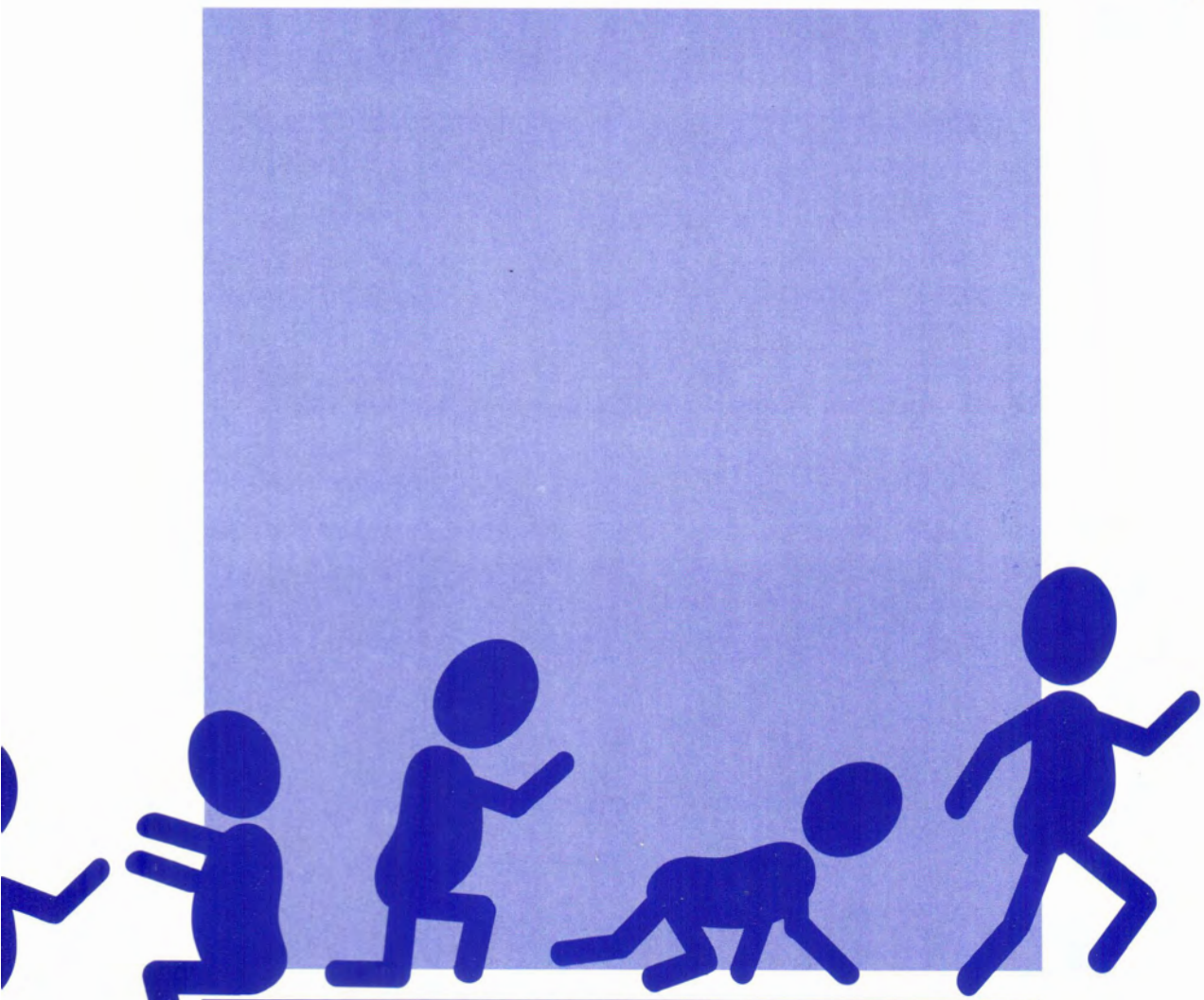
ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS

JOURNAL



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JOURNAL OF THE ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS
NUMBER 93 DECEMBER 1999

CONFERENCE 1999

EDITORIAL

LIZ HARDY

Chair APCP

Question What have you got if you take one APCP Conference, a fabulous venue, 7 other specific interest groups, CSP Congress 1999, 115 exhibitors and around 1000 physiotherapists?

Answer 'A New Beginning' - the 1999 CSP Annual Congress.

Well, it's over. Some of us went, and some even bought the T-shirt! The CSP's new all-singing, all-dancing congress was an event of which APCP were proud to have been a part. True, there weren't as many APCP delegates as would have attended our own independent conference, and there could be a number of reasons for this. However, those who did attend gave feedback such as 'THIS is the way forwards for APCP', 'what a wonderful and stimulating experience' and 'I wouldn't have missed this for the world'.

It seems a long time ago that the idea of a 'mega-conference' was first suggested by the Chartered Society. APCP's National Committee spent much time debating the issue before we finally agreed to participate,worrying especially that we would lose our own identity as part of such an enormous gathering. Finally, we thought 'we are an adventurous, innovative and forward thinking organisation - so we have to go for it!' Consultation with the wider membership agreed, and so . . .

The standard of presentations and lectures was universally high. The keynote lectures were stimulating, enjoyable and, yes, different. The timetabling worked, and perhaps the only fault was the perennial hot-potato for all conference organisers, of allowing enough time and service points to get your coffee during the breaks. In a speciality such as paediatrics, encompassing such a huge variety of sub-specialities, it was great to have the opportunity to go to other sessions outside of paediatrics. I know that many of us enjoyed meeting with old friends who had chosen to specialise in fields other than paediatrics. And the trade exhibition had to be seen to be believed - I even met some paediatric physiotherapists carrying several bags, who were competing to get the most 'freebies'!

Well, whatever your reason for attending this year's congress/conference - it was worth the effort. The London branch are to be congratulated on organising the conference at long distance - a task which I know was not always easy or straightforward.

I am sure the APCP will soon join together with CSP again, but next year we will be holding our own conference in Bristol. I hope to see many of you there.

LETTERS

Mrs Sue Whitby
Paediatric Physiotherapist
Hinchingbrooke Health Care
NHS Trust
Community Unit
Primrose Lane
Huntingdon
Cambs PE18 6SE

Dear Lin

In reply to the request for information on baby walkers, APCP September 1999, readers may be interested in a leaflet which I have recently published 'Babies Playing and Moving Safely – Information for Parents and Carers'. It is a three fold colour leaflet with photos including advice about baby walkers, baby bouncers, baby seats, look after your back, safe play in different positions and early listening and looking. My aim was to write a friendly leaflet which would give advice to all new families.

As a paediatric physiotherapist I am often asked for information on baby walkers and baby positioning, especially in prone to play, so wrote a more general leaflet to incorporate this advice. I collaborated with my local Health Visitors as they have the initial contact with all new babies. We are hoping to put a copy of the leaflet in the 'Red Book' issued to all new born babies as their patient held record.

A more comprehensive document about 'Baby Walkers' is being written by the Child Accident Prevention Trust as a childhood injury fact sheet.

If anyone is interested in my leaflet contact:-
Mrs Sue Whitby
Community Paediatric Physiotherapist

Helen Buswell (SROT)
Project Manager - Training For Transition
Plymouth Community Services
NHS Trust
Westbourne Unit
Scott Hospital
Beacon Park Road
Plymouth
Devon PL2 2PQ

Dear Editor

Transition to Adult Health Services

I am an Occupational Therapist from Plymouth, currently on secondment as 'Project Manager - Training For Transisition'. My role is to identify the gaps in clinical service provision in the area of transition between child and adult health services in both the acute and community trusts, identifying staff / carer / parent training needs, recommending / initiating appropriate training based on best practice.

My focus is on the professions allied to medicine (Occupational Therapy, Physiotherapy, Speech and Language Therapy, Dietetics, Dentistry, Chiropody/Podiatry) and I would be grateful to hear from anyone who has focused on the issues surrounding transition in their region particularly the formation of standards/policies, indicators of best practice and any knowledge of current initiatives (or projects) aimed at ensuring children with all disabilities (whether they are physical needs, mental health needs or a learning disability) experience a smooth 'seamless' transition into adult services.

Please contact me at the address / telephone number above - I look forward to hearing from you!

Helen Buswell

LETTERS

Stella Howell
Supt. Paediatric Physiotherapist
Children's Centre
Stoke Mandeville Hospital
Aylesbury
Bucks.

Dear Lin,

We have been asked to become involved in the development of a protocol for the management of children and adolescents with Chronic Fatigue Syndrome.

We would be very grateful to hear from any one who has experience in this field no matter how small.

Yours sincerely,

Stella Howell

Melanie Steyn
Senior Occupational Therapist
Debbie Shadbolt
Senior Physiotherapist
North Herts NHS Trust
Children's Therapy Service
Child Development Centre
Danestrete Centre
Southgate
Stevenage, Herts, SG1 1HB

Dear Ms Wakley

Re: Manual Handling

We are currently reviewing our manual handling policy with regard to children. We are experiencing some difficulties in the practicalities of moving children for therapy, as our Trust operates a non-lifting policy. Access to hoisting equipment is limited.

We would be grateful if anybody who has experienced these problems and has come up with solutions to them, could contact us with advice.

We can be contacted at the Child Development Centre, Danestrete Centre, Southgate, Stevenage, Herts, SG1 1HB. Tel: 01438 781457 Fax: 01438 781470.

Yours sincerely

Melanie Steyn and Debbie Shadbolt

Patricia M Pott
Physiotherapist
Laila Baig
Occupational Therapist
Lancasterian Medical Unit
Elizabeth Slinger Road,
West Didsbury,
Manchester M20 8XA

Dear Miss Wakley

We are trying to obtain funding for the Symmetrisleep system for children and young people with disabilities. We would be interested to hear from anyone whose local authority or health authority fund this equipment, or who have successfully sought charitable funding.

If, like us, you are looking for funding we would also like to hear from you.

Patricia M Pott and Laila Baig

Sarah Henshall
Senior Paediatric Physiotherapist
Chelsea & Westminster Hospital
369 Fulham Road
London SW10 9NH

Dear Editor

Physiotherapy for Children with motor learning problems including dyspraxia. A course review.

I attended the above course at Chelsea and Westminster hospital from 21st - 25th of June 1999. The lecturer for the course was Sally Wright MCSP, a paediatric physiotherapist in private practice, who specialises in treating children with motor learning problems.

I attended this course because I had a number of children referred with this diagnosis and was not sure how to assess or treat them.

I found the course extremely helpful and very logical. The group size was kept small which allowed in depth discussion and interaction. It started by explaining the different types of motor learning problems, one of which

is dyspraxia, and the signs and symptoms that go along with them. It then continued to explain how to assess a child, what areas to look at, task analysis and how to then interpret the findings of the assessment. There was time set aside to analyse videos of children with motor learning problems which allowed consolidation of lecture material and clarification of any unclear areas. The Thursday session concentrated specifically on dyspraxia, covering assessment, behavioural aspects and treatment. The final day brought everything together and allowed informed discussion on treatment techniques for the different problems.

I found that the course was thorough and feel that any physiotherapist who treats children with motor learning difficulties would find this course extremely useful.

The course is to be repeated in April 2000 and anyone who is interested should contact Edwina Falls, Chelsea and Westminster Hospital, Tel. 0181 846 1608.

Sarah Henshall

Sally Braithwaite
Inclusion Co-ordinator
c/o Physiotherapy Department
Victoria School
Bell Hill
Northfield
Birmingham
B31 1LD

Dear Lin

I was interested to read Pauline Bateman's letter regarding the physiotherapy management of children with a gastrostomy in situ. I very much agree with her that if this is not achieved effectively, physical deterioration may well be hastened.

Until recently I have worked with a group of these children for a considerable period of time. To address Pauline's particular concerns I have usually found prone positioning to be little of a problem. It is necessary to move the children into prone very slowly to give them time to adapt to the position and I have often lined prone standers and wedges with a covering layer of soft foam or a thick quilt which accommodates the gastrostomy site comfortably and is forgiving enough to allow the tubing for children on continuous feed not to get trapped and occluded. Positioning children in elevation after a feed is something that has not really caused us a problem as a team. Following their feed children spend ten to fifteen minutes sitting in whatever position they have been fed in. This allows time for washing hands and face and cleaning teeth. After this however, the children are usually moved into whatever position they need for their next activity. As with prone positioning the key seems to be time for adaptation and avoiding over stimulation by moving them slowly, whilst any incline they would normally need to avoid reflux needs to be in place.

Orthotic provision is another question entirely. We usually manage our non-ambulant children in supportive seating (often a moulded seat insert) and good positioning, rather than with corsets to try and control their spinal posture. However I can see that with ambulant children this would not successfully control posture. A really sympathetic orthotist would be of most use, one who would be prepared to make spinal bracing out of materials that could be made with a window in the correct position to allow for the management of the gastrostomy site and its tubing. I have

only tried this when children have needed to be encased in plaster spicas or when they have a need to use hip/trunk orthosis and these windows have been quite successful.

For more tips read my lecture paper from this year's conference (it will be in this journal soon). I'm not saying that they will all fit all situations but they may give some more ideas to build on.

Yours sincerely

Sally Braithwaite

Carol Kerry
Superintendent Paediatric Physiotherapist
Paediatric Physiotherapy Service
Woodview Child Development Centre
Crow Wood Health Park
Crow Wood Lane
Widnes
WA8 3LZ

This letter is the reply to Sue Booth's letter in September 1999 Journal. *Editor*

Dear Sue

I read your letter re-defaulters in the APCP journal and must sympathise. Your service certainly isn't the only one. We do have a policy which is very tight and certainly doesn't go anywhere near giving three chances to attend.

Three years ago or more, our Trust had a drive to reduce DNAs, lead by the then Quality Assurance Manager who certainly "took no prisoners" in her approach.

Our waiting list was way outside the standards, both national and local. Giving people three chances didn't seem to increase the likelihood of them attending, so we cut it down to two appointments sent before discharge was contemplated. I felt we couldn't justify to patients whose parents would attend or who were screaming for "more physiotherapy", the waste of appointments sent to persistent defaulters.

The Quality Assurance Manager piloted a system with our Health Visitors, where a clerical officer rang the parents the day before to "remind" them but as we had little clerical support, we felt unable to use this method. As pressures mounted, we then developed a system of only one appointment being sent out.

If the visit is "no access" or the outpatient appointment is not attended, depending on the diagnosis suspected in the case referred, a defaulter letter is sent to the parents and to the referrer. If a parent has "forgotten", it serves as a prompt and they 'phone in for another appointment within the specified time. If the referrer is particularly concerned about the child, they will also act as a "prompt" and visit or 'phone parents to encourage attendance. If the condition referred is minor, eg gait anomalies in otherwise normal children and we get no reply within the time allotted, the patient is discharged.

If the case seems to be more serious, eg suspected cerebral palsy, torticollis, erb's etc. the physiotherapist will try to find another way of getting to see the child by changing the venue, the time or visiting with the Health Visitor if the child is young. In this way, we capture most children who really shouldn't be missed but also don't clog up the system with persistent defaulters. It seems quite hard, but is very necessary to be so strict. It is arguable that if parents cannot be bothered to attend an appointment, it is

unlikely they will comply with any treatment programme.
I do feel the "sins of the fathers are visited unto the sons", but the system we have :

1) reduces wasted time
2) puts the onus on the parent whose responsibility it is
3) has built-in "safety" mechanisms so patients who shouldn't miss out don't get lost.

We have used social services in cases of persistent defaulting if failure to be in for or attend appointments is considered to put a child's health "at risk".
If you wish to discuss this further, please don't hesitate to contact me on the above telephone number.

Carol Kerry

Elen Elias
Physiotherapist
Community Health South
London NHS Trust
Priory Manor Child
Development Centre
1 Blagdon Road
Lewisham
SE13 7HL

Dear Editor

As a multidisciplinary team we are looking to set up guidelines for intervention in our work with children with Cerebral Palsy. We are aiming to provide a more equal service across the trust and identify key areas of intervention.

We would be very grateful to hear from colleagues who have devised and are using such guidelines.

Many thanks

Elen Elias

Lin Wakley
Head Paediatric
Physiotherapist
Physiotherapy Department
Dorin Park School
Wealstone Lane
Upton
Chester CH2 1HD

Dear colleagues

Re : AFOs and footwear

When children wear AFOs we expect parents to provide their own foot wear. This poses few problems when the child is young and it is possible for the parents to buy wider fitting shoes. When the children are older and are in adult size shoes, parents have problems finding shoes wide enough to accommodate the splints.

We have suggested trainers with the insoles removed but they still find they have to buy them 2 - 3 sizes larger to get enough width. Even if they manage to find a pair of suitable trainers there is also the added problem that most High Schools have a strict dress code and trainers are unacceptable. Although we could ask the school to allow them to wear trainers it is yet another way of them being made to feel 'different'.

I would be interested if anyone has managed to solve this problem and has found any makes and styles of shoes that will accommodate AFOs.

Lin Wakley

GASTROSTOMY IN CHILDREN WITH A

SALLY BRAITHWAITE
MSCP
Senior Physiotherapist
Inclusion Co-ordinator
Birmingham

The purpose of this lecture is to look in general at what a gastrostomy is, and why such a procedure might be necessary; also will it be permanent, what are the advantages and disadvantages of its use, and with a gastrostomy in situ what are the implications for physiotherapy management and for a child's relationship with its parents or carers and school staff? In particular this will be related to the child with a complex neurological deficit and global difficulties who will often experience gastro-intestinal reflux causing considerable distress. Other occasions when a tube may be inserted and the reasons why will be briefly illustrated. When a child has a gastrostomy for whatever reason parents, carers and even some of the professional staff working with them are often entering unknown territory. Will handling the child be different? What will the child be able to do? Are they sick? Will I have to change everything I have been doing? The answer to these questions will be explained more fully.

What is a gastrostomy?

It is a method of artificial feeding. An incision is made in the abdominal wall and a small tube is inserted directly into the stomach, giving direct access for liquid food to pass directly into the stomach bypassing the mouth and the oesophagus. The position of the gastrostomy site may vary from child to child dependent on the degree of spasticity affecting the orientation of the internal organs. It must be remembered that with individual regions and hospital trusts the protocols and rules governing the management of gastrostomy tubes and who may have active involvement with them may vary.

Why would a gastrostomy be necessary?

This procedure is often the one of choice when :-

- A child that has been using a naso-gastric tube for prolonged periods of time and it is still necessary to continue feeding this way, rather than to begin oral feeding.
- A child fails to thrive and weight gain and growth are inhibited.
- When the swallowing mechanism is compromised and food taken orally is likely to go directly into the child's lungs rather than to the stomach, causing recurrent chest infections and episodes of choking, either of which could be potentially life threatening.
- It way also be used as a temporary measure during various types of complicated staged surgery.

Is a gastrostomy permanent?

Not necessarily; as we have already seen, it may be used as a temporary measure for feeding during complicated and staged surgery, when it may not be desirable to use a naso-gastric tube, and it is not possible to continue feeding orally.

With children who fail to thrive, it may be used to obtain suitable weight gain along with continued oral feeding for prolonged periods of time. In

this case once a desired weight has been reached oral feeding would be continued with the gastrostomy feeding gradually being decreased and then discontinued.

The weight, height and arm circumference would be monitored and charted carefully by the dietician whilst the tube was still in situ and patent, and if everything remained satisfactory over a period of time and the child continued to gain and maintain weight at an acceptable rate with oral feeding alone, the tube would then be removed. Failure to thrive in some children may be because of a variety of inflammatory bowel conditions, where feeding with solid food would not allow the gut to heal. It is possible in these cases to feed via a naso-gastric tube or possibly a gastrostomy with liquid food, supplying the correct levels of nutrition while the gut was healing to maintain the well-being of the child. More often food in this situation would be given via a naso-gastric tube unless it has been decided that healing would only take place over an exceptionally long period of time.

With children who have inadequate or absent swallowing and cough reflexes and therefore often experience distressing episodes of choking and recurrent chest infection and are unable to take either oral fluids or solids satisfactorily, the gastrostomy will at the very best be long term, until some control can be introduced into their swallowing mechanism; and the possibility is that it will be the permanent way for them to receive all nourishment and hydration in a controlled and safe way.

What will the gastrostomy look like?

Peg Button Catheter (this is a rarely seen option).

What are the advantages of a gastrostomy?

- Safe feeding
- As a route for quick rehydration when a child's fluid intake is low
- No long term need for naso-gastric tube, which can cause irritation to the face and throat and often hinders oral feeding when it is being run in tandem or being newly introduced, because a child often finds it hard to swallow with the tube in situ. The naso-gastric tube is also easily pulled out and can be difficult to re-introduce and is of course unsightly.
- No long term use of arterial lines.
- Parents feel comfortable that their child will be fed effectively and safely when they are not there to do it themselves.
- It can be hidden under clothing and is invisible when not in use.
- It restricts little activity that a child may need or want to do, if the tube and activity are correctly managed.
- It is fairly easy to replace, if this is done quickly when it is inadvertently pulled out, and is fairly quick to change when this is necessary.
- It is possible for food to be given overnight while a child is sleeping.

- There is the possibility of drug administration when it would otherwise not be possible to give these orally.
- This method of feeding makes it possible to strictly regulate the amount of calories, vitamins and minerals etc in a child's daily intake. The special liquid feed that is given via the gastrostomy is made up to the requirements of a dietician although some proprietary brands are available.
- Good nutrition helps in the preservation of a good skin condition, with less likelihood for breakdown and the potential to develop sores which are then difficult to heal; it also aids in the prevention of infections and in a quicker recovery if these occur.

Disadvantages of a gastrostomy?

- Parents and carers may find the initial idea hard to accept.
- Cultural and religious implications.
- Teaching parents and carers to feed a child by this method is not always easy; they can feel threatened or frightened by what they are being asked to do.
- The gastrostomy may fall out. It is best to get it replaced within the hour, or it may only be possible to replace it with a smaller bore tube, or if it has been out for some time and nor for any reason been noticed it may need to be replaced surgically.
- Possible infections around the gastrostomy site.
- It may be necessary for the pump administering the liquid feed to be powered off mains electricity, and therefore an electrical supply always needs to be close when the food is being given, which may severely limit mobility; while the long trailing cables that are inevitable if the child is not to be completely tethered to a wall socket can be a considerable safety hazard.
- If the food pump is a mobile one the batteries must be kept charged up; they can run out at the most inconvenient times.
- Problems with the gastrostomy tube of choice eg continual blocking off.
- Cost.

It is felt by many that the advantages of a gastrostomy far out-weigh the disadvantages. Some parents are actually very relieved once it has been inserted; and many others say that once they have come to terms with it and learnt about its management they feel more in control of the problems they and their child are experiencing; whilst the professionals involved are content that those children in question are getting adequate nourishment, are not having so many chest infections and are not experiencing the inevitable and often severe pain suffered with reflux (the regurgitation of contents and acid into the oesophagus); this in its turn has an adverse effect on levels of spasticity and therefore on the overall

functional ability and potential of any child with a neurological problem who may experience it.

For the purposes of this paper I am going to concentrate on the physiotherapy management of children with neurological disorders which cause them to need the insertion of a gastrostomy for safe and effective feeding. As a result of the gastro-intestinal reflux these children often suffer, they may also need to have a Nissens Procedure to tighten up the pyloric sphincter at the entrance to the stomach to help control reflux. It must be remembered that in theory at least if this latter procedure has been performed these children cannot vomit; therefore, activities undertaken with them need to be graded so that they are not over stimulated causing the need for this to occur.

Physiotherapy Management

The gastrostomy site will usually initially be a little tender, but this soon passes. Whether the entry site is a peg, button or catheter really makes little difference to handling and positioning. You do need to be a little careful although the tube will not usually pull out that easily, and parents and school staff need to be reassured that if it does, it can soon be replaced. Many parents are eventually taught how to do this themselves, and it is important that they should always have a spare tube available for this situation. Parents need to be sure that they cannot really cause any irreversible problems with the gastrostomy, they are taught how to manage all the technical things surrounding their child's tube, and how to be effective with this method of feeding. Once the gastrostomy is in situ and functioning efficiently it is really important that parents and carers can go away and establish a good relationship with their child, not feeling afraid to handle and play with the child who in turn is not frightened of being handled. Parents need to get close to their child and be able to do all the things they need to do to establish a good handling regime, and work towards modifying tone where there is neurological damage and increased postural reflex mechanisms.

Positioning

This is crucial and as in any child with hypertonicity, it is aimed at modification of tone and establishing the sensation of a more normal posture to allow the possibility for the development of more normal patterns of movement and developing a child's potential to the full. With care and the necessary support children with gastrostomies can be positioned in the same way as any other children with whom a therapist would be seeking to reduce tone. Very often these children are not unwell and they should have full access to a programme of therapy; on the occasions that they are ill this should be adapted accordingly with special attention being given to chest care if this is proving to be the main area for concern.

Some people would advocate that the feed is turned off and disconnected during any physical activities for children with severe neurological deficits.

However, on the whole our team feel that for the children we work with, if they are handled well and moved slowly and gently giving them time to adapt to changes in position this is usually not necessary, although on occasions we have found with some children it may be advisable from time to time. Careful handling and support during positioning is also necessary because these children do have a tendency towards brittle bones and the possibility of fracture, due to decreased calcium uptake both as a result of their nutritional state and because they are often not able to achieve normal weightbearing in order to stimulate this.

As a team we tend to use the following positions with slight modifications for our children :-

- Supine - On a wedge (flat on the floor or in bed will often result in unwanted reflux)
  In a sleep system of some description to maintain a good posture - but the bed may need to be inclined slightly at the head

- Prone - On a wedge
  In a prone stander
  (this may need to be less firm than you would otherwise choose or have a soft layer of covered foam or a quilt over it to accommodate the gastrostomy comfortably and if feeding it to be continued during the activity the tube must not be occluded)

- Side lying - A side lying board is ideal, the child must be positioned so that the retaining straps are not over the gastrostomy site; and it is often advantageous to put the head end of the side lyer on to a low wedge using it to create a gentle slope to avoid the problems of reflux, this also raises the height of the head increasing visual possibilities. Side lying on the left is more often the position of choice, it reduces the chances of reflux, because of the effect of gravity, with the opening of the stomach being uppermost.

- Sitting - free - in a range of positions on the floor, or on a stool, chair or therapy bench supported
  Proprietary chairs etc
  Moulded seat insert
  Foam Fit type seating
  Cushioning - combinations of cushion support within a chair or wheelchair.
  Hip trunk orthosis

whatever seating or seating support is employed it is necessary for the child to be comfortable, the retaining straps and pads should not be directly over the gastrostomy site, or pinch and occlude any tubes and they should also not cause a raise in inter-abdominal pressure which could cause reflux.

- Standing - Free
  Upright stander
  Prone stander
  Tilt Table
  Callipers and any other appropriate splintage or bracing

  It may be necessary to add extra padding for comfort to any of the above equipment by reducing pressure on the gastrostomy site, and as with the issue of support in siting care must be taken to ensure that all tubes remain patent.

- Kneeling - Prone kneeling
  High kneeling

  Neither of these positions should really be a problem if the hands are positioned well to support; great care needs to be taken if using a roll and in prone kneeling I would suggest that the feed is best turned off and disconnected before the activity is attempted.

In all of the positions, comfort, free flowing tubes and no reflux are essential. Selection of the appropriate positions and equipment are necessary to be as effective as possible in controlling tone and developing function.

Chest care

Many of these children are prone to recurrent chest infection, due to the problems they have with swallowing, unwanted food and drink ending up in their lungs and also the danger of inhalation if they vomit or if they continue to have uncontrolled reflux. Treating a chest successfully in these children is often quite difficult. Accepted postural drainage positions are not always possible to use because the child has postural deviations and deformities involving the thorax, and the direction of drainage is not where you would normally expect it to be. A chest X-ray may give some ideas as to the configuration of the airways but even so it is often not possible to tip a child down because of potential reflux. Stimulating reflux can make any chest problems significantly worse rather than better. It is more often than not a process of trial and error to find positions for maximum removal of secretions, and judicious use of a wedge for turning from side to side and support in the inclined supine position. Gentle

percussion and vibrations are usually fairly straight forward to use, but unfortunately these children rarely have a good and effective cough. Coughing is where a therapist's difficulties often begin; the one thing we do not want to do is cause the child we are treating to vomit, with the possibility of inhalation, further complicating the chest infection. Tracheal pressure is a possibility, but has to be used with extreme caution. I try to avoid using this technique if at all possible. Gentle suction, just to the back of the mouth with a fairly large bore catheter will often clean secretions which have been driven to pool in this area and can't be cleared from here by the child independently. If done with care, trying not to touch any part of the inside of the mouth, this is often quite a successful method of clearing secretions, and very gently indeed just tickling the back of the throat with the catheter may stimulate a much needed cough (if there is any cough reflex present). However, if this latter technique is employed, make sure the child is not lying too flat; in this way if their cough does cause them to vomit they are less likely to inhale. Treating a child supported in sitting is often the method of choice - for a small child on your lap and for a bigger child in a chair. If the child is usually seated in a moulded seat insert or other supportive seating system it is often desirable to treat their chest while they remain in this. The mould ensures that posturally their trunk is aligned in the best available position to allow the possibility of drainage and also they feel secure which often achieves some reduction in spasticity making for easier clearance. With the brakes securely on the wheelchair it is quite easy if the therapist is sitting on a firm seat or stool to tip the chair and mould back on to their lap to allow a variance in position, which may lead to a more successful and effective outcome, without having to move the child around more than necessary.

Hydrotherapy

There is no reason at all why a gastrostomy should be a contra-indication for hydrotherapy. There may be other issues surrounding why a child with multiple problems would not be a suitable candidate, and it is important that all children are fully assessed with this in mind if hydrotherapy is going to be considered as part of a therapy regime. It is ideal if children on continuous feeding have had their food flow turned off for a while before they go into the water. Children with a button fitted can have their external tubing disconnected, and with girls especially a one piece swimming costume ensures that the button is protected, but it is usually a good idea to note exactly where it is before it is covered with a swim suit, in order that it is not accidentally knocked or pulled out. Boys wear their normal trunks and the button is usually just left exposed; the button has a self sealing device and there is no chance of pool water entering. If the child is fitted with a catheter it is usually possible to disconnect some of the external tubing, whilst ensuring that the little clip devices have been securely set to close it off. With girls the remaining tubing can just be coiled into a well fitting swimming costume, but boys really need to have a piece of tubi-gauze or more usually net-elast placed around their trunk

to secure their tubing safely. Again it is necessary to ensure you know exactly where the tube is lying.

Children with complex needs require one to one attention in the water. Often being supported manually is more desirable than using flotation aids because it is possible to control the angle that they adopt to float in the water more easily, and if they are prone to reflux it is not ideal for them to be floating completely flat.

Using the warmth of the water may promote relaxation, and aid the effectiveness of passive stretching for all joints. It is also essential to stretch the trunk. Passive movement for all limbs is only easy to carry out if there are two people to work with the child (one to hold securely and one to do the moving). The support of the water and a friction free environment may allow children the opportunity for some independent activity, if they have any weak movement available to them; it is however also possible for them to initiate movement more easily using their spasticity and carry on reinforcing this with continued use of undesirable movement patterns. Some children do like the sensation of just having flotation aids for support, enjoying the possibility of a hands off environment for a short while; whilst others respond to the feel of a secure pair of hands. Flotation aids need to be chosen with care so that no pressure is exerted over the gastrostomy site and the child is not floating in a position which may encourage reflux. Once a session in the pool is over children need to be dressed carefully trying to maintain any reduction in tone that may have been gained. It is necessary to be fairly inventive with clothes, so that children look good, but it is easy to access the gastrostomy site and its associated tubing whatever the fashion of the day. Tight waistbands can cause problems with increased intra-abdominal pressure and direct pressure over the gastrostomy site and tight collars mean that it is not easily possible to bring a connecting tube up by the side of the neck to join it to the food source; it may also cause the tube to rub and cause soreness on the side of the neck.

Multi-Sensory Stimulation

The use of multi-sensory rooms and soft play areas are ideal for this. As we have already seen positioning in these environments like anywhere else is important for children to receive maximum benefit and ensure a feeling of security without stimulating reflux. They often provide a situation where children have the opportunities to come out of supportive wheelchair seating.

It needs to be considered that in order to come out of their chairs it is essential that a suitable method of hoisting is used to comply with manual handling regulations. It is often a good plan for each child to be supplied with a sling of their own, on which they can sit permanently to avoid the necessity of extra handling.

Water beds need to be used with care although they give pressure relief to skin areas that are prone to breakdown; the heat and constant movement they produce can cause a child to vomit. However, they are great fun for experiencing movement when a child has very little of its own. Bubble tubes and fibre optic curtains are good for developing visual skills or developing a child's ability to either move the light source or possibly move towards it.

Soft play areas are ideal for developing all gross motor skills however basic; but the use of a ball pool is not a realistic option because it is difficult to control the child's position, and the gastrostomy and all its tubing may be out of sight, where it is more vulnerabe and could well be pulled out by accident.

On a more practical note, if a child has reflux, vomits, or liquid feed leaks out for some reason, particularly in a soft play area, it is very difficult to be able to clean and disinfect well. It is therefore essential to avoid over stimulation, bad handling or any other situation that may cause any of these.

Conclusion

Children with severe neurological impairment giving multiple problems and who have a gastrostomy in situ present very few problems in their handling and management that are in any way different to those of children who can feed orally. There is no real secret to treating them; in order for this to be effective it is based on a good and on-going assessment, and knowing the child you are working with well. A base line for tolerance to stimulation is always useful and could be a good indicator for how well treatment is progressing as it increases. It is also good to get to grips with the abilities and tolerances of parents and carers. Don't underestimate them, as with any child maximal use of the handling skills you can teach them will go a long way both to their relationship with their child and to the child's possible progress. Underestimating their abilities undermines confidence; and directing them into areas where they are not ready to go will frighten and often spoil the fragile parent/therapist relationship which may take a long time to build again.

Developing a treatment/activity programme that can be used in school, bearing in mind that different members of staff have different skill areas and ways of coping with what they are being asked to do and the way you want it done is essential. It is always useful if a modified version of this programme for consistency can be used at home, taking into consideration how much time may be available to parents or carers; is the child in question the only one, or do they have to share their time amongst brothers and sisters? Are they a single parent family, do they have to spend time caring for an elderly relative? Like all families these are just a few of the day to day things that may claim time. As with all children with neurological problems different parents are able to develop different levels of handling

skills, and these have to be uppermost in a therapist's mind when constructing a home programme.

These children benefit from and often enjoy hydrotherapy, multi-sensory experiences, and soft play along with their basic therapy just as their peers without a gastrostomy do. The only difference is that extreme care needs to be taken with handling and lots of thought needs to go into how a therapist is going to achieve set motor targets efficiently and effectively without causing tubes to be pulled out accidentally, or causing reflux and vomiting. If all these can be avoided developmental physiotherapy follows the same principles for all children with a severe neurological deficit; they should be allowed to experience everything possible to help them reach their full potential without causing them any further harm.

POSTURAL MANAGEMENT & CLINICAL EFFECTIVENESS

TERRY POUNTNEY
MA MCSP

Research Physiotherapist
Chailey Heritage Clinical Services

ANNE MANDY PHD

Research Fellow, University of Brighton

This paper will examine the postural management approach developed at Chailey Heritage Clinical Services and its effectiveness in achieving an increased quality of life for children with neurological impairment. It will briefly outline the approach and discuss it effectiveness in the light of the literature on clinical effectiveness and quality issues.

Postural management is an integrated approach to the positioning and treatment of children with neurological impairment. At Chailey Heritage Clinical Services we have developed an approach which is based on a reliable and valid assessment scale, the Chailey Levels of Ability, which details changes in motor ability and biomechanics as the child progresses and forms the basis of our prescription and provision (Green et al 1995, Pountney et 1992, Pountney et al 1999, Pountney et al 1999) . The programme covers the whole 24 hour period and is designed to enable a child to take part in their daily activities whilst benefiting from correct positioning and active exercise.

This approach has been used at Chailey Heritage Clinical Services since the early 1990's. It's use has and is being evaluated in a number areas including function, cognitive ability and musculoskeletal development but its effectiveness relies on aspects other than the achievement of clinical outcomes. So, how do we know whether our approach to postural management is effective in achieving these aims?. The NHSE in 1996 suggested clinical effectiveness is:

> " The extent to which specific clinical interventions, when deployed in the field for a particular patient or population, do what they intended to do."

In 1992 Maxwell suggested that quality of interventions were crucial for them to be effective. His six points to consider were:

- Relevance to need
- Access
- Equity
- Acceptability
- Efficiency
- Effectiveness

Postural management programmes are not isolated episodes of treatment of care but if used effectively become an integral part of a child and family's life. Quality issues are therefore crucial to a successful intervention as they impact continually on the child and all who come into contact with them.

The Chailey Approach to Postural Management

Postural management equipment aims to position the child at a higher level of ability so that his starting position and movements are more efficient. The Chailey Adjustable Postural Supports (CAPS) do this by altering the areas of loadbearing and biomechanics of the child's posture. Areas of loadbearing at different ability levels were identified during a study of normal infants and are incorporated into the lying, sitting and standing supports. Children are positioned at a level where they are symmetrical, stable and can begin to control their trunk, head and limbs. All the equipment allows the child to move within it (Green et al 1995, Mulcahy et al 1988, Pountney et al 1999) . The approach is based on a standardised assessment (Pountney et 990, Pountney et al 1999) which details biomechanical changes required to reach higher levels of ability and is well supported by the evidence on neurological and musculoskeletal development (Pountney et 1999)

The equipment is designed to be used from very young ages and recent studies suggest that children should be experiencing positions at chronological rather developmental ages to ensure good musculoskeletal development (Stuberg 1992) .

Clinical Effectiveness and Quality

If interventions are to be clinically effective the consumers views must be taken into consideration. Children, families, carers, teachers and therapist all use, move or work with the equipment and needs to meet all their needs. These needs might be very diverse.

Relevance to Need

Children will want equipment to give them independence and freedom, the ability to use their hands to play, use switches, eat and drink more easily, sleep better whereas teachers may consider ability to concentrate of greater importance and parents may be glad to have a good night's sleep. Therapists will be keen to improve motor skills and prevent musculoskeletal problems.

Provision of any treatment or equipment is most effective if the child and family are involved in the decision making. Before a child can make such a decision he needs exactly what all these pieces of equipment are, why they might help him and what happens if he doesn't have one. He may need time to think and talk about his decision. Above all they must be involved in the decision because this can be the key to its success. In some cases there is no choice for the child but that he still needs all the information. Respecting a child's decision which is different from our own can be difficult.

Access & Equity

The equipment designed at Chailey Heritage Clinical Services is now largely in commercial production and training courses are available to support its use in the community. This makes availability of the equipment equitable but the funding is often fragmented and many therapy hours can

be spent applying to health authorities and charities. Services such as the posture clinical which runs at Chailey Heritage Clinical Services are few and far between. There is at present no nationally funded service which looks at a child's or adult's total postural needs and has the funding to provide them. The wheelchair service only has a remit for seating. Lying and standing supports are often funded by a mixture of health, education and charity sources.

There is a desperate need for an integrated approach to the provision of postural management services by multidisciplinary teams which have the expertise and funding to provide them. This type of service would improve dramatically the equity of service.

Acceptability

There are numerous reasons why items of equipment are moved to the garage or shed and never used. A thorough assessment of the child which includes his situation and environment should ensure that the provision is acceptable, practical and realistic for the child, family and school's use. First and foremost it needs to work for the child but it also needs to look good and be user friendly for families and carers. There can be very practical limitations such as can it be used at home and school, will it fit into the front room, can it fit in the boot and what happens when the child grows. The solution to these problems do not always lie in the child or equipment but require lateral thinking such as changes to the house or car or additional help at home.

The burden of care on families with children with neurological impairments is increased and equipment provision should relieve not add to this burden.

Efficiency

There is a growing body of evidence to support the use of postural management in a variety of areas:

- Improved level of ability
- Cognitive ability
- Driving & computer skills
- Eating and drinking
- Musculoskeletal Development

Improved Level of Ability

The Chailey Levels of Ability can be used to assess ability in and out equipment. A child who cannot maintain a symmetrical lying posture, reach to midline with his hands or move his legs freely once placed in a lying support with changes in pelvic and shoulder girdle position will begin to reach and kick. All the equipment aims to position a child at a level of ability at which use of their hands become a possibility.

Cognitive Ability

Studies by Green in 1987 showed that complex cognitive tasks could be affected by changes of support and position. A study at Chailey Heritage Clinical Services asked children who were unable to sit independently to perform a number of tasks in three different positions:

- Seated in adaptive seating in an upright balanced position;
- In the same seating system as before but with the entire system tilted back to 20° from the horizontal;
- In an appropriately sized wheelchair but without additional postural support

The results showed that the efficiency of complex cognitive tasks was affected by changes of sitting position while simple perceptual tasks were unaffected. Complex tasks were performed best when the children were positioned in an upright balanced seating position, and less well when supported in a tilted posture or were without postural support.

Driving & computer skills

A child's ability to control their hands to use switches is greatly increased by the provision of postural control. A child who can maintain their posture when they are still may require considerable additional support when moving and this is important to remember during assessment. This because an increased number of neurological messages from the body are sent back to the brain which compete in the attentional systems with the thinking required for the motor or cognitive task, producing inefficiency for all tasks - that is the motor and cognitive task and the ability to maintain the sitting position.

Eating & drinking skills

Correct positioning can dramatically improve eating and drinking skills by providing alignment of the head and trunk. Eating patterns are restricted by the head tilting back, chin poking or the head flopping forwards or to one side. Videofluroscopy techniques can show clearly the effect of posture on swallowing.

Musculoskeletal development

The effect of postural management programmes on hip dislocation has been the main focus of my research work. A benchmark study by Scrutton & Baird (1997) gave clear figures for the incidence of hip problems in children with bilateral cerebral palsy of 31% of hips in 40% of children. In the group of children not walking by 5 years this incidence increased to 58% (Scrutton 1998). A current research study at Chailey Heritage Clinical Services is retrospectively reviewing a group of children who have been using the Chailey Approach at Chailey Heritage, as outpatients of the posture clinic and in the Oxford area.

To date 30 children have been reviewed all of whom are unable to walk independently. The information that has been recorded and analysed about each child is the age at which postural management interventions and its

level, surgical interventions, their level of ability and their hip migration measures.

The two significant findings from this initial review have shown:

1. The level of hip migration prior to starting postural management programmes is significant. 66% of those who entered the study with secure hips (< 33% migrated) remained secure

   40% those who entered the programme with subluxed hips (between 34 and 74% migrated) became safe.

2. The group who had hip surgery did significantly worse than those who did not.

Although only the initial findings from the study there are clear indicators which suggest that postural management interventions should begin before a hip problem is clinically evident.

There are cost benefits to using this type of approach. Surgical interventions and secondary deformities to asymmetrical hip dislocation such as spinal curvature may be reduced. Hip surgery is often required more than once in this group (Reimers 1980) and later spinal surgery. The Chailey approach to postural management is non-invasive and improves the child's quality of life in a number of areas whilst maintaining the integrity of the musculoskeletal system. Long term costs of caring for adults with severe deformity are well known.

Improving effectiveness

The effectiveness this approach could be improved by achieving an equitable service, earlier intervention, greater information and education for children, families, therapist and teachers and a greater inclusion of children and families in decision making.

The effects of earlier intervention are currently being studied in a prospective cohort of children with bilateral cerebral palsy who are entering postural management programmes before 18 months of age and being followed until 5 years.

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A PERSONAL ACCOUNT

ANTHONY ROBERTSON
AAC Consultant
"Independent Expressions"

I am Anthony Robertson, am 27 years old and I have athetoid Cerebral Palsy. I have no meaningful movements apart from my head. For this reason, I am using an Infra-red headpointer to operate my Liberator communication aid to speak to you. I have been asked to give a personal account of developing awareness of disability. I propose taking you through my life considering many points along the way.

When I was 3 years old, I followed the principles of Conductive Education. The place was nice and bright and the programmes were good, doing everything yourself with some help. I was walking everyday, singing and a lot of group work on wooden plinths.

I believe this was an important part of my life as it let me find out what I could or could not do. During this period I was using my eyes to communicate my needs. Looking back on it now, I think the Speech and Language Therapy I was given was a bit poor as it was working on my own sounds, which were not going to come to anything, but this was 23 years ago. Hopefully, times have changed. This establishment was 14 miles away from home, so Mum had to plan my younger brother's care around getting me ready and taking me there.

When I was 5 years old, the Education Authority said I should go to a Special Needs School. However, I could have continued with Conductive Education until I was 7 years old. I went to the school and I had a great Speech and Language Therapist who went on a course to learn about symbols. However, the teaching staff did not believe my parents when they said "Anthony could understand everything". So, it was difficult for about six months to a year. I spent a lot of time on the floor which was boring for me as I could not see what was going on in the classroom or take part in what was happening. At this stage, therefore, I was little more than going through the motions of attending school but not really learning anything and seemed to me to be more like attending a Play School because I was there to learn things with the other children.

During the summer holidays I attended the hospital for therapy. I understood the importance of therapy for me because without it I became as stiff as a board which made dressing me and helping me to eat very difficult.

The provision of all therapies was good at this time because I was the only child in the school with such a severe disability and I was seen on a one-to-one basis with the therapists trying to meet my needs.

I feel now that many with a disability are often thought of as a number rather than as individuals with different needs one from another.

It was about this time that I received my first wheelchair because until then I just had a big pushchair. However, my family made it feel like fun, for example, pushing me fast up the road. Changing over from the pushchair to the wheelchair and it was hard for all of us in the family because this was the first major change and it was difficult for us, as a family, to accept it.

Another difficulty for me and my family was leaving the house before 8.00 am to get to school as this meant we were up at 6.30 am to get washed, dressed and have breakfast and not getting home until 4.45 pm or 5.00 pm at night. By then it was teatime, followed by getting ready for bed and then bedtime itself. In my opinion the idea of training parents to do pysiotherapy at night is not fair when you consider the pressure parents are already under, as mine were.

So what I would like you to consider, especially those of you who are parents, is the pressure you are under with children who do not have a disability getting them ready for school, collecting them, preparing a meal at night and getting ready for bed. Although you are following a similar routine with a disabled child, it does take longer because of the physical and communication problems. You may want physiotherapy added to this regime as do the other therapies but, in my opinion, this is just unrealistic. Perhaps this constant pressure on parents is why many do not stay together in the long term. At times, it seems to me that outcome measures are the all important factor in the provision of rehabilitation and it would seem that the better the number of patients seen and even 'cured' the better it is for that Service and on the league tables if they exist in a particular area.

Getting back to my story, when I was 7 years old, I got my first typewriter which I operated activating two switches with my head from Possum. At this time as well, for getting about in school, I had a corner chair on three wheels which I used to push backwards with my legs. This was great fun as there was a large ramp in school. I loved seeing how many circles I could do coming down the ramp.

It is important for children with disabilities to take risks as well as be allowed to take risks. If I had taken those risks today, I would probably have been stopped because there are few chances given to those with disabilities to take such risks, for example, I remember sitting on a facilitator's legs on a swing. So, again, I would like you to consider how we let children without disabilities take risks as they are growing up. For example, when they learn to walk, they start taking more risks but we should not stop them from walking but rather be there to help when they face difficulties or get hurt. So, why are children with disabilities not treated in the same way. I believe children with disabilities today are missing out so much on everyday things and if this happens children will become much more passive and dependent on those around them.

It appears the main reason for not allowing people with a disability to take risks is EU regulations and problems with insurance. This does upset me because as far as I am concerned life is for living irrespective of my disability.

If I, myself, followed those regulations to the letter, I could not work or live as independently as I do because there is not the funding for 2 facilitators and it would be difficult for me to carry about a hoist when some people find it a problem to carry in my travel commode to wherever I am spending the night.

From a physiotherapy point of view, if you follow your rules and regulations by the book, you would not be carrying out what I call 'real' physiotherapy such as sitting practice, standing or moving on the floor.

I feel it is important for me to use my legs, so it breaks my heart when I see little children being hoisted, because they are being trained to think they are very, very disabled and difficult to help. However, I do understand that those helping people with disabilities have to watch their backs when lifting but there must be a certain degree of give and take. It's all very well following all these laws and regulations on a hospital ward but if living in the community is going to work, I believe the laws need to be looked at again.

Looking back at my years at school, I feel there were many problems concerning the approach to physio, occupational and speech and language therapies. For example, the Occupational Therapist tried to get me to pull off my shirt as well as pulling my trousers and pants down both of which were mean on me as well as being unrealistic goals.

I believe there are places today where similar unrealistic goals are attempted especially when trying to get children to use their hands when it is clear they either cannot or have a significant difficulty in using them because the belief seems to be you have to physically do things to be independent. For example, I have seen children and older people using a communication aid with great difficulty because they are being forced to use their hands when they cannot and when I suggest using a headpointing system like mine or a switch for scanning, the child is more relaxed and can concentrate on learning the device rather than having to put up with the strain of trying to do something which they cannot do. So, being forced to do things which they find diffucult could significantly reduce the child's confidence which is sad because the situation need never have arisen.

I felt there were a lot of differing thoughts about me from the different therapists and this was very hard at times because I felt the physio understood my body needs more than the OTs who were more interested in trying to make me, as they thought, independent. An example of doing things for myself which I believe put a lot of pressure on my body was

eating from an Easy Feeder which was basically a plate on a pole which spun around and I picked the food up from the plate with my mouth.

I believe the time could have been used better by me to learn how to get people to do things the way I like them done.

In my opinion, the actual word 'independent' means having one's own thoughts and ideas and being able to communicate to a facilitator what you want, how you want it carried out and also make sure they have been carried out.

Another area that is very important throughout school and adult life is having good seating because if you are sitting and growing as well bones can become set in bad positions.

Between the ages of 12-17 years, life became hard for me with my body changing and I was also at a boarding school. During this time, there were difficulties such as specified toilet breaks which caused problems not only because when you need to go you need to go but also the need becomes greater when you are in a wheelchair.

My last year of school, I found hard especially when it tried to amalgamate with a College around the corner which was for students with learning disabilities while mine was for children without learning disabilities. The biggest problem was that the care staff from the College only knew how to work with students with learning disabilities and they found it difficult to adapt to working with people without such problems. I do not think the two groups can be put together because they have very different needs.

So, I walked out of my school the day I sat my last examination. As my Dad was working down in Kent near the school, I got all my things together and he picked me up in the lorry. This felt sad because if there had not been such a poor Manager, I could have been more open and said I was not coming back. However, the following morning, I got Mum to phone the Headmistress to tell her why I was not going back.

I went to College when I was 18 years old as a day student. My aims for going to College were :

1. To get an electronic communication aid;
2. To have sufficient speech therapy to learn how to use it;
3. To go to the local College to so some GCSE exams;
4. To have regular sessions of physiotherapy.

So, I used the Special Needs College to have the therapies and also had a facilitator to be able to access my mainstream College where I studied for a GCSE in Mathematics after which I went on and studied for a BTec in business studies and finance. I had 10 hours a week of speech therapy

teaching me to use my LightTalker, physiotherapy twice a week and went swimming once a week.

The teachers at the Special Needs College found this very hard because it was the first time they had come across someone who had strong ideas of what he wanted from his time there. This made for some agruments between staff members as I said "no" to joining groups who were learning about cooking and other daily living skills.

During this time, I started a student's committee and I was on the Board of Friends of the Special Needs College. I planned days out for groups of students, eg., I took a group to France for the day and to various places.

This was a very valuable time for me as a person to be able to take full control and organise these events. All this was done during June and July after the mainstream College had ended for the summer holidays.

In my second and last year of College, I heard about a new housing estate which had some purpose-built flats from an Occupational Therapist. All she did was to give me the number of the housing association, Habinteg, so after I phoned them a man visited me at home and I was the right person to meet their numbers so I moved in about April. It was very much a case of being in the right place at the right time. A friend moved in with me on an equal share. This was invaluabe as this meant I could enjoy the feeling of moving in to my first real home without having a lot of care pressure on me.

At this time, I was still doing BTec business studies and finance at the mainstream College while I was still going to the Special Needs College but this became less and less until the summer. I had some good friends around me there during this time.

In September of the same year, I got my first real Personal Assistant and enrolled myself at the College to do the second year of BTec business studies and finance. However, I did not get very far into the second year because work kept coming in from Liberator Ltd. which was more attractive to a 20 year old man. I was doing about a couple of days a week until January 1993 when it became more like 3 or 4 days most weeks. In March, when I was working out in the garden I got a phone call from the Chairman of Liberator Ltd. asking me if I would be interested in joining the staff at Liberator on a full-time basis with the title of "The Ambassador Programme and User Group Coordinator". This took some time to get going to make certain I would be better off financially working rather than staying on benefits.

In about June I started seeing a girl friend. I started work and was seeing my girl friend most days. Judy came on holiday together with me and my friend who shared the flat. In October half-term, I asked Judy to marry

me. The following July we got married and went on a three weeks honeymoon.

The next year we started looking at houses in Hertfordshire and found a bungalow which was a bit more expensive than we had hoped but when we thought it out it was about the same as putting a lift into a house to get upstairs. We got the bungalow in February 1995 and worked on it for six months to make it wheelchair accessible before moving in to it. During this time we lived with my parents. We actually moved into our bungalow in August. It had a big enough garden at the end of which we could build a large enough office for a small business.

I started my own business, "Independent Expressions", in January 1997. It concerns working with people with communication disabilities and helping them to become more independent. I am still working with Liberator as the Coordinator of their Ambassador Scheme but on a contract basis. Myself, I am still having physiotherapy once a week. We had our first baby, Amy, in April 1998.

Earlier this year I was in hospital for 13 weeks when I had an Intrathecal Baclofen Pump put into me to control my spasms and reduce the acute back pain I had as a result of my spasming causing inflammation on the scoliosis of my spine.

To sum up, I believe that the therapies should not stop at 19 years, once the person has left school or college because I think it is as important at 18 years for many reasons to keep people's legs strong enough to help them when they are being transferred and to make sure they have good seating and positioning as the person's needs change. Finally, I should like to emphasise that children with a disability should be treated in a similar way to those who do not have such disabilities and reduce the pressure on their parents while keeping them a part of the rehabilitation team.

RESULTS OF QUESTIONNAIRE SENT TO PARENTS AND CHILDREN WHO HAVE COMPLETED HYDROTHERAPY TREATMENT FOR CHRONIC FATIGUE SYNDROME (CFS)

SUE MCKECHNIE
Superintendent Paediatric Physiotherapist

Purpose

To ascertain whether the programme of graduated exercises in the hydrotherapy pool given to children with CFS

1. Has been of benefit as perceived by the children and parents
2. Was the most appropriate times in their illness
3. Whether sufficient education of the condition was given
4. Whether they had found other treatments more beneficial

Method

19 children aged 13-19 years who had been discharged from hydrotherapy treatment at the Royal United Hospital (Bath) NHS Trust, since December 1995 were sent questionnaires in February 1999. One part was for completion by a parent or guardian, the other by the child.

The questionnaire included both closed and open questions. Some questions were subdivided into a number of statements presented on a 5 point scale ranging from "poor" to "very good" or "much better". The draft questionnaire was sent to a clinical psychologist who recommended revisions.

11 completed sets of questionnaires were returned by the end of March 1999 (58%).

Analysis of results of parents questionnaire.

Child's Health

10 (91%) rated their child's health at present time compared to when diagnosed as better or much better
1 (9%) rated it as poor

10 (91%) thought hydrotherapy has been of benefit
1 (9%) thought it had been of no benefit

Parents' comments regarding benefit to child's health:

- Mobility improved; warm water soothing; relief from pain
- Initially more tired, then improved stamina; strength built up
- Only form of excercise possible
- Private; allowed to gradually start moving
- Gave a focus; something to get up for; increasing amount of exercise gave an aim
- Increased alertness; better concentration
- More confidence in walking

10 (91%) had found that hydrotherapy had not caused problems for the child.

1 (9%) found that it had caused distress and pain for days afterwards.

1 commented that travelling to the pool was sometimes too tiring.

Timing of Treatment

9 (82%) felt that the treatment had been started at the appropriate time.
1 (9%) felt it was too early.
1 (9%) felt that it was too late.

Education

11 (100%) said that the parents had received an explanation of why hydrotherapy was provided.

10 (91%) said that the children had received an explantion.

1 (9%) said that the child had not had a full explanation.

8 (73%) said that they understood the explanation but 3 (27%) felt that there were some questions remaining. One respondent would have liked to have known how many patients had benefited from hydrotherapy and if there were guarantees that this was the correct treatment.

Parents Attending

10 (91%) of parents attended with their child.
Comments made by parents regarding attending:

- Able to see progress in child's condition; rewarding.
- Able to talk to other parents; moral support; like a self help group.
- Able to see improvement in other children, very useful and encouraging.
- Only treatment and recognition of condition; relief at being able to take action; something positive a parent can do for their child.
- Difficult decision when to push a poorly child; needed the support of therapists; able to ask opinion of therapist.
- An experience that parent was able to share with child.
- Appreciated interaction with other people; seeing others both worse and better. Stimulated by other children.

When asked to score the service

a) for satisfaction
- 2 (18%) thought it OK
- 5 (45%) thought it good
- 4 (36%) thought it very good

b) for effectiveness
- 1 (9%) thought it very poor
- 7 (64%) thought it good
- 3 (27%) thought it very good

c) for convenience

1 (9%) thought it poor
3 (27%) thought it OK
5 (45%) thought it good
2 (18%) thought it very good

Other Therapies

7 (64%) of the children had received other therapies. 5 just one other therapy, 1 had two other therapies and 1 had three other therapies:
3 had only reflexology
2 had homeopathy
1 had both reflexology and homeopathy
1 had reflexology, homeopathy and a faith healer
None had psychiatry or psychology.

Other comments and suggestions by parents

- team helpful, understood emotional and mental problems
- lack of liasion between hydrotherapy and paediatric department
- many expressed thanks and gratitude
- staff very helpful and positive
- more local pools
- coffee for parents!

Analysis of results of child's questionnaire

9 (82%) felt that hydrotherapy had helped them recover from illness
8 (73%) felt that the hydrotherapy had not caused problems
1 (9%) felt the travelling to the pool was too much
1 (9%) had "pain in bones" after a session
1 (9%) felt too exhausted and distressed

Scoring of the help that hydrotherapy had given

1 (9%) thought it was very poor
1 (9%) thought it was OK
8 (73%) thought it was good
1 (9%) thought it was very good

7 (64%) thought they understood the reason for hydrotherapy
3 (27%) thought that they still had questions remaining
1 (9%) did not understand
Questions regarding other therapies: homeopathy was thought beneficial by two, reflexology by two and the rest did not comment on the benefit of other therapies.

Comments made by the children regarding hydrotherapy:

- felt fresher, less lethargic
- easier to sleep, better quality of sleep
- seeing other children with disabilities helped
- gave me exercise

- exercise in warm water helped muscle aches; exercise without getting tired or sore
- gave me something to do
- felt relaxed in water
- met other people the same age in same situation; helped each other to recover; met other people who understood what was going through and could support each other
- bigger pool would be nicer
- need to educate physiotherapists on illness; needs more understanding
- need more relaxation techniques
- many thanks to hydrotherapy staff, without them I would not be well enough to attend university.

Conclusions

Most of the children's health had improved from when they had been initially diagnosed with Chronic Fatigue Syndrome. Most thought that hydrotherapy had been of benefit and had not caused additional problems. Parents were more positive than the children were.

The majority of parents felt that the treatment had been started at the correct time but some felt that the timing had been inappropriate. With experience we have changed our practice. On receiving the referral the Superintendent Physiotherapist will judge from the consultant's letter whether the child will be fit enough to start hydrotherapy immediately or whether a home visit to assess their condition is necessary. We are guided by the Young Person's Ability Guide by Jill Moss (1.). We are suggesting graded exercise at home until the child reaches 30% on the ability scale. We are stopping at about 80% ability as the child reintegrates into normal activities.

With regards to the explanation of graduated exercise in the pool the parents were all satisfied that they had had an explanation but some felt that there were some questions remaining. Given the example of one parent who wanted guarantees that this was the correct treatment we may not be able to answer all the questions. However, we could produce a leaflet explaining the principle of our treatment and give references to the research that has shown the effectiveness of graduated exercise in the management of CFS. The children were less positive that they had understood the reason for hydrotherapy. Symptoms of the illness are reduced concentration and memory. Perhaps we should be more aware of this and repeat the explanations more simply and more frequently to the children. A leaflet aimed at the children would be helpful. With regards to the support given to parents this would seem to be a very positive contribution to the family management of the condition. Consideration may be given by other professionals or volunteers to become involved in working with the parents while the children are having their treatment, although the opportunity to be able to talk informally is obviously appreciated. Producing coffee is beyond the scope of the physiotherapist in the pool!

Overall the scores for satisfaction, effectiveness and convenience indicated that parents were generally happy. All scores were affected by one reply when we obviously took on treatment of a child too early in the course of the condition. Hopefully, this would now be recognised.

We are unable to alter the siting of the pool or increase the number of pools. Although some families found travelling very difficult most of the scores for convenience were in the "OK" to "very good" range.

With regard to other therapies, the majority had tried homeopathy or reflexology with half feeling that these therapies had been beneficial. No one admitted to seeing a psychiatrist or psychologist. Although I do not have details of the referral rate to Child and Family Therapy Service and also the questionnaires were anonymous, anecdotally I am surprised that no one mentioned having seen someone from the Service. Overall comments and suggestions showed that most of the parents found the team helpful but others thought that there was lack of liaison between the hydrotherapy and paediatric departments, presumably meaning between doctors and physiotherapists. I think that this is something that is improving, as we are all gaining experience at managing these children, and exchanging ideas.

The feeling of helplessness was expressed by the parents and they were pleased to have an acivity that was not only helping the child but involving the parent and child together. The mutual support felt by the parents was very positive. Also the children apreciated the support of other children in a similar situation.

Summary

1. Graduated exercise in the hydrotherapy pool is beneficial to children with CFS
2. We are already aware of the appropriate stage at which to start hydrotherapy. We need to liaise with medical staff regarding referrals and communicate our decision to start programmes of exercises at home before commencing hydrotherapy.
3. We should improve our education of parents and particularly children about the principles of graduated exercise.
4. Some families find complementary therapies useful. None have had cognitive therapy from a psychologist or psychiatrist (2.).
5. Both children and parents benefit from the support of others with similar conditions. Informal meeting seems to be appropriate at the poolside.
6. Greater communication between medical and physiotherapy staff is indicated.

Action

1. Continue with graduated exercise programme
2. Physiotherapists to provide educational material for children and parents
3. Liaise with medical staff regarding referral and progress of condition.

References

1. Moss J I (1995) Young Persons Ability Guide, Somebody Help Me, (Sunbow Books).

2. Royal Colleges (1996) Chronic Fatigue Syndrome: Report of joint working group of the Royal College of Physicians, Psychiatrists and General Practitioners. Royal College of Physicians London CR54, 1-58.

Further Reading

Fulcher, KY and White, PD (1998) Chronic Fatigue Syndrome - A description of graded exercise treatment PHYSIOTHERAPY 84 (4) 223-228.

On behalf of the Paediatric Physiotherapy Team
Children's Centre
Royal United Hospital (Bath) NHS Trust
Combe Park
Bath
BA1 3NG

Acknowledgements to Ruth Taylor MCSP, Paul Stallard, Clinical Psychologist and Mandy Harris

MANAGING THE CURRICULUM FOR CHILDREN WITH SEVERE MOTOR DIFFICULTIES

A PRACTICAL APPROACH

Pilla A C Pickles

David Fulton Publishers London 1998

ISBN 1-85346-511-9 114 Pages

This soft-backed, A4 sized publication offers practical advice on the inclusion of children with severe physical disabilities in mainstream education. The author, Pilla Pickles, previously ran an integrated resource for children in Harrow and now co-ordinates physical support for children in schools in Barnet.

The book may be useful to a wide readership including therapists, education staff - particularly those with little or no experience of working with children who have special educational needs - and parents.

There is a very useful introductory section which allows easy reference on how to use the book giving a brief outline of the content of each chapter.

The book is then divided into two sections.

Part One focuses on working as a team and setting up support systems.

Part Two gives practical ideas on how to access the curriculum looking at specific areas including computers and technology, writing, reading, maths and science, physical education, technology and geography, music and art.

There are two chapters in Part Two devoted to the inclusion of therapy into the curriculum.

The author gives ideas on how to introduce therapy, using very specific targets, into everyday classroom activities.

This would certainly be a useful starting point for Special Educational Need Co-Ordinators, Headteachers, teachers and non-teaching assistants when planning admission of a young person with special needs to their school. It would assist in giving ideas about the type of questions staff should be asking of themselves, as well as of the young person. The book also gives very good practical ideas for the setting of targets for Individual Education Plans (IEPs).

The chapter regarding physical education is not only useful for PE teachers - listing questions they may need to ask the therapist - but it could be used by the therapists themselves as an 'aide memoire' when discussing the child's needs with the teaching staff. The author stresses the importance of good communication, liaison and record keeping when working with these children and all the many professionals that may also have a role to play.

The author concludes by emphasising the importance of team work - due to the high number of professionals often involved and the need to see the child as a whole person. There are appendices which are full of useful addresses, listed in relation to each chapter and a bibliography containing reference and further reading.

This is certainly a book that I would advise schools to purchase and to keep to hand for practical advice and ideas.

Julia Graham MCSP BSc(Hons) Physiotherapy

PAEDIATRIC PHYSICAL THERAPY

Edition 3

Jan Stephen Tecklin

Lippincott Williams and Wilkins

Philadelphia 1999

ISBN 0-7817-1010-3 606 Pages Hardback

There are several contributing authors to this American book which provides a comprehensive guide to normal motor development, tests used to assess levels of child development and then a range of conditions commonly met in paediatric physiotherapy. When reading the book one has to take into account the language and terminology differences between Great Britain and the USA as

well as the procedural and legal differences, particularly in the last chapter relating to 'physical therapy in public schools'. However, it is useful to compare how other systems work in relation to those in this country.

Some of the language, long felt to be outdated here, is still in evidence in the book, particularly in the chapter relating to Down Syndrome and should be read taking into account the cultural differences between countries.

Language differences aside, this is a really useful reference source containing a great deal of well structured, clearly presented information.

There are fifteen chapters and each, by a different physiotherapy author, gives a clear outline of the content which follows.

Subjects covered include : The High Risk Infant; Cerebral Palsy; Spina Bifida; Neuromuscular Disorders; Traumatic Brain Injury; Down Syndrome; Paediatric Oncology; Orthopaedics; Juvenile Chronic Arthritis; Burns and Pulmonary Disorders.

There is also a chapter on adaptive equipment and physiotherapy in schools. Each chapter concludes with a list of references of further reading.

The book is indexed but there are no appendices.

The book is written by Physical Therapists for members of that profession and would be an extremely useful resource not only for individual therapists' use but for hospital libraries and departments and for student use - giving practical treatment advice.

It is very readable and easy to handle with clear typeset and pictures, tables and diagrams to support the text. A worthy investment!

Julia Graham MCSP BSc(Hons) Physiotherapy

CLUMSINESS AS SYNDROME AND SYMPTOM

Human Movement Science Vol. 17 Numbers 4-5

August 1998.

ISSN 0167 9457.

Human Movement Science is a journal devoted to pure and applied research on human movement. It provides an interdisciplinary forum for the publication of both theoretical and empirical papers. This special issue "Clumsiness as Syndrome and Symptom" is a collection of peer reviewed papers which according to the editor represents some of the best work in this field which was presented at a 2 day conference on Developmental Coordination Disorder held in Cardiff in 1997.

The introductory section tries to define and categorise children who are described as "clumsy", into those who had no medical reasons for their movement problems and the second group whose Clumsiness is but one sign or symptom of a broader medical or psychological condition e.g. Asberger syndrome.

This issue incudes studies of children who fall into both categories but does not provide an answer to the cause of the movement deficits.

There are 13 papers divided into 4 sections. The first section looks at classification of movement difficulties, Developmental Coordination Disorder versus Dyspraxia versus Clumsiness and the various terminologies used to define the problem. The second and third sections are a series of studies looking at children with and without the D.C.D. diagnosis and various interventions and comparative works covering areas such as postural control, physical growth, visuomotor control, motor skills acquisition and specific language impairment.

The final section is devoted to questions of assessment and intervention and looks at comparative studies using the Movement Assessment Battery For Children and other such tests.

The papers are representative of work from around the world notably Japan, Netherlands, Scandinavia

and the U.K. Each one is well written and referenced and the variety of topics covered and the depth of research undertaken by the authors gives the reader a "state of the art" viewpoint of the knowledge base and work undertaken in this field.

Scientific papers such as this deserve time spent reading and critically appraising in order to gain the maximum benefit from the author's kowledge. This is therefore not a journal to be read cover to cover but by selected article. Each article tends to promote questions and not necessarily provide answers and discussion with colleagues would be a useful forum to gain the best from these works (a Journal Club for example).

The journal is well indexed at the beginning and easy to read although the cover would be helped by some additional backing to strengthen it should it have many readers.

I would recommend this journal to any health professional working with children with D.C.D. It provides a wealth of valuable information about current philosophy and studies and would be a useful tool to those professionals looking to formulate clinical guidelines on the management of this group of children.

Sue Walmsley MCSP

HALFORD TRAVEL PILLOW

This is manufactured for use as a travel pillow for young children. It is made of fairly soft foam and the back section is tapered to fit the contour of the neck. The cover is removable and washable.

I have also found it extremely useful as a positioning aid, eg when working with a child in supine on a wedge. Nursery staff and parents have also found it useful for many other purposes, eg to aid head alignment for feeding and when changing nappies or dressing.

Available from larger branches of Halfords, in various colours, priced £5.99

Pam Evans

Copy for the

MARCH 2000 JOURNAL

must be with the editor by

1st FEBRUARY 2000

The editorial board reserve the right to edit all material submitted

If possible, please submit copy on floppy disc in Word 6 format, together with a printed copy.

DR. GRACE WOODS
1912 - 1999

Grace Emily Woods died peacefully on September 22nd at a Nursing Home in Bath following a long and courageous fight against illness.

At an early age Grace decided she wanted to be a doctor - not an easy goal for any young girl in those days - and, despite all the difficulties she had to encounter, she succeeded due to her great determination and hard work. These were two hallmarks of her future life and work as she fought for good services and a future for children and adults with disabilities and their families.

After qualifying at the Royal Free Hospital in 1936, and holding various House posts, Grace married and moved to Bristol where she gained the Diploma in Public Health in 1938. It was the war that brought Grace into Paediatrics whilst at the same time bringing up her three children and giving them a childhood of rich experiences, mischief and fun. She worked at the Children's Hospital, in Public Health and Child Welfare Clinics, with mothers and babies and midwives in Knowle West which was one of the poorer areas of Bristol. She looked back on those days with affection, and with true Grace enthusiasm said it was "such fun".

"Fun" was another of Grace's hallmarks. In nearly all the places where she worked so hard and with such determination there was fun. At the long-stay hospital for the mentally handicapped, Northam Hospital in Bristol, and then at St. Ebba's Hospital in Epsom where she became Medical Superintendent and Administrator, she joined in wholeheartedly with the social activities for the patients and the staff.

It was through these experiences that in later years, as the old hospitals were being closed down, she campaigned vigorously with parents for "village home" type residences for adults with mental handicaps, for she had seen what good lives could be achieved for this vulnerable group of people in a well-run and safe environment within the community.

Grace's long involvement with children with cerebral palsy and their families began in the early 1950s at Claremont School in Bristol, one of the first special schools for educating children with average intelligence, but often with severe physical handicaps who had been considered ineducable at that time. She followed these children into their adulthood by keeping records on her own designed "punch" cards which provided valuabe information and were used by her in various articles which she wrote. As a result of her work she gained an M.D. at Bristol University in 1956.

Through this work and further work at the Spastic Centre at Cheyne Walk, London, she also became involved with the Spastic Society (now Scope) and was a regular attender at their conferences and supporter of their work.

My association with Grace began in the early 1970s when she was appointed Consultant Paediatrician in Leeds, specifically to set up and run the first Regional Child Assessment Centre. The base was to be a prefabricated building - one of five distributed by the DHS to various sites in Yorkshire. In true Grace fashion she soon discovered there was one more unused prefab, and she negotiated for it to be joined with the one at Seacroft Hospital giving us double the space!

Grace was always a champion of therapists, and she made sure she had the services of Physiotherapists, Occupational Therapists, Speech Therapists and Orthoptists at the Centre and, with her great interest in

Education, insisted that an Educational, rather than Clinical, Psychologist was employed. To complete the team to run the playroom she negotiated for the appointment of Nursery Nurses - another professional she wholeheartedly supported.

Grace was always pleased to pass on her extensive knowledge by giving lectures to school medical officers, fellow paediatricians, therapists, teachers and parents as well as publishing useful books such as "Handicapped Children in the Community" and "Care for the Mentally Handicapped Past and Present" which were easy for all to read and understand.

In her retirement Grace retained her interest in the work and treatment of children with disabilities, still attending conferences and visiting places of interest both home and abroad. She was a great traveller and made the most of any visits she made by moving around and getting to talk to local people as well as her fellow travellers. On her return she was full of information and enthusiasm for those places she had visited.

Grace Woods was made an Honorary Member of the APCP in recognition of her great contribution to paediatrics, and in particular by increasing the knowledge and improving the services for babies and children with cerebral palsy and the welfare of their families.

Mary Barton

Retired Paediatric Physiotherapist

SUMMARY OF ISSUES DISCUSSED AT THE APCP NATIONAL COMMITTEE MEETING HELD AT THE COPTHORNE HOTEL, BIRMINGHAM ON 8th OCTOBER 1999

PUBLICATIONS

A car sticker promoting paediatric physiotherapy has been produced and is available from the publications officer, Eileen Kinley.

A second edition of the Dyspraxia booklet is being written.

APCP in collaboration with The Child Accident Prevention Trust is producing a leaflet and poster on guidelines for safer use of baby walkers.

MEMBERSHIP

Membership of APCP has reached the magic figure of 1500!

Any member who wishes their name to be included on the register of private practitioners should contact the Vice Chair, Di Coggings.

The Committee plans to establish a database of paediatric physiotherapy departments or establishments, which deliver a paediatric service. Any member who feels their establishment may not be on the list should contact their regional representative.

RESEARCH

The Research Officer, Carrie Jackson, would like any member who is undertaking a research project to contact her with the details in order that she may update the database.

EDUCATION

The next Introduction to Paediatric Course will be organised by the Welsh regional committee. Information can be obtained from Sian Howells, Welsh Regional Representative.

The Msc Paediatric Module, due to commence at Queen Margaret University College, Edinburgh in September will be launched during conference.

CONFERENCES

APCP Conference 2000 will be held at the University of The West of England, Bristol from 4th - 6th May.

The Conference in 2001 will be hosted by Trent region.

AGM

The Annual General Meeting of APCP will be at 11.30am on Friday 5th May 2000 during Conference.

NEXT MEETING

The next meeting of the APCP National Committee will be held on Friday14th January at The Chartered Society of Physiotherapy, London.

A full copy of the minutes of the meeting can be obtained from your regional representative.

PRO REPORT

I hope that nearly everyone has a copy of APCP/SCOPE folder regarding 'Working Together Parents and Physiotherapists'.

I need your work address and telephone number if you have not received a copy, so that I can check if a copy was sent to your Trust.

I am making a list of all work addresses of Paediatric Physiotherapists. The Regional Representatives are collating details for each area. If you think your Regional Representative does not have up to date details, please let her know or send information directly to me at:-

Paediatric Physiotherapy Department
Hinchingbrooke Health Care NHS Trust
Primrose Lane
Huntingdon
Cambs
PE18 6SE

Tel: 01480 415203.

NOTICE

The 25th Annual General Meeting of the Association of Paediatric Chartered Physiotherapists will be held on Friday 5th May 2000 at The University of the West of England, Bristol

All paid up members of the Association are entitled to attend. Voting is restricted to full members of the Association and a current membership card is required

Minutes of the last AGM are available from the secretary on receipt of a S.A.E.

Nominations are invited for four committee vacancies.

Nominations should be sent to the secretary by the end of February 2000 together with the names of a proposer and a seconder who must be paid up members of the Association.

The retiring committee members are:
Liz Hardy, Angela Glyn-Davies,
Telerie Robinson and Eileen Kinley

Telerie Robinson and Eileen Kinley are eligible for re-election

Nomination Forms can be found on the last page of this Journal

MSc MODULE

A new Paediatric module will be offered within the MSc Physiotherapy programme at Queen Margaret University College from September 2000. This module can be studied on its own or in conjunction with other modules offered within the programme. The module has been developed in conjunction with the Association of Paediatric Chartered Physiotherapists and will be facilitated by Terry Poutney, Di Coggings, Carole Hurran, and Liz Hardy with Dr Marie Donaghy as the module co-ordinator.

The 30 credit module takes a thematic approach to: Musculo-skeletal, Neurology and Cardio-respiratory and integrates within these themes: principles and concepts of epidemiology, communication; learning and family systems; psychosocial issues; legal and ethical issues; clinical effectiveness and standards of practice.

The programme requires attendance as follows:

1 week in October
2 weeks in January
1 week in May

The cost of the module is £600. In addition you can study within the same period a further two modules to enable you to exit with a PgCert.

Further details of the module content and information on the PgDip Physiotherapy and MSc Physiotherapy can be obtained on request from :

Dr Marie Donaghy
Senior lecturer, Physiotherapy
Queen Margaret University College
Leith Campus Edinburgh EH6 8HF
Tel 0131 317 3820 fax 0131 317 3815
M.Donaghy@shore.qmced.ac.uk

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For order form and further details contact :

Carole Hurran, 23 Bayswater Avenue, Bristol, BS6 7NU

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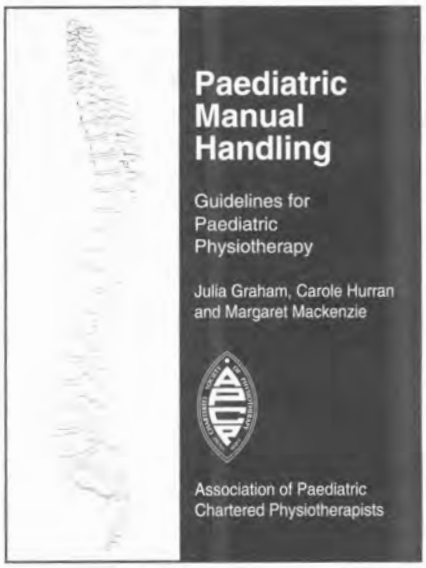
APCP GUIDE TO PAEDIATRIC MANUAL HANDLING



Authors: Julia Graham, Carole Hurran
and Margaret Mackenzie
33 pages (A4)
Cost: £10 (inc P&P)

Working with babies, children and young people places staff, parents and carers in a continuous 'at risk' situation. The very nature of the work involved means that one is often bending and stooping to low levels, and carrying a moving, unpredictable load!

Although the weight of the load may be small, the environment may be ergonomically unfavourable. Handling over the sides of cots, moving from the floor, carrying into and out of a car are just a few typical examples.

This guide has been produced to assist paediatric physiotherapists, not only to comply with current legislation, but to provide them with background information as a useful resource for carrying out risk assessment in their workplace, (be it a domestic, community or hospital environment) and on the babies, children and young people with whom they work.

CAR STICKER

APCP car stickers are now available from the Publications Officer at a cost of £1 each. The text and logo are blue on a white background.

APPLICATION FORM FOR APCP PUBLICATIONS

TITLE	PRICE	QUANTITY
Serial Splinting in Hemiplegic Cerebral Palsy by Margaret Jones (2nd Edition)	£3.50	
The Children Act 1989 'A Synopsis for Paediatric Physiotherapists'	£2.50	
Dyspraxia - A Handbook for Therapists by Michelle Lee and Jenny French	£5.50	
Guidelines for Calculating Caseloads	£1.00	
Baby Massage	£1.00	
Standards of Practice for Paediatric Physiotherapy	£2.50	
Statutory Assessment of Children and Special Educational Needs	£4.00	
Tests and Measures Resources Pack (2nd Edition)	£3.50	
Haemophilia Booklet	£3.50	
Human Postural Reactions - Lessons from Purdon Martin by Dr. John Foley	£5.00 (incl. of P&P)	
Manual Handling Booklet	£10.00 (incl. of P&P)	
Car Sticker	£1.00	

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Royal Liverpool Children's NHS Trust, Alder Hey Hospital,
Child Development Centre - Physiotherapy Department, Eaton Road, Liverpool L12 2AP

Name and Address for delivery: .....

.....

.....

REGIONAL REPRESENTATIVES

EAST ANGLIA

Mrs Trisha Brosnan
Hope Cottage
10 Church Street
Great Shelford
Camb. CB2 5EL

LONDON

Mrs Ann Shanks
2A Oak Lodge
Chigwell
Essex
IG7 5HZ

SCOTLAND

Mrs Lesley Smith
Physiotherapy Dept.
Royal Hospital for Sick Children
Yorhill NHS Trust
Glasgow G3 8SJ

SOUTH EAST

Mrs Sarah Crombie
10a Record Road
Emsworth
Hampshire
PO10 7NS

SOUTH WEST

Mrs Pam Evans
York House
New Road
Swanmore
Hampshire SO32 2PF

WALES

Mrs Sian Howells
17 Carlton Close
Thornhill
Cardiff
CF4 9EF

TRENT

Louise Kelleher
11 Main Street
Costock
Loughborough
Leicestershire
LE12 6XD

NORTH WEST

Mrs S Walmsley
4 Hartland Ave
Urmston
Manchester
M41 9OG

NORTHERN IRELAND

Mrs Judith Morrison
Physiotherapy Dept.
Whiteabby Hospital
Doagh Road
Newtownabbey
N.Ireland

WEST MIDLANDS

Mrs Fiona Nicholson
Physiotherapy Dept.
Birmingham Children's Hospital
Steelhouse Lane
B4 6NL

NORTH EAST

Mrs M Harrison
11 Whitsundale Close
Knaresborough
N. Yorkshire
HG5 0HX

OVERSEAS

Mrs Sue Whitby
PRO
3 Manor Way
Hail Weston
Huntingdon PE19 4JG

SOUTH EAST

I apologise for the long delay in any news about our region. Since our very successful study day on neuroplasticity back in February, we unfortunately had to cancel the last scheduled one in June. This study day was on neonates and there were not enough applicants to run the course.

Over the past few months we have recruited new members to our committee and are now enthusiastically organising next year's meetings. Initial plans are for a day on paediatric manual handling in March and gait analysis later in the year. We will keep you posted on these and other news via a newsletter in January.

Our AGM will be in March. If any members in the east Kent area are considering joining our committee please let me know. We desperately need more input from that area of the region.

SARAH CROMBIE

NORTHERN IRELAND

We enjoyed a very interesting evening meeting in September when Dr Fiona Stewart gave us a very informative talk on genetics.

The date for the study day on the "Neurophysiological basis of the Bobath concept", has been confirmed to take place on the 18 February 2000. Dr Margaret Mayston will be the lecturer.

The last evening meeting has still to be confirmed, for March 2000.

Lastly, I would like to wish all the N.I.A.P.C.P. members a Happy New Year, and all the best in the next millennium!

JUDITH MORRISON

NORTH EAST

There has been an excellent response to the questionnaire which was sent out to all members asking for their views and requirements regarding future study days. I do thank all of you who took the time to fill them in as I am now in the process of collating the information and this will be available to you all on the next flyer.

The study day on the 18th September 1999 in 'Chronic Fatigue Syndrome' and 'Reflex Sympathetic Dystrophy' was most informative and helpful to those of us who see the occasional child with such problems. A big thank you to the three speakers for well planned presentations. It was a shame that the attendance was so poor.

The next study day will be on Saturday 4th March 2000 along with the AGM. The topic will be 'Alternative Approaches'. Further details will be available on the flyer.

Welcome to Heather Angilley who has very kindly agreed to come on to the local committee as a co-opted member.

You will all have received your renewal subscription forms and direct debit forms. Do join asap - if at all possible by direct debit. This will be most helpful for our membership secretary who does an excellent job. Also do encourage your colleagues who are not members of APCP to join by giving them a copy of your membership renewal form.

A MERRY XMAS AND A HAPPY NEW MILLENNIUM

MARY HARRISON

SOUTH WEST

This year we have had study days on Orthotics in June in Poole and Orthopaedics in November in Taunton. I hope that the more westerly venue of the latter meant that many more members in Devon and Cornwall were able to attend. Please note in your diaries now that next year's AGM/Study Day wil be on 4 March 2000, the venue is yet to be finalised, the subject will be Syndromes. APCP Conference 2000 is in Bristol so I hope the SW membership will be well represented.

We are continuing with the Wessex Workshops - please contact me for details and please let me know of any similar workshops elsewhere in the region.

Finally, we have a growing number of members in the SW but a dwindling committee! We have room now for 2-3 more members so please contact me if you are interested: it is really not too arduous and involves attending a few, very informal, meetings each year and being prepared once in a while to help organize a Study Day. Keep sending in your news and views, so we can stay in touch with the whole region.

With best wishes for the Millennium.

PAM EVANS

WALES

The Study Day on Cerebral Palsy with David Scrutton was a very interesting and informative one. It was well attended and much discussion was had, giving plenty of food for thought!

We're hoping to arrange a lecture with Mr Paul Davies, Orthopaedic Consultant, on "The Management of Spinal Problems in Children" as a follow-on with the Orthopaedic theme.

The Paediatric Manual Handling Day, in association with the AGM, will be held on March 17th, 2000 at Trinity Fields Special School in Ystrad Mynach.

We've rearranged the Muscular Dystrophy Study Day from May to June 16th and it will be held at Hensol Conference Centre for easier access to our guest speaker, Marianne Maine from the Hammersmith, London.

Our main news this month is that we are organising the "Introduction to Paediatrics" course next year in Cardiff! (so we're postponing the two courses we had originally planned for July and November until the year 2001). Obviously, this will entail a lot of work and commitment but it is also very exciting for us to have it here at home in Wales - especially as it is the all important Millennium year!!

SIAN HOWELLS

WEST MIDLANDS

Early in October we had a fascinating lecture based it around Functional Electrical Stimulation. I rather think that Jane Burridge posed more questions than she answered, which could mean we will need to look at this subject again in the near future - what do you think?

Your committee are finalising plans for a two day course on Developmental Co-ordination Disorder. This will be in Birmingham hopefully in February and led by Michelle Lee. More details about application forms will be available shortly.

Please let any of the committee know if you have any ideas for study days or evening lectures.

Don't forget your membership is due for renewal in the next month or so. Tell your friends and colleagues about APCP. Now is a good time for them to join too.

May I take this opportunity to wish you all a Happy Christmas and the Very Best for the New Century.

SALLY BRAITHWAITE

TRENT

Having been inspired by the 1999 APCP conference, the committee are busy arranging the conference for 2001. This will take place in Sheffield during the Easter holidays. The provisional programme includes the latest research on neonates, anterior knee pain and progressive working practices in cystic fibrosis, to mention but a few.

On December 2nd there will be a one day course entitled, "Assessment of babies - A practical workshop for physiotherapists" at Rotherham District General Hospital. This should prove to be an excellent day, topics include neurophysiology, video workshops and the reading of scans.

Please continue to send in ideas for other study days/ courses. Study bursaries are available through Sue Foster at the Leicester Royal Infirmary.

We are hoping to set up a video library within the region and if you know of any suitable videos that we may wish to purchase please contact me.

LOUISE KELLEHER

NORTH WEST

The "Pat Alexander" moving and handling day at Booth Hall was a success and is to be repeated in November to satisfy the waiting list. It has linked in well with the new Manual Handling Guidelines.

AGM 2000 is Saturday February 5th, venue Trafford General Hospital. Topic for study session Dynamic Lycra Splinting presented by "Second Skin". You will also have a mail shot - no excuses for non attendance! There will be some vacancies on committee so please consider joining us (G.S.O.H. and teamwork spirit essential!)

We are unable to proceed with the June study day on principles of Paediatric Neurological Treatment but N.I.D.C.A.P. with Inge Warren is planned for November so watch for the flier!

We continue to consider requests for study Bursaries from North West A.P.C.P. members and our video library is keen to expand if you know of any new titles we can consider buying. Contact Gill Holmes at Alder Hey for videos and Lorna Stybelska at R.M.C.H. re Bursaries.

May the Millennium Holidays be extra special! See you next year.

SUE WALMSLEY

EAST ANGLIAN

We had an excellent study day at Cambridge in October, given by Dr. J. P. Lin of Guy's Hospital. He gave us a very full, comprehensive, in-depth course on Gait Analysis. Somehow he managed to condense such a wide field of study and research into one day; giving us the opportunity for lively discussion.

Many thanks to Sue Coombe from Norwich for organising it.

The Study Day in November at Huntingdon on 'The treatment of cerebral palsy children' given by Colin Stevens is now over-subscribed.

The committee are now busy organising the programme for the next year:

a study day on serial plastering is being planned for March.

a 'respiratory techniques' day, covering neonates and cystic fibrosis children, is being organised for later in the year.

And finally, to extend a warm welcome to Linda Fisher who has joined the committee.

TRICIA BROSNAN

SCOTLAND

Christine Shaw and I, as Scottish Committee members attended the CSP Congress at the beginning of October and Birmingham proved to be a wonderful venue with superb facilities.

This Autumn we have run a successful half day respiratory course shared with our ACPRC colleagues. This worked well and we had a good turnout.

November meant Edinburgh and a day of Multidisciplinary Approach to Developmental Co-ordination Disorder.

50 delegates from Physiotherapy, Occupational Therapy, Education and Medicine shared in a most stimulating and thought provoking day as to how we can best influence this area and work collaboratively both between therapies and between Health and Education.

Spring study day will be The Move Programme . . . A Tool for Inclusion.

Jenny French has recently secured innovation funding from Education and is at the outset of a 3 year project.

The APCP Scottish Region AGM will take place on this day.

Date Friday 24th March 2000

Venue possibly Dundee.

LESLEY SMITH

DYSPRAXIA FOUNDATION
Professional Conference

University of Durham
22 - 23 September 2000
"New Beginnings"
CALL FOR PAPERS AND POSTERS
The Professional Conference of the Dyspraxia Foundation will feature health and educational programmes including free paper sessions and posters. Abstracts are invited for research, assessment and treatment programme analysis from professionals in Health and Education involved with Dyspraxia.
Guideliens for presentation of abstracts and further information are available from the Medical and Education Committee, Dyspraxia Foundation, 8 West Alley, Hitchin, Herts SG5 1EG.
The closing date for receipt of abstracts is 30 April 2000.

YORKSHIRE NORTHERN REGIONAL NEUROMUSCULAR FORUM
A Study Day on Aids and Adaptations for Children with Neuromuscular Conditions.

Speaker : Philippa Harpin
Occupational Therapy Advisor Muscular Dystrophy Campaign
Date : **Wednesday, 26th January 2000, 9.30 a.m. - 4.30 p.m.**
Venue : Post Graduate Centre, Halifax General Hospital
Cost : £10
Please contact :
Sue Sharma/Sue Robinson
Physiotherapy Department
Halifax Child Development Unit, Halifax General Hospital
Salterhebble, HALIFAX HX3 0PW
Tel. No. 01422 357171; extension 4156
Closing date : 15 December 1999

Forthcoming Events at Alder Hey Education Centre, Royal Liverpool Children's NHS Trust - Alder Hey

Liverpool Paediatric Week
13th - 17th March 2000
Topics include - New Therapeutic Advances, Neurology, Advocating for Children, Growth & Nutrition
GMFM and GMPM Workshops
Royal Liverpool Children's NHS Trust - Alder Hey would like to hear from anybody who has an interest in attending a GMFM workshop or a GMPM Workshop in April 2000.
For further details of any of these courses, please contact the Conference Organiser on 0151 252 5106.

MORE: Integrating the Mouth with Sensory & Postural Functions

3rd, 4th & 5th May 2000
Sheila Sherlock Education Centre, London
Cost Fee: £230
Speakers: Patricia Oetter, MA, OTR, FAOTA
Eileen Richter, MPH, OTR, FAOTA
Sheila M. Frick, OTR
For further information please contact Dianne Fair
Tel: 07899 944715 Email: difair@yahoo.com

Association of Paediatric Chartered Physiotherapists

NOMINATION FOR NATIONAL COMMITTEE

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BRIEF PERSONAL PROFILE IN SUPPORT OF YOUR NOMINATION.

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Please return completed form to : APCP Secretary, Mrs. Christine Shaw, Physiotherapy Dept., Westerlea School, 11 Ellersley Road. Edinburgh EH4 8EX to arrive no later than 4 weeks prior to the A.G.M.

Notes for Contributors

The Editorial Board welcomes research material; referenced articles and evaluations of physiotherapy practice; informal articles.

Manuscripts should be sent to Lin Wakley, 2 Ash Bank, Pipers Ash, Chester, Cheshire, CH4 7EH, U.K.

Copy to be submitted should be typed on one side of the paper, double spaced and with ample margins. All pages should be numbered consecutively.

Manuscripts should provide the title of the article and the author(s) name(s) and full postal address for correspondence.

References should be given in the Harvard System.

In text — Author(s) name and initials followed by the date of publication. Use a,b, to indicate more than one publication in the same year. Where there are 3 or more authors use first name followed by et al.

For books — Laszlo, J. & Bairstow, P. (1985) *Perpetual Motor Behaviour* (Rinehart and Winston)

For chapters within books

Morley, T.R. (1992) Spinal deformity in the physically handicapped child, in : G.T. McCarthy (Ed). *Physical Disability in Childhood* (Churchill Livingstone)

For articles — Scott O.M., Hyde S.A., Goddard C.M., Dubowitz V., (1981a) Prevention of deformity in Duchenne muscular dystrophy. *Physiotherapy* 67(6), 177-80.

Tables and Figures

The approximate position of the tables and figures should be indicated in the manuscript.

Keys to symbols should be included.

Tables should be numbered by Roman numerals and figures by Arabic numerals.

Figures should be supplied in a finished form, suitable for reproduction. Figures will not normally be redrawn.

Proofs will be sent to authors if major alterations have been made to the text.

The Editorial Board reserves the right to edit material submitted for publication.

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