Chapter 6

Child, family and therapist working as a team

This chapter will look at ways in which therapists and families can best relate to each other and work together.

I have chosen to talk about families rather than parents because, very often, the whole extended family can work in partnership with the therapist to help the child function better at home. Although in most cases mothers are the main carers, sometimes a brother or sister has more time than a mother to use play to help the child to function better. Sometimes an aunt or uncle can persuade a child to do more difficult activities. This is not a criticism of the mother; rather, it is a realisation that a mother’s relationship with her child may not always be compatible with her working with him as a therapist does. A child looks to his mother for protection and comfort. Exercises may challenge him and make him feel insecure, and he may feel confused if it is his mother who instigates such a feeling.

Another reason for choosing to work with the wider family is that the attitude of the family as a whole can have a huge impact on how the mother feels about her child, and even how she handles him in his daily care. This makes it important for therapists to seek opportunities to work with other members of the family as well as the mother.

This chapter is divided into two parts. Part 1 deals with the issue of partnership between therapist and family. Part 2 deals with how therapy can be carried out as part of daily care.

Part 1 - How can therapists be good partners

Research has shown that, no matter how expert the treatment, physiotherapy or occupational therapy alone cannot make significant improvement in the child’s condition. There has to be carry-over from the treatment into the child’s everyday life. As therapists, it is our responsibility not only to help families understand this, but also to enable them to put it into practice.

This poses a problem for many therapists. Instead of treating children ourselves and using our skills to enable them to do things they could not do before, we are being asked to
pass on our hard-earned knowledge and skills to every family, no matter what its circumstances or level of education may be. Many therapists feel that by doing this they are undermining their own professional status.

I think we should look at it like this: as therapists we have the knowledge and skills that enable us to assess, and then design a programme for, children of all ages with all types of CP. We are passing on to each family the understanding and skill that they need to enable them to work with their own unique child. By doing this we are planting the seeds from which an effective partnership will grow and bear fruit. And there is the even more compelling reason that if we don’t teach the families what we know about their children, we cannot bring about any lasting improvement in their condition.

So, as well as being therapists, we must also be teachers and trainers. To some extent we have to be social workers too, because before we can work with a family we have to understand a good deal about them. We need to know

- what their attitude to the child and his disability is,
- what their home situation is like,
- what coping mechanisms they have,
- what capacity for learning they have, and
- what relevant knowledge, skills and insight they have.

We have to learn the skills that enable us to gather this information from the family, without seeming to be inquisitive. This requires us to develop a friendly way of behaving and interacting with them. At the same time, they have to feel able to trust us to keep the information they give us totally confidential. They have to feel safe, that the secrets they share with us will not be used for anything except the benefit of their child. I think there are very few therapists who have been trained to do these things as part of their basic education. They are expected to learn ‘on the job’, often without any role models. This is a very difficult thing to do. It means making a fundamental change in how you see yourself as a therapist. In order to do this it might help to look at some recent material that has been written on the roles of professional people (such as doctors, lawyers, therapists, accountants).

Reading the research, as a professional, can be depressing. Professional people, it seems, are not very popular! This attitude to professionals is reflected in the findings of a number of research projects that have shown that patients and clients feel oppressed by the power they feel professionals exert over them. In his book, Challenging the Professions: Frontiers for Rural Development (London, 1993), Robert Chambers describes how rural communities in developing countries were the very last people to be consulted when the economists and engineers were planning a project. After the project had been completed it was discovered that it was quite inappropriate for local needs. If only the professionals had consulted the local people in time, a lot of money and effort would have been saved. Situations like this
have encouraged people planning services to feel they can manage without professionals. In some countries, community-based rehabilitation programmes are being run without therapists, because the planners say that therapists bias the programme towards the medical model when what local communities need is the social model.

The medical model tends to focus on the individual as a patient, attempting to make him or her as ‘normal’ as possible. Control of rehabilitation is solely in the hands of medical experts. Success or failure is seen only in terms of how the medical programme enables the disabled person to conform to what society regards as normal. Those who cannot achieve this ‘normality’ are considered failures by society, and of course the therapists will also feel they have failed.

The social model tends to imagine that impairment is not the real obstacle. Efforts are focused on encouraging the community to accept the person just as he or she is, and on adapting structures within the community to accommodate to disabled people’s needs. Control of these efforts is much more in the hands of the community and of disabled people (or their families) themselves.

The balanced model is the model accepted by the World Health Organisation. It combines and integrates good quality individual rehabilitation with efforts to bring about social inclusion for the child and his or her family. In this model the evaluation of needs and the search for solutions are shared between all concerned in a cooperative way.

I have seen the failure of the medical model in many of the different countries where I have taught. In these countries I often hear therapists complain about parents: ‘They don’t care enough about their children to work with them,’ ‘They are not educated enough to understand the importance of treatment,’ or ‘Parents are lazy, they just want us to do all the work.’ I believe what happens is this: parents come to therapists in the hope and expectation of a medical cure for their child’s condition. They are likely to be very worried and depressed about their child and they are not likely to be impressed by a cure that comes in the form of exercises that may seem just like playing. And so either they do not comply, or they carry out the exercises but without any faith in their value. After some time they lose hope that even these efforts can make any difference.

The therapist, on the other hand, has a huge number of children to treat. It is tempting to concentrate time and effort on those families who listen easily to advice, who understand that the exercise programme will help and who have enough time and energy to give to their children. The therapist thinks, ‘It’s not my fault if people don’t listen to my advice,’ and he or she takes less and less time and trouble over those families who seem not to care. In the end they stop coming, and the child is left untreated at home. In places where there are few therapists and a large number of children to treat, this happens to the majority of children. Only a few parents are able to act on the therapists’ advice.

The social model may be successful in giving the family and the child a much better environment in which to function. Families, however will very often worry that their child
is not having opportunities, to learn to walk, for instance. This is because no one involved with the programme has the necessary expertise to advise them as to how they can best help with this. Without good therapy, it is certain that the dangers of contractures and deformities will be much greater.

Padmani Mendis in her paper on community-based rehabilitation (CBR) wrote that when physiotherapists (or well-trained rehabilitation workers) were involved in a programme the output, in terms of both quality and coverage, was greater. So there is recognition that expertise is necessary. It is not, however, the existence of the expertise that is in question, it is the way in which this expertise is delivered to people with disabilities, or to their families, that can be a problem. In his book Disability, Liberation and Development, Peter Coleridge has written in a very sensitive and telling way about the relationship between therapists and people with disabilities. He says, ‘nobody is arguing for fewer professionals: let us be very clear about that. They are vital. What is at issue is the underlying attitude they bring to the job. What disabled people want is to join with professionals in formulating policy on rehabilitation and then to work with them to implement it. This is an exciting positive process which in no way detracts from or undermines the importance of the professional task; on the contrary, it enhances it.’ The ‘underlying attitude’ he is talking about is the way in which therapists tend to think of the people they work with as ‘cases’ or ‘patients’ rather than people. A ‘case’ is something to be cured and made ‘normal’. What a disabled person wants is to be seen as a whole person. This includes these children and their families. To be able to work with a family successfully, the therapist needs to

- include the family and the child in the planning of the child's programme,
- help the family and child to accept what cannot be cured, and
- always work towards functional goals that the child or family have chosen and that help towards social integration.

We must give up the idea that in some way we are in control of the children and their families. We are there to serve their needs, and we can only do this by understanding those needs and by using our knowledge and expertise to help the family to meet them in their own way.

One of the most important tasks we have is helping the family to come to terms with their child's condition. Both therapists and parents have the difficult task of realising that therapy can give good but limited results. Through therapy some children will become independent, and perhaps able to earn a living, others will become partially independent, and still others can only be helped by making them easier to look after. This can be a painful and difficult truth to accept. The process of acceptance will be slow and costly, but without it there will be only disappointment and despair.
There are personal qualities that we can develop, in the same way that we develop handling skills, to help us in this difficult task. These qualities are: being able to

- listen and show you understand,
- allow family to participate as equal partners,
- give information clearly, and
- teach handling skills.

Listening and understanding

These skills need to be thought about and practised. Not being ready to listen is one of the most frequent criticisms families make about some professionals.

We need first to think about what makes for good listening. Think about the following list of elements of good listening and ask yourself how many of them you employ in your listening to families.

- Putting aside your own opinions. Don't judge parents and don't allow your own assumptions to interfere with your ability to pay attention and absorb information from them.

- An open posture. Does the way you are sitting show that you are interested? Sitting with crossed legs and folded arms, for example, can make you look tense and impatient. Your posture should show that you are relaxed but attentive.

- Eye contact. The amount of eye contact you make will vary from one culture to another. The important thing is to make sure that you make eye contact in the right way to give the parent the feeling that you are taking in what they are saying.

- Facial expression. Again, this will vary from one culture to another, but the way you change your facial expression as you listen should reflect your interest and sympathy. It should never reflect disapproval or criticism. Even if a mother tells you that sometimes she feels total rejection for her child, it is not appropriate for you to be critical of this feeling. Rather, it is necessary for you to show that you accept and are trying to understand her feelings and you are glad she is able to tell you about them.

- Attentive silence. It is important to leave enough silence for the parent to be encouraged to go on talking.

- Giving the right encouragement. Small acknowledgements from time to time that you have heard and understood what the parent has said—but don't interrupt the flow of
speech—are good encouragement. For example, you could say things like, 'I see,' or 'Really,' or even just 'Mm-hm.'

- Asking open questions. These are questions that have to be answered at length. They cannot be answered with 'Yes' or 'No.' For example, you could ask a parent, 'How does your child spend her day at home?' or 'How did you feel when you first learnt that your little boy had cerebral palsy?'

- Giving feedback. Letting the parent know that you have understood by summarising the answers. For example, 'I see, so your little boy spends most of his day lying on the floor but you sometimes prop him up on a chair.' Sometimes it is difficult for a parent to describe a situation, and then you could ask further questions to help them give you a clearer picture. For example, 'I’m sorry I don’t quite understand, do you mean...?'

It is important to be aware, though, that getting a parent to talk, and listening in an open, accepting way can cause uncomfortable feelings. The parent may feel he or she is taking up too much of the therapist's time, or feel frustrated because the therapist is not coming up with an instant solution to their problem. The therapist, on the other hand, may be very tempted to abandon the quiet listening approach and to come in too quickly with solutions and advice. The opportunity may then be missed to hear everything the parents want to say, and the therapist will not have the full picture of how they manage as a family.

Coming to an agreement for action

According to the medical model, the therapist decides on a programme for the child and gives the family a list of exercises they must do with the child at home. This seldom works. A better approach is one of equal participation of the therapist and the family in the problem-solving process.

The therapist and the family each come to the situation with a very different point of view. The therapist comes with the responsibility for achieving the best rehabilitation for the child; he will be thinking about how to prevent contractures and deformities and how to enable the child to be as independent as possible and to achieve the best quality of life. The family, on the other hand, have the responsibility for the child as a whole and for the family as a whole. A deal has to be struck that accommodates both these perspectives.

Forming a partnership is a process which must start with open and honest sharing of information between parent and therapist. As can be seen from the diagram below, this leads to a shared definition of the problem. From the parent's point of view, the problem may be the other demands on their time and effort besides what they have to give to their child. From the therapist's point of view, the problem may be what will happen if the child is not given at least a minimum amount of the parent's time. What is important, if the partnership is to be successful, is that each one understands the other's point of view. Once both
partners have accepted each other’s definition of the problem, both of them can suggest solutions. The parents’ solutions are given equal weight to the therapist’s solutions as long as the therapist’s reasons for doing things in a certain way are understood and accepted, and as long as the parents’ reasons for perhaps not being able to carry out certain activities at home are also understood and accepted. Then the decision to carry out the programme can be made and implemented in true partnership.
Case study

Mariam is 2 years old and has cerebral palsy. She is mainly floppy but she is beginning to show some involuntary movements. She needs to be placed in good sitting and standing positions so that she can develop some postural control in an upright position. If she does not get this experience she will start pushing herself around the floor on her back and this will reduce her chances of developing any hand function and of, later, learning to walk.

Mariam's family are extremely poor. She lives with her three brothers and two sisters in very cramped conditions. Her father is a small farmer. Her mother has been bringing Mariam to see the physiotherapist for several weeks, but it is clear that she has not been carrying out the home programme.

The physiotherapist decides to take a whole session just talking with Mariam's mother to try to negotiate a decision on how to solve the problem. At first, Mariam's mother is very defensive, and tries to insist that she does work hard with her daughter at home. The physiotherapist does not challenge this but instead points out that it must be very hard for her to find time and energy to do any extra work at home. She sympathises wholeheartedly with her and shows that she understands what life must be like for her. Mariam's mother starts to cry and then she pours out all her concerns. Her husband gets angry because he feels she shouldn't take time to work with Mariam. He thinks Mariam will never be of any use and she should just leave her without much attention. Also, before Mariam was born, her mother used to sell some vegetables to supplement the family income. Now she can't do this any more because she doesn't have time. She is also too tired and depressed.

The physiotherapist realises that the mother alone cannot deal with these problems. She tells her this and then suggests that, if possible, on her next visit, she bring along her husband and any other member of the family who might be willing and able to help. Mariam's mother is greatly relieved to be told that the responsibility for her daughter is not hers alone.

The following week, Mariam's mother manages to bring her husband with her, and also her husband's mother. The physiotherapist finds a quiet place where they can all discuss the problem together. She then asks some open questions to the husband and mother-in-law to find out what they think about Mariam's condition, and also to learn more about the whole family's situation and ways of coping.

She discovers that Mariam's father is indeed angry about the time his wife spends with Mariam. He hints that this is because the family income has reduced as a result of her no longer being able to sell vegetables. She also discovers that his mother has time to spend, but that she has the idea that Mariam's case is hopeless. (The therapist is giving the family the chance to talk openly.)
Problem defined

- Family point of view: No use working on a hopeless case
- Therapist's point of view: Without work at home, the child's case will be less hopeful

The therapist lets the family know that she understands completely what they have told her, and that she does not in any way judge or condemn their feelings and attitudes. She then tells them that she needs them to understand her point of view about Mariam. She needs them, first to know that many children who are floppy like Mariam can learn to walk in time if they are given some good handling early in their lives. Second, she tells them that they need to understand that if Mariam is not given opportunities to be in standing and sitting, she will be much more difficult to handle and look after as she grows bigger. (The therapist expresses her opinions clearly.)

She tells them that she will help them to find ways to put Mariam in standing and sitting that will not make extra work for them. She asks them if they have any ideas about how to solve the problem of who will help Mariam's mother in carrying out Mariam's care. She explains that if Mariam is dressed in the right position, carried about in the right position and encouraged to use her hands when playing, this will be her treatment. If everybody who handles her does these things in the right way, then in three months' time Mariam will, very likely, be sitting alone at least for a minute or two. (The therapist puts forward some helpful suggestions.)

The idea that there is hope for Mariam to improve and that a definite goal can be achieved is very encouraging for the family. The grandmother immediately says she will help for an hour or two every day so that Mariam's mother can start growing vegetables for the market again. Her father says that he is willing to help her play whenever he is home, and that he will encourage the other children in the family to do the same.

Decision reached by both therapist and family

- Each one is happy that what has been decided is possible and likely to be effective
- Participation increases responsibility

These suggestions are, largely, the family's own ideas. They are not imposed on them by the physiotherapist. Therefore, the family will be more likely to carry them out.

Before they leave, the physiotherapist shows all of them how best to lift and carry Mariam, and also shows them some satisfying games to play with her in a good position. She tells them that next time they come, they will discuss together what kind of chair and standing frame they will find most useful so that Mariam could be placed in sitting and standing.
The physiotherapist says you must stand if you don’t you will never be able to walk.

I can’t manage to make him stand. It’s too difficult.

I know it’s not easy and you have so much else to do. Let’s invite other members of your family here to discuss the problem.

I can look after the baby while your mother works with him.

I can play with him when I have finished my work.

I can put him in his standing frame sometimes.

If you prepare him by holding him like this it will be easier to put him in the standing frame.

Come and knock down this tower, Sami.
Being able to give information

Different people grasp the information they are given in different ways. Some people need to have the information written down, others understand better if the information is explained verbally and demonstrated. As therapists, we need to find out how each family member we are working with can best understand the information we are giving.

We have to also remember that often parents are feeling too upset to take in any information. When a mother is in a state of shock and disbelief that her child is disabled, the only information she can take in is something that gives her hope and comfort. A way of carrying her child or positioning her that is clearly making the child less stiff or less floppy will be the kind of information that she might be able to understand and remember. She will also be more able to accept information given to her by someone she trusts, someone whom she knows understands her feelings and respects her as a person. In her vulnerable state she may think that the world has a right to reject her. As therapists, we are responsible for building up her confidence in herself as a person and as a mother. We can do this by giving her only as much information as she can take in and by helping her to act on that information.

Families are not in a state of shock all the time, however. They manage in many ways to come to terms with their situation, and we must support them as they learn to cope. As Mariam's case study demonstrated, giving information to the family as a whole, rather than just one member, is a good way of doing this. If the mother is the only person being given the information, she has the extra burden of acting on that information alone and of trying to convince other family members that this is the right thing to do. They may not be convinced, and then the therapist will have caused divisions in the family.

It is strange how we human beings decide which information to act upon and which not! For example, we know it is bad for us to be overweight, to smoke, to not exercise or to lift things in the wrong way. But do we, truthfully, always act upon this knowledge? It is interesting to reflect upon why we don't. We are more often tempted to do the things that are bad for us when we are depressed and our self-esteem is low. The same is true for families with children who have CP. They know they should do 'exercises' with their children, but they are tempted to neglect this difficult duty because they don't believe they can make a good job of it. Our first duty, then, is to convince them that they can, and that it will make a difference. The information we give to the family must be just enough for them to understand exactly what we are asking them to do and why we are asking them to do it. For example, 'If you place your child in a standing frame for 10 minutes every day, he will start to be able to balance better in sitting.' The information should also be linked to some aspect of the child's lack of ability that the family have expressed worries about. If the activity we are asking them to do is directly linked to overcoming a problem they are concerned about, they will be more likely to be motivated to carry out that activity.
Choosing short-term goals

A key to giving families hope is being able to choose short-term goals and inform the family about them. This means being able to say that some measurable improvement will happen if the programme agreed between the family and the therapist is carried out.

An example might be of a child who pushes back into extension with any stimulation, and whose mother is having problems carrying him or leaving him in any position except supine on the floor. The programme negotiated with the family is that the child will be carried in a sitting position with no pressure against his head, and that he will be placed in a prone standing frame for 15 minutes twice a day. He will have one meal while standing in the standing frame. He will spend as much of the rest of the day as possible in a side lying position with toys suspended so that he can touch them with his hands. The measurable improvement at the end of six weeks of this programme might be that the child can hold his head erect for one minute while he is held in a sitting position. This small piece of improvement may not seem very impressive. However, if it has been predicted by the therapist and the programme has been faithfully carried out by the family, all concerned may be justified in feeling a sense of real achievement and be encouraged to move on to the next step.

Some families find it helpful to have a notebook in which the programme is written down and the goal they are working towards described. They might like to place a tick on a chart for every part of the programme they carry out. Over a period of a year or more, they will be pleased to look back at the number of goals they have achieved. They will also have built up a high level of confidence in their own ability to bring about improvement in the child’s condition.

<table>
<thead>
<tr>
<th>Date</th>
<th>Placed in standing</th>
<th>Placed side lying</th>
<th>Ate whole meal in standing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1/6</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>2/6</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>3/6</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>4/6</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>5/6</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>6/6</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>7/6</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
</tbody>
</table>

The following table could be written at the back of the same notebook so that the family can see the slow but steady progress their child is making.

Of course, it is not easy to accurately predict the child’s improvement. It takes experience to know what is possible and what might be too ambitious. If you find you are being overoptimistic in your predictions, try to choose a slightly longer timeframe or a less difficult task. The important thing is to offer realistic hope without giving too definite promises.
Exceptionally difficult relationships

With most families, it is possible to form a working relationship that benefits the child. Sometimes the therapist has to accept that a family cannot do as much with the child as she would like, and she has to adapt her programme to suit the family’s needs and abilities. At other times the family has to listen to the advice of the therapist so that they can make an informed choice about how to manage their child. As long as there is a close relationship between therapist and family, these issues can usually be resolved.

In some instances, however, it becomes difficult to the point of being impossible to work with a family. This usually comes about because the family is under some severe strain other than that of having a disabled child. The family may be living in dire poverty, or one of the parents may be suffering from mental illness. Perhaps the family have lived through terrible experiences that have left them traumatised.

On the other hand it must be recognised that, sometimes, therapists themselves become stressed and overburdened. Many hard-working, conscientious therapists burn out because they are overwhelmed by the emotional and physical stress of the job they do. In such cases it may help all concerned if the therapist takes a few weeks’ break from therapy. During this time off, the therapist should have the opportunity to discuss her problems with a colleague or with a programme manager. Perhaps the family would do better with a new therapist for a while, or perhaps the colleague or programme manager could negotiate with the family so that a different member of the family works with the therapist and child for a while.

While everything possible must be tried for the sake of the child, sometimes cooperation fails and the relationship between the family and the therapist is one of disagreement and even hostility. Even so, it may not be necessary to give up on a family completely. It may be possible to get back into a relationship with them when their circumstances or access to resources changes, or when they recognise their child’s need for therapy. That is why it is important, even with the unfriendliest family, to try to part without harsh words so that the door is left open for a return to cooperation.

Example of page in home programme notebook

<table>
<thead>
<tr>
<th>Short-term goal</th>
<th>When set</th>
<th>When achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sammy will be able to hold his head erect for one minute while he is held in sitting</td>
<td>3/6/99</td>
<td>18/7/99</td>
</tr>
<tr>
<td>Sammy will be able to lift his head and hold it up for one minute while lying face down over a roll</td>
<td>18/7/99</td>
<td>2/9/99</td>
</tr>
<tr>
<td>Sammy will be able to balance alone in sitting on the floor for one minute</td>
<td>2/9/99</td>
<td>20/10/99</td>
</tr>
</tbody>
</table>
Partnership with children

So far, this chapter has concentrated on working in partnership with the adults in a child's family. It should, however, be every therapist's ambition to draw children themselves into the process of working in partnership. It is easy to underestimate how much even very young children understand. It can cause serious distress to a child and his family if a therapist talks about the child as if he is not there or as if he can't understand, when in fact he understands well. This is particularly true of children who have difficulty speaking. It is a wise therapist who, from the first contact with a child, talks to that child in a manner that conveys a readiness to be close and to understand what the child might want to communicate.

Above all, the therapist should understand every child's fundamental need to be able to play. Their cerebral palsy, and perhaps also their learning difficulty, may be preventing them from using play in the way that normal children do, to explore the world around them and to make some sense of it. The programme the therapist decides on for each child must take this into account, and the child must be helped to play in a way that is satisfying. In order to engage children in active participation in their treatment, it is essential to choose play activities at the right level and within the intellectual capability of the child. Once the child realises that his therapist can help him to play in the way that he so longs for, he will be more ready to cooperate and work with the therapist to also achieve some of the therapist's objectives. The therapist may want the child to be placed in standing, perhaps, or balance in sitting, but the child just wants to play. Both can achieve their objectives if the therapist sets the scene in just the right way.

Figure 6.1

The child is playing, while the therapist is looking for good active extension
From a very early stage the therapist can communicate to the child, for example, how it is good to be in standing: how he can see more, how tall it makes him and how strong it makes his legs. Later, when the child can understand a lot, it is very important to explain clearly why exercises are important.

Many children are capable of taking responsibility for some of their own treatment from an early age. But this can only happen under certain conditions. The first of these conditions is that the therapist and the child's family believe the child is capable of taking responsibility, and they communicate this to him. The second is that the child feels capable and is proud of this. Choosing the right task to start the child working in this way is obviously crucial. It must be a task that the child understands to be useful. An example might be a child who spends some hours sitting at a school desk every day. To counteract this, when he comes home he does some active hip and knee extension in standing. This is a self-disciplined way of working. The child knows it helps him and he trains himself to do it. It would help if he knows of other children who work in the same way. Children who have learnt to be self-disciplined will take a great load off their parents' shoulders. They will avoid the usual ineffectual nagging that parents fall back on when things are difficult, and they will be prepared for a lifetime of understanding their condition and taking responsibility for making the best of their lives.

All this achievement, however, depends on the therapist communicating in a good way with the family and the child. It depends on him choosing the right tasks for the child to take responsibility for, and finally it depends on him being able to teach the child to carry out the exercises in the right way so that the child feels good about his achievements and motivated to continue.

PART TWO

In the chapter on treatment I touched on a few ways of carrying and positioning children. This chapter will cover more fully the different ways in which the handling and placing of children can be made easier for families. It will also show how everyday activities can be actual treatment for a child.

It is likely that a child will have to be lifted and carried around at some point in the day. He or she may also have to be dressed and undressed, bathed and taken to the toilet, and in between left in one position or another that is safe. Some families are so stressed and busy that they may not be able to do anything more with their child than take care of these basic needs. If we can at least help them to carry out these activities in a way that is easier for them and of benefit to the child, we won't have to feel the child is getting no treatment.

The most important thing of all to teach the whole family is how to lift the child. Many people lift a child up from the floor as in the following illustration.
Figure 6.2
Lifting like this puts a strain on the lifter’s back.

Figure 6.3
Holding the child close to the lifter’s body and using her leg muscles to lift protects her back from strain.
Lifting with straight legs and a bent back puts all the strain on the small muscles of the lifter's spine. In time, these muscles are damaged and back pain can become chronic. The secret to protecting the lifter's back is to lift in such a way that the legs, rather than the back, take the strain. The child must be held close to the lifter's body, not at arm's length, and the back should be kept straight while the hips and knees bend.

Most parents tend to handle children too quickly. It may be necessary to take a good deal of time to explain to them that if they handle their children more slowly and give them time to respond, they will be helping them to develop. As a child is lifted up in stages from the floor, for instance, she will try to hold her head steady in each stage. If she is just scooped up, there is no time for her to begin to take control. Another example is when a child is dressed quickly and given no time to try to push his arm into a sleeve or lift one foot to place in his trousers.

Teaching handling skills is an art. Often therapists try to teach families how to handle their children just by demonstrating, and parents may be embarrassed about trying out the skill in front of the therapist. Without specific training, however, it is not possible to expect a parent to change from the way they have always handled their child to a wholly new way. Success will come only through step-by-step teaching of parents and family while giving them constant reassurance that they are doing a good job. But they will only be doing a good job if the therapist has chosen the right task for them to do and has been a patient and skilful teacher.

As you teach people these handling skills, try to remember how you felt the last time you had to learn to do something difficult. When you were a student, learning to carry out passive movements or set up electrotherapy treatment, how easy was it to learn when your teacher was watching every move? When he was patient and encouraging, was it easier to learn than when he was critical or when his body language made him seem so?
### Possible ways of carrying a child*

<table>
<thead>
<tr>
<th>Type of CP</th>
<th>One way of carrying small child</th>
<th>Alternate way for small child</th>
<th>Large child</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severe spastic extended child</strong></td>
<td>Push back is prevented by holding hips in flexion and not supporting head</td>
<td>Prevents abnormal push back and facilitates postural control of head</td>
<td>Flexion and abduction of hips prevents abnormal push back</td>
</tr>
<tr>
<td></td>
<td>Child is held in good extension and encouraged to actively lift head</td>
<td>Child is held in good extension and encouraged to actively lift head</td>
<td>Arms are prevented from pulling down into flexion. Head and trunk encouraged to actively extend</td>
</tr>
<tr>
<td><strong>Severe spastic flexed child</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Moderate spastic quadriplegia</strong></td>
<td>To prevent flexor spasticity and facilitate active extension</td>
<td>To prevent adduction and internal rotation of hips and facilitate postural control of head and trunk</td>
<td>To inhibit pull down in arms</td>
</tr>
<tr>
<td><strong>Spastic diplegia</strong></td>
<td>To prevent adduction and internal rotation of hips and facilitate postural control of head and trunk</td>
<td>To prevent adduction and internal rotation of hips and facilitate postural control of head and trunk</td>
<td>To prevent adduction and internal rotation of hips and facilitate postural control of head and trunk</td>
</tr>
</tbody>
</table>

*These are only suggested ways for carrying children. If they work to help the mother carry her child more easily or to help the child to have better postural control, use them. If not, try some other way. (continued)*
## Possible ways of carrying a child (continued)

<table>
<thead>
<tr>
<th>Type of CP</th>
<th>One way of carrying small child</th>
<th>Alternate way for small child</th>
<th>Large child</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hemiplegia</strong></td>
<td>Hemi side facing forward helps head turning to affected side</td>
<td>To inhibit retraction of hemi side</td>
<td>Child walks alone but, if insecure, hold hemi hand</td>
</tr>
<tr>
<td><strong>Athetoid</strong></td>
<td>To facilitate symmetry and postural control of head</td>
<td>To facilitate symmetry and postural control of head</td>
<td>Held in alignment for symmetry and postural control of head</td>
</tr>
<tr>
<td><strong>Athetoid with dystonic spasm</strong></td>
<td>To prevent extensor spasm and encourage active extension</td>
<td>Hips held flexed to prevent push back</td>
<td>To prevent extensor spasm and encourage active extension</td>
</tr>
<tr>
<td><strong>Floppy child</strong></td>
<td>To give sensori-motor experience of upright position and facilitate postural control of head</td>
<td>To give sensori-motor experience of upright position</td>
<td>To facilitate holding head erect</td>
</tr>
</tbody>
</table>

(continued)
Suggested positions in which to dress children

<table>
<thead>
<tr>
<th>Type of CP</th>
<th>Baby</th>
<th>Older child</th>
<th>More able child</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severe spastic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>extended child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prevents extensor spasticity facilitates active extension</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Severe spastic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>flexed child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Movement of mother’s legs helps prevent flexor spasticity</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Moderate spastic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>quadriplegia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourages active extension in trunk and movement of arms away from trunk</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Athetoid</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Flexed hips prevent push back. Neck cushion gives possibility of head in midline</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(continued)
Suggested positions in which to dress children (continued)

<table>
<thead>
<tr>
<th>Type of CP</th>
<th>Baby</th>
<th>Older child</th>
<th>More able child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athetoid with dystonic spasm</td>
<td>Hip flexion prevents push back. Neck cushion gives symmetry</td>
<td>Prevents extensor spasms. Facilitates holding head and trunk in mid-position</td>
<td>Mother's legs (one behind pelvis, the other over child's legs) give proximal fixation so child can actively help</td>
</tr>
<tr>
<td>Hemiplegia</td>
<td>Use opportunity to get head turning to hemi side. Put hemi limbs in first</td>
<td>Mother sits at hemi side. Prevents neglect of hemi side and unequal weight bearing</td>
<td>Using hemi hand with help while holding on with unaffected hand</td>
</tr>
<tr>
<td>Floppy child</td>
<td>Possibility of seeing own limbs and helping in dressing</td>
<td>Good position to facilitate head raising</td>
<td>Mother's legs (one behind pelvis, the other over child's legs) give support so child can be active in trunk and arms</td>
</tr>
</tbody>
</table>

It is not possible to describe the exact dressing position that is best for every kind of child. These tables are meant only to give guidelines. Try to remember that weight-bearing on arms is very important and functionally useful for all children. If you can use dressing to facilitate this then try to include it in your instructions to the family. Rotation in the body axis is also very useful and helps to reduce spasticity. It is often easy to facilitate rotation while the child is prone over the mother's knees. In a more able child, shifting weight from one side to the other, to lift one leg and put on a sock for instance, is another way to facilitate rotation.
Before teaching family members about dressing the child, however, do ask them to show you how they do it themselves and ask what difficulties they have with it. If you see something going very wrong (for example, the child becoming very asymmetric) then gently suggest, show them and let them try a different way and explain why you think it might help the child. As a general rule, choose only one thing at a time to change so that the family is not overwhelmed with new instructions.