

# Celebration of a Transformation



## 50 Years of Action for Sick Children

Compiled and edited by Pamela A. Barnes  
with contributions from Dr. Peg Belson and members.



The UK's leading children's  
healthcare charity 1961-2011  
Registered charity no 296295



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# Foreword



Dr Sheila Shribman

Action for Sick Children has made an incredible journey over the last fifty years from Mother Care for Children in Hospital through the National Association for the Welfare of Children in Hospital into Action for Sick Children. The Robertson films, *A Two Year Old Goes to Hospital* (1953) and then *Going to Hospital with Mother* (1958) were instrumental in highlighting the emotional and social needs of sick children. This in turn was the

impetus behind the Department of Health setting up a committee under Sir Harry Platt "To make a special study of the arrangements made in hospitals for the welfare of ill children – as distinct from their medical and nursing treatment – and to make suggestions which could be passed on to hospital authorities." The findings of this committee were published in 1959.

There was little progress on this report and it was not until Mother Care for Children in Hospital was inaugurated in 1961 that things began to change in the emotional care of sick children. Fortunately through the constant campaigning of this charity, change has come about. The charity has continued to contribute to the welfare of children in hospital in many ways over the last fifty years. The inequalities in children's health continues to persist despite the enormous efforts from many healthcare professionals and government but progress is happening. Much is owed to Action for Sick Children, as it is now known.

Without the continuous efforts from such an organisation, the professionals would have found their job more difficult. Action for Sick Children has helped enormously in the transformation of services for sick children over the last 50 years.

The charity needs to be congratulated on its continuous efforts on behalf of sick children and young people. A short history of the work carried out alongside reminiscences from some of those involved makes interesting reading and captures fifty years of incredibly hard endeavour.

Well done Action for Sick Children.

**Dr Sheila Shribman, CBE FRCP FRCPCH**

National Clinical Director for Children, Young People and Maternity Services

# Introduction



Pamela Barnes

It is difficult to conceive how an enlightened approach to the care of sick children may have evolved without the efforts of a small group of dedicated parents in 1961. Already in place were the guidelines known as the "Platt Report", the Welfare of Children in Hospital, but where was the action? This small group of six mothers was so dedicated to improving the experiences for sick children that their enthusiasm spread. Groups of

parents and many professionals joined in a unanimous plea to make it better for sick children. Gradually the movement spread and the organisation was recognised as a very influential and successful voice in this field. At first, the movement was known as Mother Care for Children in Hospital but soon changed its name to the National Association for the Welfare of Children in Hospital. Now, when sick children are treated both in hospital and their communities, the charity is known as Action for Sick Children.

This short history written by one of the founder members, Dr Peg Belson, outlines the transformation of children's services and the part played by Action for Sick Children. Reminiscences from many involved, including doctors, nurses, parents and children, highlight the passage of this enlightenment of children's services and the contribution of Action for Sick Children.

Now, as we move on from the celebrations of the Charity's 50th anniversary, is there still a role for this charity? With the unfolding of the 2011 Health and Social Care Bill, with little mention of children, the answer is emphatically yes! Action for Sick Children is an umbrella organisation, covering all sick children. There must continue to be a "watchdog" for children and young people's health services. We cannot allow all that has been achieved to slip off the radar. Action for Sick Children needs to continue to be ever vigilant on behalf of sick children and young people and in supporting all those involved in their care, including families.

**Pamela Barnes, M.Phil**

Chairman, Action for Sick Children



## Look at Me

What do you see when you're looking at me?  
Simply the girl in bed three?  
But look at me

A person  
Insecure and apprehensive as doctors whirl by.  
A person  
With thoughts and feelings.....a heart

What do you see when you're looking at me?  
Simply the girl in bed three?

But I am a person who longs to roller skate,  
dance and skip....  
to be well again

So, I lie here, calm and still,  
As I do as you wish.

As I eat at your will  
Study me closely as you're rushed off your feet.  
You're busy on night shift, no time for a seat.  
An unusual case, a case to confirm  
No, I'm one of many  
If only you'd learn.

So open your eyes, doctor,  
Open and see,  
Not a fascinating case.

Look more closely  
Try to see me

**By a young girl, Age 11 – 1991**



“ Of considerable influence in the past few years has been the lay movement called Mother Care for Children in Hospital (recently re-named National Association for the Welfare of Children in Hospital). When the Platt Report made public a topic which had engaged the hospital professions for some years, MCCH was founded by parents to express their consumer interest and to press for the full implementation of the Report. MCCH has forced the topic beyond the women's columns into the main news pages where it is now recognised as a social problem of importance. As a pressure group which is constructive, ready to help as well as to draw attention to discrepancies between official statements and actual practice, it has the respectful ear of the administration. As a body which is active but not militant it has won the open support of many doctors and nurses. Not the least of the achievements of MCCH is to have created the first slender bridges between the traditionally remote hospital system and the community it serves, with many constructive interchanges to its credit. ”

**Quote from James Robertson – 1966**



# Early Days

## The early days prior to Mother Care for Children in Hospital

My connection with the Platt Report of 1959, began in February 1957 when I started a research post with The Medical Research Council in the Burns Unit of Birmingham Accident Hospital. Like so many of these events it was largely due to chance that a colleague of mine at Ealing Child Guidance Clinic mentioned that a friend of her's who was a technician working at the Burns Unit was aware how distressed and emotionally disturbed the burned children seemed to be. The question was being asked, "Do emotionally disturbed children get burned, or do severe burns produce emotionally disturbed children?" As I was about to be married and going to live in Birmingham, and was looking for some interesting work there, I visited the Burns Unit. I felt dismayed on doing so, to be shown small girls with normal, though scared-looking faces, peeping out from bed clothes which when drawn back showed horrifically scarred bodies from their ankles to their chins. At that time most of these burns were caused by nightdresses being caught in unguarded fires as small girls brushed their hair looking into mirrors placed above mantelpieces.

It soon became apparent that I would have to propose how such a study could be made. It was agreed that I should interview the mothers of children who had received burns 4 or 5 years earlier, of 10% or more of their body area, as this was when clinical shock was most likely to occur. The big time gap was due to the fact that burns take a long time to heal and children return for further plastic surgery time and again.

The attitude to such research was clearly shown by the fact that I had no offer of a room, desk or even a telephone to do the work and only a six months contract. At the time there was no visiting for the under fives and only half an hour twice a week for the older children, the stench in the dressings room that had to be passed through to reach the wards, was overpowering and the children were nursed on the same ward as the adults.

During the first four months I visited the homes of 98 children. I heard at length about the symptoms of emotional disturbance in the burned children and I asked about their siblings as well to provide some sort of 'control group'. 70 questionnaires were sent to the burned children's teachers where relevant and I wrote my first report.

At this stage 90% of the children were showing symptoms of emotional disturbance. According to their mothers, these were a direct result of their burns. This contrasted to 7% in their siblings. I had two very different responses to the report. The



Joan Woodward

Director of MRC wanted a "more scientific response with more statistical comparisons." The Consultant thought it "too scientific" and wanted "more case histories". In spite of this, my contract was extended for another three months. This left me five months in which to investigate another 100 children, burned two to three years previously. Later, I was able to investigate a properly composed control group. I continued to work in the hospital for the next two years, seeing parents on the wards and in outpatients, helping the mothers express their anxieties and feel more confident to help their children recover emotionally from the experience. Sadly I had to contend with a huge amount of hostility from the nursing staff which could have been lessened if they had been properly included in the purpose of the study at the beginning.

In 1959 the BMJ published the outcome of the Study after I had investigated the mothers' view of 198 children who had received severe burns. 81% were showing emotional disturbances and a high proportion of their mothers complained of "upsets" due to their children being burned, with 16% of the mothers having a psychiatric referral. **Of the many factors examined to explain this high level of emotional disturbance, only lack of visiting the under fives was statistically related to it.** Following these research findings being published, the Platt Committee used them as "evidence" of the need for parental visiting of children in hospital.

Another factor that enabled me to persuade the staff at the hospital to introduce daily visiting, which later led to open visiting, was that infection levels went down when there was regular parental visiting. It was good to have the belief that mothers were the source of infection proved as a myth! I was able to do a further study of the beneficial effects of parental visiting of the under fives, coupled with social work support, which led to a big reduction in the levels of emotional disturbance in the children. It went down to 27% and none of the mothers had psychiatric referrals. This study was also published in the BMJ but not until 1962, by which time I had left the Burns Unit and was at home.

In the summer of 1961 my husband and I were able to adopt a three week old baby. As at that time one had to swear in Court not to take up any paid employment during the child's infancy, this left me able to respond to Valerie Elder's request to set up a Birmingham branch of MCCH. At that time my mother, who was a journalist, had written a letter that was published in the Guardian newspaper's women's page, telling of the plight of unvisited children in so many hospitals in spite of the Platt



Report's recommendations. As a result, hundreds of mothers responded and MCCH became of intense interest at a national level overnight!

I was able to spend the next seven years devoting a great deal of time and energy to setting up MCCH in Birmingham, which later became NAWCH. Although eventually I was able to do a paid job I continued to work with a large group of other mothers in order to help bring about the Platt Report recommendations. It is hard to over estimate what was involved in this effort, as it required such a huge variety of tasks. These covered organising hospital visits, spreading information to the public, lectures, writing, advertising, petitions and an endless ability to patiently persist with a belief in a campaign based on sound research findings. Now, fifty years on it all feels worth it, as the main aims have in general been achieved.

**Joan Woodward**

## Early Days 1948 – 1961 James Robertson (1911 – 1988)

Excerpts from "Separation and the Very Young"  
J. & J. Robertson (1989) Free Association Books

James Robertson stumbled on the inhumane conditions faced by young children in hospital when in 1948 he was sent to observe children separated from the mother, sometimes for years, in hospitals, TB sanatoria etc. In his last years he wrote up the history of his campaign. *"He was reluctant because the very nature of the single-minded battle that he fought on behalf of parents and children in hospital, and the eventual success of his endeavours, could make it sound like a self-congratulatory exercise, and an unavoidable streak of criticism of fellow professionals and lay people might irritate readers... I suggested he write it for our grandchildren who were becoming interested in our lives. Once he got started he could admit the real purpose of the writing. This generation of parents, doctors, nurses and social workers needed to know that some of the improvements were hard won, and called for a continuing awareness if the improvements were to be held and built upon. He knew only too well that defences could come into play and erode the improvements."*

(Joyce Robertson, 1989, in the preface to 'Separation and the Very Young')

*"In 1948 James Robertson joined Dr John Bowlby at the Tavistock Clinic to study the reactions of young children to separation from the mother. In psychiatric clinics around the world it was believed that certain forms of psychological disorder had their origin in early separation; but these theories were largely*

*based on reconstructions from the psychotherapy of disturbed children and adults. There were virtually no direct observational data on the behaviour of young children during separation from the mother."*...

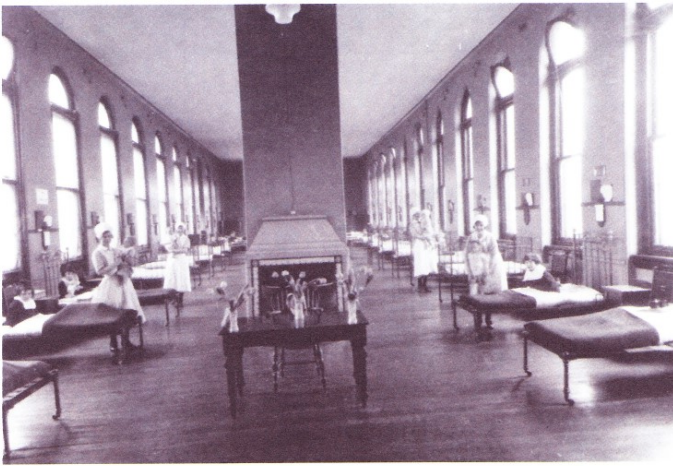
*"I was to observe and describe the behaviour of young children during and after separation and thus to help fill the gaps in first-hand observational data.*

*The task seemed simple enough. First thought was to observe children at home while the mother was in hospital; but to locate and gain access to numbers of individual children would have been difficult and time-consuming. So in order to get a first impression I went to a place where there was easy access to numbers of young children separated from the mother – to the children's wards in local hospitals.*

*On 11th February 1948 I went in all innocence to the short-stay children's ward at the Central Middlesex Hospital, the parent hospital of the Tavistock Clinic. This was solely for the convenience of observing a batch of young children in one location, and not because of any awareness on my part that young children in hospital presented a special problem."*...







*"Within a few hours I had grasped the essentials of a problem of distress that was not being acknowledged in the hospital professions."*

*"With colleagues at the Tavistock Clinic to whom I reported on my work I had a sense of inadequacy of words to convey what I saw and how I understood it... No matter how well I chose the words each listening colleague could construe them differently and have differing impressions of the child... The answer came by chance. I read somewhere that visual communication pierces defences, as the spoken word cannot do. It allows what is shown, to be examined and re-examined... Misunderstandings of verbal descriptions would be avoided; everyone in a group would see the same scenes, while sequences could be viewed and reviewed in order to heighten perception and understanding by repetition".*

So the now famous film "A Two-year-old Goes to Hospital", which is still in use worldwide 57 years later, came to be made by James Robertson.

At the Film Premiere at the Royal Society of Medicine in November 1952 "the film encountered much resistance. Some accepted its truths, but the majority reacted negatively. Various speakers said hotly that I had filmed an atypical child of atypical parents in an atypical ward: that young children in their wards were happy; that they had never heard parents complain; that I had slandered paediatrics; and the film should be withdrawn." We decided the subject was so explosive that the film should be withheld from general release until the professions were given time to come to terms with it, lest the premature mobilising of public discontent with the treatment of young patients should provoke attacks on hospitals and cause hardening of resistances." (Robertson J & Robertson J, 1989, p45) The film was then shown only to professional audiences with trained people introducing the film and taking discussion.

In 1957 "A Two-year-old Goes to Hospital" was shown to Sir Harry Platt and members of the Committee on the Welfare of Children in Hospital (the Platt Committee), by James Robertson

and Dr Dermot MacCarthy (in whose ward at Amersham Hospital "Going to Hospital with Mother" (1958) was filmed.) "Going to Hospital with Mother" was also shown to Sir Harry Platt. James Robertson submitted a memorandum on behalf of the Tavistock. Platt asked for this to be shaped into a book and published immediately in 1958, before the Platt Report was published in 1959. ('Young Children in Hospital' 1958 James Robertson. Tavistock., republished in 1972 with a substantial postscript). The book was immediately published in eight European languages and Japanese.

Publication of the Platt Report brought the whole subject of conditions for children in hospital into the public domain. In January 1961 "The Observer" published a series of articles by James Robertson "Children in Hospital" in which he urged parents to organise themselves to work for implementation of the Platt Report. He also appeared in a one-hour television programme presenting sequences from the films in discussion with Dr Ronald MacKeith, Dr Dermot MacCarthy, Sister Ivy Morris and Joyce Robertson. For the last two minutes of the programme he ignored direction from the producer and spoke directly to the camera inviting parents to tell him about good and bad experience of paediatric wards. This brought forth more than four hundred letters, which were sorted and turned into a book "Hospitals and Children. A Parents' Eye View" (Robertson J. 1962) with an impressive foreword by Sir Harry Platt.

The publicity prompted a group of young mothers to go to the Tavistock to seek James Robertson's help to combat hospital restrictions. He was delighted to offer his specialised knowledge of child development, of children in hospital and of campaigning to improve conditions for children in hospital, to support the setting up of '**Mother Care for Children in Hospital**', later called the '**National Association for the Welfare of Children in Hospital**' **NAWCH**, now '**Action for Sick Children**'.

**NAWCH** became a very effective pressure group. The rest, as they say, is history.

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# Founder Members

## Celebration of a Transformation – A History of Action for Sick Children

Over the past five decades the care of sick children in hospital has been transformed. Fifty years ago children faced long, lonely stays in hospital. Visiting hours were short and sometimes non-existent. It was generally believed that parents of sick children should be discouraged as much as possible from visiting. The accepted opinion was that they might 'bring infection into the ward' and their visits 'evidently upset the children' who, if left to themselves, would soon 'settle down' and forget about home'. There were a few hospitals offering exceptions to this pattern and it was from these and from the work of the Tavistock Institute of Human Relations on maternal deprivation and separation anxiety that a gradual rethinking came about regarding the role of parents, especially the mother, in the care of the sick child in hospital. James Robertson's contrasting documentary films, *A Two Year Old Goes to Hospital* (1953) and *Going to Hospital With Mother* (1958) clearly showed that the more distressing part of hospitalisation for a child was separation from mother, rather than illness or pain.

In 1952 the Health Ministry's Annual Report recorded that only 23 per cent of hospitals allowed daily visits while 11 per cent prohibited all visiting. By 1954 daily visiting had risen to 65 per cent but these visits seldom lasted more than one hour. By 1956 sufficient concern had been aroused for the Ministry of Health to set up an enquiry under the chairmanship of Sir Harry Platt to investigate the arrangements made by hospitals for the welfare of children in hospital as distinct from their medical and nursing needs. The committee's report, published in 1959, *The Welfare of Children in Hospital – commonly known as the Platt Report* – made 55 recommendations for the non-medical care of children, recognising the importance of parental involvement and understanding children's emotional needs. The most significant recommendations were that visiting to all children should be unrestricted, that mothers should be able to stay with their children, especially if they were under five, that the training of medical and nursing staff should include the emotional and social needs of children and families, that children should only be admitted to hospital if their care could not be given at home or in the community and children should not be admitted to adult wards. The Platt Report was adopted as official policy by the Ministry but without any mechanism to force hospitals to adopt its recommendations. Consequently there was little change nor was there any appreciation of the need for change. A medical correspondent could confidently state "the great majority of hospitals seemed oblivious to the enormous amount of



Peg Belson MBE BA PhD

suffering put upon children and their parents by rules which break important relationships necessary for the maintenance of good mental health"

In 1961 James Robertson contributed a series of articles to the Observer and showed his films on television during which he urged community pressure to improve conditions for children in hospital. Some Battersea mothers heeded Robertson's call and set up, under his guidance, a group initially called Mother Care for Children in Hospital – MCCH. Having visited hospitals where parents were welcome they investigated the care available to children in local hospitals where they found little recognition had been given to the Platt Report. Discussions with medical, nursing and administrative staff brought forward a number of factors frustrating change. Those caring for sick children considered it 'natural' for children to cry in hospital: tears had long been accepted as inevitable. It was thought that children soon forgot what happened in hospital: children's memories were very short so no permanent damage could result. Many children who cried bitterly when first left soon settled down and could even become 'quite happy'. They 'just didn't miss their mothers'. Many seemingly good reasons were given for not changing the traditional arrangements. Most hospitals were old with little space to spare. Cross infection might increase. The routine would be disturbed. Mothers would be 'difficult'. Very few mothers asked for longer visiting hours or beds to be with their children. In any case they all had competing home commitments. Many children were far from home and would be treated unfairly if the others had frequent visitors. Thus the need for change went unrecognised and the probable effects of change were exaggerated or mistaken. Nor was there any understanding of the emotional effect of separation especially on the young child.

Mother Care for Children in Hospital aimed to persuade hospital staff that the new concepts were worthwhile and could work, and to persuade parents that they had a vital role to play in the care of their sick child. Public meetings were organised with both professionals and parents to promote these aims. Extensive publicity in the national press and in women's magazines soon stimulated the formation of more MCCH groups. By 1962 ten groups had emerged and following some very sympathetic coverage in The Guardian by the famous journalist Mary Stott, the total grew to twenty-three by the end of the year. The first survey of visiting, carried out by post in 1962, and supplemented by information from the groups provided the information for the MCCH Hospital Information Service through which parents could be directed to the most co-operative hospital for their particular needs. In 1963, the 23 MCCH local groups came together to form a national association



at a conference where the presentation of current topics to a lay and professional audience set the pattern for the many successful conferences that followed. In 1965, in order better to recognise its lay and professional membership, the organisation became the National Association for the Welfare of Children in Hospital – NAWCH.

Surveys of visiting and accommodation continued allowing NAWCH to contest Ministerial statements of major improvements in unrestricted visiting (75% of hospitals) with the more accurate information collected at ward level (only 23%). These early surveys revealed a variety of meanings for the term unrestricted. 'It is our aim to have unrestricted visiting but visiting in the morning is not encouraged'. 'Visiting on this ward is unrestricted but do not stay more than half an hour'. 'Visiting on operation day is at Sister's discretion and is discouraged to save parents any unnecessary distress'. By 1966 NAWCH discussions with the Ministry and questions by Members of Parliament in the House of Commons had established a clear definition of visiting arrangements. *HM (66/18) Visiting of Children in Hospital* stated that fixed visiting hours were to be abandoned, that there should not be any rule restricting visiting, before or after any operation or of children who have an infectious illness, that a decision not to visit a child on a particular day should only be made by the consultant in charge, that hospital information leaflets should make it clear that parents could visit at any time during the day and that mothers of young children should be able to stay in hospital with their children. This precise clarification of the position greatly helped NAWCH in its campaign to get its ideas accepted both by hospital staff and by parents. Since that time the Association has campaigned, with considerable success, for family centred care, with particular emphasis on the removal of all restrictions on visiting. By the early '80s it could report that more than half the wards admitting children could offer some accommodation for parents and at least the same number had completely open visiting. Since then there has been continued improvement demonstrated by local and national surveys.

By 1967 NAWCH was an expanding organisation of fifty-five branches in England, Scotland and Northern Ireland, there being a separately established and managed organisation in Wales. With a grant from the Sembal Trust the Association opened its first office in London. *Coming into Hospital*, an advice leaflet for parents, issued in 1967, was the Association's first publication. Now in its seventh revision and sold in its millions to hospitals and to parents, it has helped families to a more enlightened hospital experience and formed the model for many hospital admission leaflets. In 1984 the Association took on a new role as the standard setting body with the publication of the *NAWCH Charter for Children in Hospital*. This was immediately recognised by the Department of Health and endorsed by more than fifty professional and voluntary organisations involved with the health and social care of children. In 1989 the Charter principles were expanded into *Setting Standards for Children in Health Care – The NAWCH Quality Review*. Many Health Authorities and NHS Hospital Trusts used this as the basis for the specifications and contracts required by the 1991 changes

in health care provision. In 1991 NAWCH became Action for Sick Children, the new name reflecting the fact that an increasing amount of children's health care was now taking place in the community or at home rather than in hospital. This pattern of care had been reflected since 1963 in the first clause of the NAWCH constitution and formed the basis of the first clause of the 1984 NAWCH Charter.

Action for Sick Children has published a series of *Family Information Leaflets*, purpose designed for parents and children ranging from the original, updated *Coming into Hospital* to four further *Parent's Guides: You and Your GP, What to do in an Emergency, Going to Outpatients and Hospital Isn't That Bad*. Others in the series included *Children and Pain, Needles – Helping to Take Away the Fear* and *Teenagers in Hospital*. The Quality Review Series continued with an updated and extended version of its first review now called *Health Services for Children and Young People – a Guide to Commissioners and Providers*. Other titles in this standard setting series include publications on such subjects as adolescents in hospital, children's surgery, mental health care, appropriate health care of black and ethnic minority children and emergency services for children and young people. Action for Sick Children developed a unique library and information service for parents, professionals and the media. An historical collection of articles traced the developments in the hospital care of children since the 1960's and library searches on specific topics were available. This library is now housed at the National Children's Bureau.

Action for Sick Children branches have acted as a consumer information base to bring to public notice inadequacies and inappropriate provision in children's health services. They have been available to give advice, confidence and support to parents who know what their children need but were frustrated by staff unwilling to change. Surveys of visiting have depended on branch members to obtain a national picture. They have funded hospital facilities such as hospital play programmes, parents' accommodation, admission leaflets, slide sets and videos, hospital comics and painting books and set up travel services to take families to hospitals for appointments and to visit sick children. One such travel service, Manchester Sick Children's Transport, has been a long-standing independent charity. Branch members also take part in training programmes for nurses and medical students, provide relevant publications for their reference libraries and have funded their own members and hospital staff to attend local and national conferences and government consultations. Others provide hospital information programmes in the community for children in play groups and nursery schools using specially designed Play Boxes and some have run a hospital crèche for siblings.

Association members were early appointed to health service management bodies thus participating in service provision and hospital planning. Many members have served on Health Authorities and Trusts and represented the interests of children and families on consumer councils monitoring health care such as Community Health Councils and their successor bodies. Through its annual conferences and its journal it has brought



topics of interest and enlightenment to a wide lay and professional audience. Members have made contributions to many national and international conferences promoting family centred health care and presentations have been made both locally and nationally on television, radio, in the press and via the internet. The association has served as a pattern for other countries wishing to develop similar programmes.

Demonstration visits to the UK have been arranged for staff from overseas and ASC members have visited many countries to spread the message. Participants in such programmes include the Netherlands, Kuwait, Saudi Arabia, Malta, Finland, the Czech Republic, Poland, Switzerland, New Zealand, Australia, Japan and China. Action for Sick Children is a founder member of the European Association for Children in Hospital whose Charter published in 1988, is based on the 1984 NAWCH charter.

Though always a lively critic of government ASC has been praised by ministers and officials for its careful fact finding and its sense of responsibility as well as its persistence in following up cases where practice was thought to be wrong. It has made significant contributions to government consultations and national and professional co-coordinating committees. Consultations have included such seminal Department of Health memoranda as *Visiting Children in Hospital* (1966), *Hospital Facilities for Children* (1971), *The Court Report* (1976), *Play in Hospital* (1976), *The Welfare of Children in Hospital* (1991) and *The Care of the Critically Ill Child* (1997). More recent contributions have been to the *Parliamentary Select Committee Report on Child Health Services* (1996), *The Care of the Critically Ill Child* (1997), *The Bristol Inquiry* (2001), the *National Service Framework* (2004) and its consequent monitoring report *Every Child Matters*, (as well as the many hospital committees overseeing its implementation), the *Child Health Strategy* (2009) and the White Paper '*Equity and Excellence: Liberating the NHS*' (2010).

Travel costs for families visiting and attending hospital have been an issue for the Association since the first NAWCH Fares Enquiry in 1972. Further campaigns followed but despite firm representations to the Department of Health, as well as questions in the House of Commons, few changes have ever been made. A more targeted enquiry into the variable cost of parking in 2004, *Park the Car Park the Charge*, demonstrated that travel costs were still an ongoing issue. Recent enquiries into parking and travel costs in collaboration with the University of Salford have shown some welcome improvements but overall parking costs have increased by a third.

In 2001 in celebration of its fortieth anniversary ASC launched its Best Practice Awards to recognise excellence in children's health care. In 2008 The Norah Rees Award for a Master's dissertation from a nurse that best reflects the aims and values of Action for Sick Children was launched. It continues to attract a high calibre of submissions. Another new project was the Dental Play Box to help children learn through play about dental treatment and encourage them to cooperate with the dentist, thus making going to the dentist less scary. First developed and now generally in use in Scotland the Dental Play

Box is soon to be available across England. The Play Box has an accompanying leaflet and a video available on the ASC website.

Since 2004 ASC has been developing processes and techniques to enable children and young people to participate in decision making in response to the requirement of the *National Service Framework* (2003), to communicate with children and young people, to determine their specific needs and involve them meaningfully in the decision-making process regarding their healthcare needs. Publications from these projects include *Evaluating Children's Health Services – the Adolescent User Perspective*. Adolescents as a resource group are mainly underused when planning for their needs in hospital is undertaken. This report, published in 2006, demonstrated the development of a unique survey process to assess the views of adolescents undergoing health care. In 1959 the Platt Report recommended that this group of young people should receive significant and separate provision in hospital, a recommendation not generally implemented. *The Principles for Involving Children and Young People in the Service Planning Processes of Hospital Services*, also published in 2006, is a practical guide for staff working in health settings on how to consult and involve children and young people. It demonstrates that consultation involves more than simply asking for views but also requires attentive listening followed by relevant action to turn the ideas offered into reality. *Consent to Treatment for Children and Young People*, a 2006 project funded by the Department of Health, offers advice to parents and staff and defines the way in which children and young people should be personally involved in decisions affecting their own health care.

*Voices for Children and Young People – a review of the literature*, by Dr Jane Coad, followed in 2007. This should prove useful for those concerned with decision-making in health care provision and the need, as recommended by its eminent paediatric reviewers, to ensure that the views of children and young people are fully considered. To make such a process easier, and possibly more likely to occur, ASC has now published *Involving Children and Young People in Healthcare – A Planning Tool*. This tool kit, launched at the Royal College of Paediatrics and Child Health on 6th October 2009, aims to support those working in the health care sector, both primary and secondary, by providing a programme to enable them to engage with children and young people. These tools should prove of great value to the new commissioning bodies to be established by the GP Consortia, given that one of the principles of the White Paper is the value and necessity of patient involvement, a role emphasised by Action for Sick Children since its inception in 1961.

In 2009, ASC celebrated the fiftieth anniversary of the publication of the Platt Report by holding a national conference in Manchester with presentations from many eminent contributors. Honorary membership of Action for Sick Children was awarded to two long-standing members and a DVD outlining the development of the charity was produced. In 2011, to celebrate the fiftieth anniversary of the founding of the Association in April 1961, ASC is holding a Jubilee Lecture at the Royal Society of Medicine to an invited audience. It is also sponsoring



an Art Competition for children who are in hospital in April and has invited hospitals to organise birthday celebrations.

Action for Sick Children is an astounding success story. Working in a collaborative and persuasive manner it has been influential in promoting a pattern of health care for children and their families, which meets their specific needs. It has gathered information from users and professionals, undertaken and sponsored research and translated the results into standards of care, which have been adopted nationwide. The organisation has used its expertise to influence key policy makers nationally and locally to help make children's health a priority and has developed a good working relationship with professionals to achieve change. As an independent voice in health care for children and families for fifty years, the Association has seen major changes in the recognition of the emotional, social and psychological needs of sick children, so clearly stated in the Department's 1991 policy document *The Welfare of Children and Young People in Hospital*. "We now have a far greater knowledge of how children develop both emotionally and physically. With that understanding has come an awareness of the emotional vulnerability of the young child and the effect which early experience can have on later development. A good quality service should provide for the child as a whole, for his or her physical and emotional wellbeing, not just for the condition for which care is required. It must be child and family centred with children and families experiencing care, treatment and support as they move through the constituent parts of the service." A great deal has been achieved but there is still more to be done.

**Peg Belson MBE BA PhD**

Hon Fellow RCP&CH Hon Fellow ASC

16 December 2010

## Reminiscence of Liz Beeson – Founder Member

Liz was 27 when Caroline was born on a summer Saturday in Battersea in 1958. Liz was feisty, sociable and, after a year in Paris, a fluent Francophile, mother and cotton-town Rosenthal resilient; Grantley Dick Read; natural childbirth days; home births; Bowlby at work. A year at London's Institute of Education had introduced Liz to emerging ideas. Battersea was a nourishing and supportive milieu.

The birth was uncomplicated, as men may say. But there was an awkward asymmetry in the baby's lower limbs and she was wrapped before being presented to Liz, with tears of joy and relief. But within moments the GP, a wonderful man, was summoned and after a muted explanation, Caroline was off to St. Thomas's. Liz was not to see her again for two or three agonising days but the baby was vigorous, vocal and alert as ninepence.

At another muted briefing, Liz learned from the Consultant, a distinguished Knight, that Caroline was spina bifida – an occasional congenital condition – with a poor prognosis. Liz asked would she walk? She's unlikely to sit up, said the Knight from a gloomy Cervantes, as the Matron poured a glass of sherry.

Caroline was put on a maintenance feed, but thrived nonetheless and then the trouble started. Visiting times – Strict – Sister rules. For the good of all. Children unmanageable after visits. Consultant's powerless. Children distressed at visits, visitors barely tolerated. Bells and out. Meanwhile, Caroline is in a cot with an exposed and unprotected meningocele at risk of rupture and the consequences. In due course, a technician at 'Tommy's' did devise a tortoiseshell.

Still, Caroline put on weight, yelled and defied the gloom-sayers and put the bit between Liz's teeth. Friends, neighbours rallied and, most important of all, the GP, who was familiar with what was going on at the Tavistock Institute and, surgically, across London, found an awkward, iconoclastic, irascible, baseless orthopaedic surgeon who wandered between Roehampton, Mile End Road and elsewhere. He took a look at Caroline, saying "What do you expect me to do with her? Somebody has got to see to that thing (her meningocele). You need a neurosurgeon". Leon Gillis lashed with his tongue. Enter Great Ormond Street.

Some transformation! Far from what it is now, of course, but becoming aware. The neurosurgeon, Mr. McNab, managed all he hoped but dared not promise. Caroline was robust, determined and a little girl.

Then came the Platt Report of 1959. Then came the widespread use of James Robertson's films and the expressing of parental concerns, from the ground up. But then came the backwash. Marching Matrons like nuns in Bunuel films, assiduous sisters who knew Platt had it wrong. So it was at the point when Caroline was to come under the care of the orthopaedic surgeon that Liz came up against the die-hards who ran the wards. Gillis was to perform an innovative sequence of procedures which would, all being well, enable Caroline to walk – a capacity promised when she had managed to throw herself out of her hospital cot. So, surgeon ready and waiting, students anticipating, Liz checked with the ward over visiting. Total obduracy.

Well, this mother, with tremendous encouragement from the mum's about her, went as public as she could, withdrawing the child from the proposed treatment, waving the Platt Report, enlisting Douglas Jay, the local and totally honourable MP and, ultimately, Enoch Powell, Minister of Health. Panorama – still sometimes a big hitter – featured Liz and daughter presenting the issues. Grudging capitulation from above.

Good grace on the wards did not readily prevail. Rather a veil of mute hostility, balanced by a somewhat awed respect from the surgeon – a state to which he had become unaccustomed. In time, MCCH changed all that, not readily, not everywhere, so its successors are still busy.

**Mark Beeson**



## Action for Sick Children Charter for Children's Health Services

1

All Children shall have equal access to the best clinical care within a network of services that collaborate with each other.

2

Health services for children and young people should be provided in a child centred environment separately from adults so that they are made to feel welcome, safe and secure at all times.

3

Parents should be empowered to participate in decisions regarding the treatment and care of their child through a process of clear communication and adequate support.

4

Children should be informed and involved to an extent appropriate to their development and understanding.

5

Children should be cared for at home with the support and practical assistance of community children's nursing services, unless the care that they receive can only be provided in hospital.

6

All staff caring for children shall be specifically trained to understand and respond to their clinical, emotional, developmental and cultural needs.

7

Every hospital admitting children should provide overnight accommodation for parents, free of charge.

8

Parents should be encouraged and supported to participate in the care of their child when they are sick.

9

Every child in hospital shall have full opportunity for play, recreation and education.

10

Adolescents will be recognised as having different needs to those of younger children and adults. Health services should therefore be readily available to meet their particular needs.

These are our aspirations for the future and the reasons why we continue to advocate and lobby for children's and young people's health services.

Email: [enquiries@actionforsickchildren.org](mailto:enquiries@actionforsickchildren.org)  
[www.actionforsickchildren.org](http://www.actionforsickchildren.org)







# Doctors

## The Work of National Association for the Welfare of Children in Hospital

My earliest memory, at the age of two in the late 1940s, is of being dragged off to an infectious diseases hospital where my mother was allowed to come and look at me through a window for two hours each Wednesday.

How things have changed.

I have been working in paediatrics since 1969 and have seen enormous changes for in the medical care that we give to children and also in the way we care for children and families.

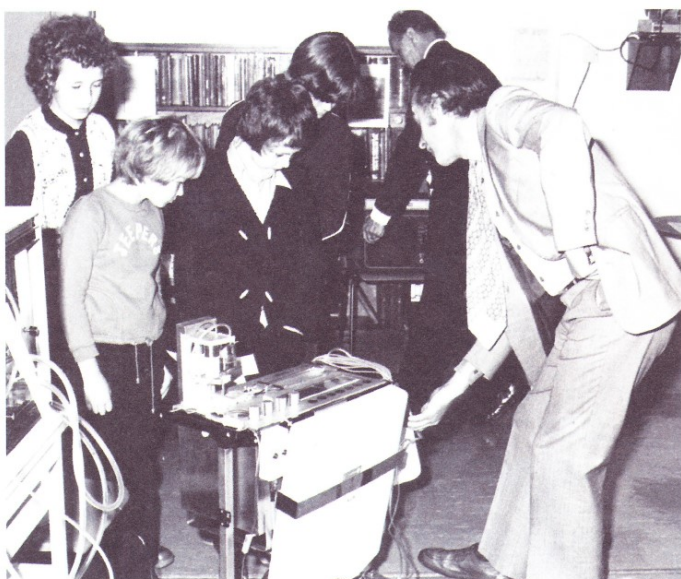
There is no doubt that NAWCH/Action for Sick Children has played an enormously important role in campaigning for better care for children.

My predecessor James Spence in the 1930s was one of the first to suggest using mothers as important partners in the care of their sick children and his philosophy probably had an enormous effect on Lord Platt when he wrote his seminal report fifty years ago.

It has taken fifty years to implement his advocated changes but, in 2010, it is unusual for children to be cared for in an adult ward without free access for parents. Children and their families owe an enormous amount to both Lord Platt and to NAWCH for their vision and persistence.

### Professor Sir Alan Craft

Former Sir James Spence Professor of Child Health and President of the Royal College of Paediatrics and Child Health.



Professor Houston demonstrating new dialysis equipment, 1979.

## Golden Jubilee Reminiscences – National Association for the Welfare of Children in Hospital/Action for Sick Children

For the Silver Jubilee Sidney Brandon wrote a paper on the development of Health services designed for children and the part NAWCH had played in this. At that time NAWCH was riding high – there was much to do but a great deal of activity. There were many active groups, powerful conferences, outstanding staff led by Jean Davis, researchers like Rosemary Thorne, and prominent supporters. I was one of an Advisory Panel with paediatricians like Dermot McCarthy, Tom Oppe, David Morris and David Hull. We had politicians like Peggy Jay and Angela Rumbold, and nurses and social workers. NAWCH had invaluable support from some child psychiatrists and paediatric surgeons, but at the centre was the motivation and the work of the parents.

At that time we were still fighting the battles over visiting hours, beds for parents, travel costs, and the care of children needing anaesthetics. While we sought Government action most of the changes were ultimately achieved by determined local action. We had learnt that Government pronouncements were valuable ammunition but did not themselves lead to change. At that time there were many small paediatric units with one or two consultants, but we were looking at the effects of increased specialist expertise, and how regional centres could work with District General Hospitals for example by having clinics with visiting specialists. Now there are fewer units, often with ten or more consultants and a consequent difficulty in providing continuity of care. The quality of care in hospital was increasing, but we were also setting up Day Care units to replace 'ward attenders', and teams of outreach nurses to provide both direct care and support to parents giving care at home. The quality of care by general practitioners was relatively good. Working with the Play in Hospital Liaison Committee and the National Association of Hospital Play Specialists the provision of trained Play Specialists was increasing.

We were beginning to look more widely at the care of children with special needs including adolescents, provision of paediatric A/E Units as parents used them increasingly, and issues such as children's consent.

There were problems; sometimes with those who opposed our views particularly surgeons, but occasionally with friends as when NAWCH was criticised for providing information to school children about hospitals. Another was funding and in 1990 NAWCH faced a major crisis which led a group of





Dr. Richard Wilson

paediatricians to add their support by not only lobbying the Government but writing to every paediatrician in the country for funds. We survived.

Later there came a point where the Council no longer felt they needed an Advisory Panel and even later changes in staff led to a low point when it seemed NAWCH, now ASC would close.

However, that was averted. Despite many achievements there are still a few old problems and some new ones. There is a dearth of General Practitioners with any Paediatric training, community services have been crippled by cuts to health visitor, school nurse and medical staffing and by multiple reorganisations. There is a major lack of continuity of care in both general practice and hospitals. The importance of play is not understood and savage cuts are being made. Travel costs are still not met. Parents are displaced from the bedside to distant dormitories.

Children still have no effective voice and are at the mercy of political reorganisations and managers money juggling. Many improvements have been achieved but after fifty years we need to research and review the way our health services are treating the many millions of our citizens who are children.

**Dr. Richard Wilson**

## A Paediatrician's Thoughts

NAWCH seemed such an obvious link for a paediatrician. I joined as a Senior Registrar more years ago than I now admit and have never regretted my membership sub or understood why all paediatricians are not members too. From resident mothers to family focussed and child-centred care, to travel expenses and car parking costs, we are always on the same side and speak for sick children in our different ways. Again and again the power of a combined approach from the children and families as users and the health professionals as providers has achieved success

where either group alone had failed. Every year our AGM amazes even ourselves with the achievements that NAWCH and now Action for Sick Children has made.

I have worked with ASC locally in Leicestershire, nationally in Scotland and "internationally" on the UK Trustee Group and each has taught me lessons never learnt in medical school that have helped me as a paediatrician. How else could I learn that providing a toothbrush, comb and nightdress could help a mother cope with being unexpectedly resident with her acutely ill child, or that asking for adult menus and helpings for teenagers in the Children's Ward could make their stay in hospital tolerable. Add to that the inside information about what exactly Hospital Play Specialists do and what leaflet to offer a parent who is worried about her child having a blood test, and my membership subscription was a bargain.

At a national and Health Board level I have seen the power of effective user action in improving services for children. The Standards for Children and Young People in Hospital have stood the test of time and I well recall the anxiety caused by an ASC inspection visit to our A&E department that led to action on issues the staff had raised for years.

More recently I have enjoyed using ASC as an example of how to work together with patients when teaching medical under- and post-graduates and nursing students. One student complained that nobody had ever told her about all these resources till she came to our ward and I encouraged the students to explore the ASC Library and website. We have the same reaction when we use the teaching materials such as Child's Eye View, and the newer DVD from ASC (Scotland) on Children's Health Rights and the EACH Charter. I think what I love most about working with ASC is its relevance to our speciality of paediatrics, its willingness to adapt and move forward to address the changing needs of children and families and to take up new challenges when they arise. I look forward to the outcome of ASC(S) projects on dental care for children with additional needs, the care of looked after and accommodated children and young people when they are sick and the preparation of children referred to specialist centres far from home.

We have achieved an enormous amount of improvement in the care of sick children and can look back on the past 50 years with pride but then look forward to the future and remember a living growing organisation thriving on challenge and innovation and building on its strengths.

Here's to ASC and its future success.

**Dr. Una Macfadyen**



# Nurses

## Those were the days

I well remember the early days of 'NAWCH'. I had just completed my Sick Children's training after general nursing. Children were then in hospital much longer than now and visiting times for parents were very restricted.

As a junior, I often had at visiting time (twice a week) to pull back the screens at the ward doors (to stop parents looking in) and collect all the sweets from the parents, which were saved to share with all the children with the mid-morning milky drinks. Frankly, I found these times chaotic and upsetting. I had seen the first Robertson film about the admission to hospital of a young child which illustrated clearly the distress felt by the child on being separated from everything that was loved and familiar. Many hospital staff then accepted this to be 'settling in.'

The Platt Report had recently been published when I became a ward sister of M2 at the Brook Hospital, Woolwich, where I was fortunate to work with Dr. David Morris and Bianca Gordon, a psychotherapist from the Anna Freud clinic. The ward was Nightingale design (long and narrow) some fixed glass panels were used to divide up the space with a couple of single rooms and a treatment room. Unrestricted visiting was introduced and parents encouraged to stay and share in care. Incidentally, in those days the wards had a round from Matron's Office twice a day, and yet it was only after several months that one deputy Matron commented that there were a lot of mothers around! The facilities for parents were rather primitive, many slept on the floor, sharing toilet facilities and the facilities for meals was limited. To phone home entailed a long walk to the nearest phone box for the parents.

I was invited to speak at the second national conference of NAWCH which was held in London. After this I moved to The Hospital for Sick Children (London) where I was the first ward sister to introduce facilities for resident parents. When I discussed (rather nervously) the concept with the consultant (Dr. George Newns) he instantly agreed!

I found in practise that there was a lot of support from hospital hierarchy to provide facilities for the parents that wished to stay in the ward. A fold up bed designed and made by the hospital carpenter proved very comfortable. Visiting was unrestricted and siblings were invited. I recall one occasion when the ward teacher said 'she often found that she had more pupils wanting school work than she had registered on her books'!



Barbara F. Weller

Reflecting on these early days brings to mind many faces and names who supported and encouraged changes in nursing and medical practice. Hurdles of course were met and in many situations institutional inertia and apathy were the most difficult to overcome. But for me, together with the authority of the Platt Report, it was the particular support and encouragement of the original Battersea mothers who together formed 'The National Association for The Welfare of Children in Hospital' that was that was the most important factor in moving forward the national care of sick children.

**Barbara F. Weller**

## Reminiscences

"Nurse, I want my Mummy!" This was the often-repeated cry of young children in hospital in 1959 when I started nursing. It was also the title of the research undertaken by Pamela Hawthorne published in 1974 providing credibility to my opening remark.

Today in children's wards in the UK the situation is totally different. This achievement is due to the commitment of the National Association for the Welfare of Children in Hospital/ Action for Sick Children (NAWCH/ASC) to achieve change.

My career in nursing children began in the year of the publication of the Platt Report and ended in 2001, thus spanning a massive time of change in care, from limited parental access to their child in hospital to real partnership between children/ young people and their families and health care staff; from long periods in hospital, often confined to bed, to care in the child's home; from the majority of children cared for by health care professionals with very limited knowledge and skills in the particular needs of children and their families to the majority receiving care from health care staff specifically educated and skilled to meet their needs.

I was fortunate that the only nurse member of the Platt Committee, Marguerite James was an influential figure in the children's hospital in which I qualified as a Registered Sick Children's Nurse. Resident parents were common, on the babies' wards although visiting was restricted on the children's wards for a few more years.



Sue Burr OBE