

# MY HOME — THE HOSPITAL

## A CASE STUDY

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### INTRODUCTION

The first years of life, so important in a child's development, should be spent with its mother in a normal family environment. If the child is denied this, then permanent emotional and intellectual disability can result.

This article describes how we tried to prevent this from occurring in Andrew, a little boy who had to spend the first three years of his life in hospital because of a tracheostomy.

Hopefully, this account will help others who deal with chronically hospitalised children to anticipate some of the problems that can arise and give them an insight into the vital role of the nurse in dealing with the situation.

### THE PATIENT

Andrew was the first-born son of a sixteen year old mother. She lived with her parents who did not approve of her association with Andrew's father. Andrew's father was twenty years older than his mother. Because he was frequently unemployed, Andrew's father gave financial assistance at irregular intervals only. The relationship between Andrew's parents was unstable and the emotional support so necessary during any pregnancy was denied Andrew's mother.

Her pregnancy was complicated. She often felt physically ill, alone and abandoned. At an ante-natal visit the early signs and symptoms of pre-eclampsia were detected. These became steadily worse and by the twenty-eighth week of her pregnancy, Andrew's mother was in grave danger of losing her own and her baby's life.

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### OPSOMMING

**Permanente emosionele en intellektuele gestremdheid kan intree as 'n kind nie die eerste jare van sy lewe by sy moeder, in 'n normale gesinsomgewing, deurbring nie.**

**Andrew was weens 'n tracheostomie vir die eerste drie jare van sy lewe in die hospitaal. As 'n premature baba het hy hialien-membraan siekte ontwikkel, waarna 'n vernouing in the trachea 'n tracheostomie genoodsaak het. Tot op 15 maande is hy in die respiratoriese intensiewesorg-eenheid verpleeg.**

**Op dié stadium was sy ontwikkelingsmylpale vertraag en 'n gekoördineerde multi-dissiplinêre program is gevolg om die nuwe-effekte van die lang hospitalisasie te oorbrug. Andrew het goed hierop gereageer en geniet vandag 'n normale en gelukkige lewe tuis.**

Because the effects of the pregnancy on her health were so severe. Andrew's mother was advised to have her pregnancy terminated by caesarean section. She was told that the operation would save her life but could be fatal to her baby since he was not developed enough to cope with life outside the womb. If she did not have it, she and the baby would die.

Her anxiety and uncertainty, it is believed by some, could be appreciated by her baby even before birth.

When Andrew was born by caesarean section at the local maternity hospital he had spent only 28 of the normal 40 weeks in utero and weighed 1 150 grams. From birth Andrew suffered severe hyaline membrane disease.

In this condition there is a lack of surfactant, a substance that lines the alveoli of the lungs and is necessary for normal alveolar expansion. Without surfactant the lungs are very stiff and collapse, causing respiratory failure. He required artificial ventilation for ten days until his lungs started producing surfactant. However, the endotracheal tube that helped to save his life damaged his larynx, just below his vocal cords, so that a stricture developed at that point.

Many attempts were made to try and avoid a tracheostomy, but eventually one had to be performed when Andrew was eight weeks old. He now weighed 1 400 grams and was so small that the

doctors had to make a special tracheostomy tube for him because one small enough was not commercially available. The laryngeal stenosis had caused a pneumonia for which he had to be ventilated again.

### THE INTENSIVE CARE UNIT

Following his tracheostomy Andrew was nursed in a cubicle with five other patients in the respiratory intensive care unit on the fourth floor of the Red Cross War Memorial Children's Hospital. The unit is staffed by six professional nurses and twenty six nursing assistants — the latter forming the main work-force of this unit. The nurses are allocated on a non-rotational basis and Andrew grew to know them well.

The variety of cases that are admitted require a high standard of care. Careful observation is essential to anticipate and recognise problems early. The stressful environment, the technical equipment and the frequent need to deal with death is very conducive to the development of tension amongst staff members. One must always be aware of this and act in such a way as to defuse the tension. Otherwise, the standard of care suffers as people become more concerned with their own problems, at the expense of the patient.

For the next two months Andrew's life depended on careful monitoring of vital functions and on maximum respiratory support.

## ANDREW'S PROGRESS AND DEVELOPMENT

### Initial nursing

Andrew was nursed on an over-bed radiant heater, where he could easily be seen and handled. Very close attention had to be paid to his oxygenation, keeping the tracheostomy tube patent in the correct position and also making sure that the ventilator was always working properly. With the tracheostomy tube in place, and exposed to hospital pathogens, infection was a particular problem.

Nursing a critically ill child like Andrew was a real challenge and demanded the highest degree of efficiency and knowledge. We were responsible not only for Andrew's physical care, but also for his psychological needs. His parents were encouraged to visit as frequently as possible. Even when Andrew was critically ill, they were encouraged to physically touch their baby. Visiting in the unit is flexible to minimise child-parent separation. Gradually, as Andrew's condition stabilised, we tried to give him as much mental and physical stimulation as possible.

When Andrew was four months old he was taken off the ventilator but he had to stay in hospital because his tracheostomy tube had to remain as his own airway was still too narrow. He now weighed three kilograms and had very delayed motor milestones. He was floppy, had no neck control, made no attempt at smiling, and would not grasp at objects.

Bottle-feeding was an impossible task as his suck-reflex was completely absent. He had not had an opportunity to suck until then and tube feeding was continued. We started having grave doubts as to whether Andrew would be mentally normal.

As Andrew grew older, his mother brought his own clothes and toys. We encouraged both parents to participate in his care and they tube fed and suctioned him under supervision.

### Developmental training

Although we all worked towards one aim — sending home a normal, healthy, socially acceptable child, we felt that the efforts of a few doctors and nurses were not enough. A multi-disciplinary team, co-ordinated by the ward sister and social worker, was formed. It consisted of a group of professional people who would work together closely. The team

comprised: medical staff, nursing staff, social worker, physiotherapist, occupational therapist, nursery school teacher, speech therapist, voluntary play-workers.

The team's aim was to anticipate, prevent and deal with the problems of the chronically hospitalised children and to structure and implement a programme of developmental training. Andrew's emotional development became their greatest challenge. We did not want to send home a medically fit, but emotionally deprived child.

Particular problems that the team faced were those of developmental delay, regression, poor speech and language, low self-image — manifesting itself as aggression and attention seeking and a breakdown in parent-child relationship.

A minute to minute detailed daily programme was drawn up for Andrew, which allowed time for each team member to participate. They had meetings once a month to share experiences and ideas and to report on the child's progress. Parents were invited to discussion groups as well because they needed much psychological support. We felt it necessary and essential to reduce any confusion they may have had about their child's future. They were given the assurance that a team member would always be available should they need to discuss problems.

At first these meetings tended to be strained and formal, but gradually a very personalised and relaxed atmosphere developed as each team member became totally involved in training Andrew.

The following was a programme of a typical day in Andrew's life:

07h00	Potty
07h15	Bath time, brushing teeth and hair
08h00	Breakfast
08h30	Physiotherapy
09h00	Playschool
09h30	Potty and feeding
10h00-11h00	Nursery school (individual occupational therapy)
12h00	Potty and lunch
13h00-14h00	Rest
14h00	Potty, physiotherapy and feeding
15h00	Occupational therapy, nursery school, group therapy
16h30	Supper

A homely atmosphere was created for Andrew as far as possible. He wore his own clothes as he would at home, had his own toiletries and cot. Photographs of his mother and father were placed within easy view of his cot.

A specific colour was used whereby his belongings could be identified and Andrew's colour was blue. As he grew older, Andrew became very possessive about anything coloured blue — if anyone touched his cot, chair, or toilet-bag, for instance, Andrew would react immediately.

The team's daily activities took Andrew out of the ward more and more. At first he was scared to leave the well-known hospital surroundings — scared to venture outside the double doors which led to lifts and stairs. There were other fears that had to be overcome — meeting men without white coats terrified him. All the males he had known since birth wore white coats.

Andrew was gradually exposed to as many normal everyday situations as possible — we acquired a portable pool and he was allowed to play outside in the water on warm days. A sand-pit was another novelty to which Andrew was introduced.

In nursery school Andrew was given paints to experiment with. Here, in a special room equipped with the necessary utensils, Andrew could watch a simulated cooking session and was served — things a child would normally see in his mother do at home.

Andrew often had severe temper tantrums. In trying to draw attention to himself he would try to pull out his tracheostomy tube, his only life support. We had to guard against this constantly.

Andrew's weight-gain was poor and very slow. He insisted on wanting only pureed foods and as soon as solid foods were introduced into his diet, Andrew would induce vomiting. The hospital dietician was patient and very co-operative as regards our needs. Nursing staff became despondent and dreaded meal times when the anticipated vomit would invariably occur. We persisted, however, until a nurse eventually and very excitedly reported no vomits at breakfast or lunch that day. We had overcome yet another obstacle.

Toilet training Andrew was no easy task and required patience and perseverance. Each time that he used the potty successfully, he was given a star and Andrew would smile and nod in acknowledgement. Our earlier misgivings about his mental status were soon erased as we watched Andrew develop and respond to our training.

Walking remained a problem. In an attempt to help him along, we gave Andrew a walking-ring, only to be seriously reproached by our physiotherapist. Andrew tended to run around in the ring on his toes without bearing his full weight on his feet. Out of the ring, Andrew made no attempt at walking at all and it was consequently removed from the ward.

Speech also remained a problem with full comprehension and no vocalisation.

## Going home

Gradually, as his mother became more orientated to Andrew's needs and could handle him more confidently, we considered sending him home for week-ends. The social worker in the team visited Andrew's home to inform other family members of our intentions before we made a final decision. The home conditions seemed favourable and the visit was much anticipated by the family. A nurse accompanied Andrew on the first visit, but subsequent visits were managed by the mother herself. We were worried that when he went home, there would not be enough stimulation and that he would be *homesick* for hospital, but we were wrong.

When Andrew was one-and-a-half years old the stricture was resected and his larynx reconstructed (Laryngotracheoplasty). He still required a tracheostomy tube post-operatively but his airway improved gradually. More than two-and-a-half years after admission, Andrew was successfully extubated, following numerous unsuccessful attempts and repeated tracheal infections.

At this stage Andrew could walk well on his own, could feed himself and was potty trained. He also tolerated a normal diet well. We all realised that soon he would have to leave us permanently, and we were sad at the prospect but experienced a wonderful sense of satisfaction in a job so well done. We had nursed Andrew through a stormy course into the arms of his very happy parents.

Andrew is now living a normal happy life at home. His mother has left her work to take care of him herself. Delayed speech, remains a problem for which Andrew now receives speech therapy.

Andrew's father visited his son regularly throughout his stay in hospital. Through regular counselling with our team social worker the parents have formed a happier and more mature relationship. The parents always visit the ward when they come to hospital. Andrew invariably hesitates at the doorway, clings to his mother's hand and with pleading eyes says *Please don't leave me here*. Andrew now enjoys the wonder of playing in the sand with toys, of having his hands and face and hair dirtied by a lollipop and of watching the miracle of trains and cars go by.

At the last follow-up visit to the assessment clinic Andrew functioned at a slightly lower level than appropriate for his age. He was, however, catching up rapidly to normal levels, showing that even our best efforts in hospital could not entirely replace a normal home environment.

## CONCLUSION

This account demonstrates how a child became developmentally retarded as a result of long-term hospitalisation and how a co-ordinated multidisciplinary programme was able to reverse most of the ill-effects. We were fortunate in this instance as it is not always possible to correct this situation once it has developed.

It is important for the paediatric nurse to be aware of the consequences of prolonged hospitalisation on child development so that she can help to prevent them. It is sad when an emotionally deprived child's behaviour is regarded as naughty and he is disciplined, when he is only yearning for signs of love and attention from those around him.

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## SAMEVATTING

Eerstens is psigiatriese verpleegkunde omskryf en daarna is daarop gewys dat in die uitvoering van die verpleegproses die gebruik van self as terapeutiese instrument deur die psigiatriese verpleegkundige, kennis, selfkennis, positiewe houdings, terapeutiese kommunikasievaardighede en die gebruik van terapeutiese verpleegmetodes insluit.

Verpleegkundiges wat in ander areas van verpleegkunde funksioneer kan by die gebruik van hierdie kennis, houdings, vaardighede en metodes baat vind in die uitvoering van hulle professionele taak sowel as op persoonlike vlak.

## BIBLIOGRAFIE

- Aiken, Linda; Aiken, J.L. (1973). A systematic approach to the evaluation of interpersonal relationships *American journal of nursing*. 73(5):863-867, May.
- Albano, C. (1974). *TA on the job, how to make your work life happier and more productive*. New York. Harper & Row.
- Brammer, L.M. (1979). *The helping relationship, process and skills*. Englewood Cliffs, N.J. Prentice Hall.
- Burgess, Ann, W.; Lazare, A. (1976). *Psychiatric nursing in the hospital and the community*. Englewood Cliffs, NJ. Prentice-Hall.
- Carson, Verua. (1980). Meeting the spiritual needs of hospitalized psychiatric patients. *Perspectives in psychiatric care*. XVIII(1): 17-20, Jan.
- Egan, G. (1982). *The skilled helper, models, skills and methods for effective helping*. Monterey, CAL. Brooks/Cole.
- Frankl, V.E. (1963). *Man's search for meaning*. New York. Pocket Books.
- French, P. (1983). *Social skills for nursing practice*. London. Croom Helm.
- Grace, Helen, K.; Layton, Janice; Camilleri, Dorothy (1977). *Mental health nursing, a sociopsychological approach*. Debuque, Iowa. Brown.
- Haber, Judith; Leach, Anita, M.; Schudy, Sylvia, M.; Sideleau, Barbara, F. (1978). *Comprehensive psychiatric nursing*. New York. McGraw-Hill.
- Irving, Susan. (1978). *Basic psychiatric nursing*. Philadelphia. Saunders.
- Jourard, S.M. (1971). *The transparent self*. New York. Van Nostrand.
- Kaplan, H.I.; Sadock, B.J. (1982). *Modern Synopsis of the comprehensive textbook of psychiatry/III*. Baltimore. Williams & Williams.
- Kreigh, Helen, Z.; Perko, Joanne, E. (1983). *Psychiatric and mental health nursing, a commitment to care and concern*. Reston. Reston.
- Lieberman, R.P.; King, L.W.; De Risi, W.J.; McCann, M. (1975). *Personal effectiveness, guiding people to assert themselves and improve their social skills*. Champaign, Ill. Research.
- Lore, Ann (1981) *Effective therapeutic communications*. Bowie, Maryland. Brady.
- Maslow, A.M. (1954). *Motivation and personality*. New York. Harper.
- Mereness, Dorothy, A.; Taylor, Cecelia, M. (1978). *Essentials of psychiatric nursing*. Saint Louis. Mosby.
- Murray, Ruth, B.; Huelskoetter, M. Marilyn, W. (1983). *Psychiatric mental health nursing, giving emotional care*. Englewood Cliffs, NJ. Prentice-Hall.
- Murray, Ruth, B.; Zetner, Judith, P. (1979). *Nursing concepts in health promotion*. Englewood Cliffs, NJ. Prentice-Hall.
- Okun, Barbara, F. (1976). *Effective helping, interviewing and counseling techniques*. Massachusetts. Duxbury.
- Okun, Barbara, F. (1982). *Effective helping, interviewing and counseling techniques*. Monterey, CAL. Brooks/Cole.
- Poggenpoel, Marie. (1982). *Die funksies van die geregistreerde psigiatriese verpleegkundige in die Republiek van Suid-Afrika* Potchefstroom. P.U. vir C.H.O. (Ongepubliseerde D. Phil proefskrif).
- Trower, P.; Bryant, B.; Argyle, M. (1978). *Social skills and mental health*. London. Methuen.
- Weiner, I.B. (1975). *Principles of psychotherapy*. New York. Wiley.
- Wilson, Holly, S.; Kneisl, Carol, R. (1983). *Psychiatric nursing*. Menlo Park, CAL. Addison-Wesley.