

---

# GROWING UP WITH ANDREW

---

## MARGARET HYDEN

---

---

*The mother of a retarded child tells of some of the battles, frustrations and the rewards of caring for her retarded son.*

*It is hoped that contributions such as this one from Margaret Hyden will become a regular feature of the Journal.*

---

---

My husband was elated to hear at long last that our son Andrew had arrived, but at the time little did he realize the full implications of the trauma of the birth which was then closely followed by septicaemia and bronchial pneumonia.

Andrew fought many battles in the first few months of his tiny life, but the greatest battle was yet to come — when he finally came home.

His feeding was very difficult — every 2 hours and taking 1 hour each time. Andrew had great difficulty in sucking. I persevered with breast feeding for nine months. We believed that Andrew was “retarded”, but the doctors were unable to make any definite statements.

Obviously, considerable strain was placed on all members of the family. Often they went to bed wishing that tomorrow would never come, so great was the emotional strain.

Andrew was constantly ill. Weekly visits to specialists were necessary. The first two years were a nightmare. Our two older daughters

must have been crying out for more attention.

Our families are all very good, but at that time no-one lived in Melbourne. When Andrew was two my mother died very suddenly. Mum always knew the correct thing to say — even perhaps a good “dressing down” when necessary. We were desperate for help and did not know of any council assistance and certainly were unable to afford any other. Friends were marvellous, but somehow it just was not enough. I hated asking for help and would not!

### Tension

When Andrew was six months old our elder daughter, then five, showed great nervous tension. A serious problem was triggered — another calamity. We just could not believe it. Why us? Eventually, we found a paediatrician who understood the condition. We tried desperately to alleviate the strain as much as was within our power.

At last, when Andrew was approximately 12 months old, I rang the matron at the Blind Home. She came to our home on the appointed day, as the three children were home with chicken pox. Andrew was very ill. She was wonderful; very understanding, sensible and at long last someone who took the time to

listen. She assured me that when Andrew was old enough she along with her staff could help, but at the moment he was much too young. I will never forget her kindness and understanding. Never for one moment did she show any pity for me, which was the last thing needed at that time.

I attended the Royal Children's Hospital for weekly therapy sessions when Andrew was 2½. A few mothers with visually handicapped children met to discuss our problems, but as Andrew was so active, and appeared to be much “slower” than any of the other children, I dreaded these outings. I felt so alone.

### Blind Home

Finally, when Andrew was three I visited Matron at the Blind Home. She insisted that he should be given physiotherapy to assist him to walk. The physio was indeed superb. After a few weeks of regular therapy Matron suggested that Andrew should live in for three days per week, as he was ready to learn and the regular pattern and help of the staff was what he needed. I was stunned. My baby was leaving home at three years of age. This was on the Friday. Andrew commenced school on the Monday. I feel that only a mother in my position could understand how I felt. On the Monday I took my baby to school with case in hand. I was unable to speak. I settled him in as best I could and just waved to the staff, who were very sympathetic, especially Sister. I suppose this was “old hat” to her, but to me she was gentle and with the understanding of a mother.

Having waved goodbye I went home, sobbing all the way. I shall never forget that February day, 3½ years ago. I thought life was finished, but in fact it was only just beginning.

It wasn't until Andrew was living away for three days that I realized how much time and effort was involved in caring for him. What was I to do all day! The other children were more relaxed. My husband and I were more relaxed. The tension and strain in the house was noticeably reduced. We took our daughters on outings during the week, entertained and had "time to breathe", for the first time in three years.

### **Co-ordination**

Andrew's co-ordination is very poor. He does everything awkwardly, but tries so hard. He can feed himself with a spoon now, dress himself in a fashion, go to the toilet with assistance and now we are going "all out" for night toilet control. Andrew, now seven, lives at school Monday to Friday. Without the assistance from the Blind Home I often wonder what would have become of our family.

For all the tension and strain over the years, the girls have thrived with Andrew; they love him dearly and welcome him home with open arms, kisses and cuddles. They have a wonderful outlook on life and an increased capacity for human weakness.

### **Fought So Hard**

As for our little man — his love and constant demonstration of it — well, we could never be without that. For all the assistance and guidance we give him, we feel he gives far more in return. He has

fought so hard for life and every milestone since. He is trying to talk now and we hope that with help and encouragement he will make it. He certainly can make himself understood without it. Recently, Andrew commenced at a Kindergarten on a limited basis. This experience, plus a series of other broadening experiences, appears to be providing him with greater stimulation. I can't thank the Blind Home, teachers and staff enough, for all that has been done for Andrew and the rest of our family.

### **Surgery**

Last year when Andrew was six, I needed immediate surgery, a stay in hospital for 18 days and a month's complete rest when I came home. Andrew was due home for Christmas holidays three days after I arrived home. We were fortunate that the Blind Home was able to mind Andrew for several weekends. I had heard about council help so decided to obtain some assistance. At first I was very apprehensive, but no other help was available. The day arrived for our first lady to come. I was terrified. What would she think? How would she take to Andrew? She came each day for a week and was marvellous, caring for Andrew as she would her own child. Why did I take so long to seek this assistance?

### **Numerous Ladies**

Since then we have had numerous ladies in our home and they have all been most capable. This is a wonderful facility for families who qualify, and is provided at a nominal charge. It certainly is a great step forward. I thoroughly recommend this scheme. It must greatly assist mothers with small babies — go ahead Mum and use it.

I felt guilty and most inadequate asking for help, but nearly everyone needs help at times, especially when there is a handicapped child in the home.

I feel very fortunate that we have had the assistance from the Blind Home and the council. For the past two years we have been able to have a fortnight's holiday without Andrew, as the Blind Home has been able to mind Andrew at the weekends. This is not always convenient for the Home, but no other alternative is available. However, this necessitates the girls missing valuable time from school, as there is no way that Andrew can be minded during school vacations. It will not be possible to continue this arrangement for much longer, because the girls will be in secondary school.

### **Facility**

Some facility to mind a handicapped child during school holidays would enable the rest of the family to have a brief holiday free from strain. Another possibility would be for a handicapped child to be minded for the occasional weekend, to give the family a break or to enable the other children to follow their interests free from the constraints which are necessary when Andrew is present.

### **Main Worry**

Of course our main worry is the future. I definitely don't want our daughters to have the responsibility, as they have the right to lead lives free from this complication. By that time we hope that there will be some niche and home for our boy — our little boy who is desperately trying to be a somebody.