devastating experience in the life of a family than the fatal illness or death of a child. Each member is affected individually and separately while the family functioning as a whole is thrown into disruption." (Straker and Schmaman, 1980).

Elizabeth Kübler-Ross in her book on *Death and Dying* (1975) describes fully the stages of adjustment to an impending death namely, shock and denial, anger, bargaining, depression and finally acceptance. Families too, go through these stages and it is important for the physiotherapist to understand these feelings and reactions. One of the most difficult situations is when the family and more particularly the mother, is feeling angry. The anger may be directed at any member of the staff and if not understood, it may result in feelings of hostility between staff and parents which will interfere with decision making and treatment of the child.

"A good way of helping parents and the family over their denial and anger is to enlist their aid in caring for the child. Giving the parents a sense of worth and feeling that they can do something about the situation can go a long way to helping them combat their feelings of guilt, futility and inadequacy." (Straker and Schmaman, 1981).

OPSOMMING

Die rol van die fisioterapeut in die behandeling van die sterwende kind is tweevoudig: Eerstens word behandeling toegespeit op die ontwikkeling van die kind se potensiaal, om funksie te behou, pyn te verlig, en misvorming te voorkom. Tweedens dra sy tot die ondersteuning van die ouers en familie by. Die behoefte aan 'n tuisbesoekende fisioterapeut word aangedui.

The primary reason for a referral for physiotherapy treatment would be to improve the physical state of the patient or in the long term to improve the quality of life e.g. by keeping the patient mobile and not reverting to a wheelchair too early. The secondary benefits from involving the family in treatment should not be underestimated. A defect or delay in motor development is often the first sign to be recognised by the family that something may be wrong. The parents may realise that the child is moving abnormally or that movement is lacking long before they are aware of visual, auditory or intellectual impairment.

Similarly the loss of motor ability e.g. in muscular dystrophies or cerebral and spinal tumours, may be the first sign of the disease. The physiotherapist may for these reasons receive the first call for help, sometimes even before a diagnosis is made.

The aims of physiotherapy then are:

- Active treatment is then indicated to develop the infant or child to its maximum potential in all areas, respiratory, musculo-skeletal or neurological. Emphasis would be in the area which is most affected, e.g. a motor or musculo-skeletal problem causing a delay in motor development or abnormal development would require a neuro-developmental therapy or other appropriate developmental programme. A child with cystic fibrosis would require an exercise programme aimed at reaching the greatest vital capacity possible for that child.
- It is important to maintain the strength and mobility of all the muscles and this would be especially indicated in the treatment of the muscular dystrophies. It

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is also important to maintain muscle strength during a lengthy period of bed rest whatever the condition.

- The prevention of contractures and deformities is of prime consideration. The physiotherapist must be familiar with all aspects of the disease and its expected progression and must not wait for the development of a deformity before taking action. Early splinting, starting perhaps with night splints is essential. It is the responsibility of the physiotherapist to ensure that the child will grow up to look as normal as possible. "Pride in physical appearance and prowess is at its peak in adolescence" (Straker and Schmaman, 1981). Ghastly, unsightly deformities are distressing to patient, family and society. I refer here especially to the untreated musculo-dystrophies who cannot even sit in a chair due to severe spinal deformities. These deformities involve the rib cage and lead to respiratory and cardiac failure. A combined programme of exercise, splintage and positioning needs to be started early in order to minimise such deformities.
- The child must be assisted to remain as independent as possible for as long as possible. Independence, at whatever stage or whatever level, is the backbone to the individual's integrity and feeling of worth. Creeping or crawling, walking with or without aids, standing up from a chair and sitting down again, activities of daily living like feeding, dressing, toileting etc. help to do this. These activities and skills also lessen demands made on the family or staff. It is in this area that the ingenuity of the physiotherapist is essential in terms of aids and adaptations. She needs to work in close co-operation with the occupational therapist wherever possible.
- As the disease progresses the aims of treatment change and become more palliative. Where possible the therapist helps to alleviate the pain and make the child as comfortable as possible. The final cause of death, whatever the condition, is often pneumonia and respiratory failure. When the realisation that a cure or even a functional improvement is not possible and after consultation and careful consideration with all members of the team, active treatment to prolong life may be prolonging suffering and could then be contraindicated. The aims of physiotherapy would be to make breathing easier and prevent the patient from choking in their own secretions, by very careful suctioning. Sudden termination of therapy should be avoided. "A nine-year-old described how frightened she was when nobody talked to her about her downhill course. It was like they were getting ready for me to die." (Cynthia Birrer, 1979). The child could be made more comfortable by changing positions and suggesting frequent alteration of position. This sort of advice and management could change from week to week, or even daily, as the condition deteriorates.
- The physiotherapist plays a large part in supporting the family during this time of stress. The diagnosis of a fatal disease may be made early in the life of the child and the parents need to retain some hope and anticipation for the future, however short it may be. "It is this glimpse of hope which maintains them through the days, weeks or months of suffering." (Elizabeth Kübler-Ross, 1978). The therapist should never say that there is no more that can be done for the child and that treatment must be terminated.

It is these words that send the parents into despair and into a desperate search for any alternative treatment which may be costly and ineffectual. Initially the child may be treated daily and later weekly or monthly, as indicated. A comprehensive home programme must be included and its success will depend on the skill of the physiotherapist to motivate the parents to carry it out after explaining exactly what is required and teaching them exactly how to execute it. In view of the fact that the infant or child is growing and developing, the treatment will be varied as the needs of the child change, e.g. aids will become too small and exercise will change as the child grows, although the reason for doing the exercise will remain the same. Parents should be made to feel free to contact the therapist at any time without feeling guilty, should the need arise. A word of advice or a sympathetic ear on the telephone is often the most comforting and supportive. The physiotherapist may often spend more time than any other member of the team with the patient and family by virtue of the nature of the treatment. Her association with the family may be over many years and she may find herself deeply emotionally involved — she may need the support of the other members of the team to help her sort out her own feelings, e.g. the social worker or psychologist. She is part of the team which consists of consultants and other medical personnel, social worker, psychologists, speech therapists, occupational therapists, nurses and spiritual leaders. The members of the team will vary depending on the particular needs of the child and they will need to work closely together. Regular case conferences will need to be held. These services are available at most large hospitals and institutions. But, what of the family who wishes to keep their child at home for as long as possible? It is here that the services of a domiciliary physiotherapist would be most beneficial. Such a therapist could still function as part of the team at the hospital, but would also be able to carry out her treatment in the comfort and security of the child's home. After the death of the child the family will need the assurance that everything possible was done for their child and that he died peacefully. The physiotherapist, having been fully involved, will be able to contribute to this assurance, so that the family will also know that their child realised his full potential, however limited.

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