

## PERSONAL PRACTICE

# Restrained rehabilitation: an approach to children and adolescents with unexplained signs and symptoms

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The validation of treatment approaches for children and adolescents diagnosed with unexplained signs and symptoms is made difficult by the variety of clinical presentations and the different developmental levels of different patients. There is little evidence about what combination of approaches is most successful. This article uses what evidence is available to develop a coordinated multidisciplinary rehabilitation package that ensures consistency and can be evaluated. The package is organised around a psychologically informed physical rehabilitation programme. The need for coordination and a common approach between medical, allied health and psychological staff, and family is formally addressed. The approach is illustrated with a case study.

conflicts being manifest as physical symptoms; communication of certain thoughts or feelings in physical symptoms that cannot be expressed verbally; reinforcement and social learning variables<sup>8</sup>; underlying depression, anxiety, or abuse<sup>9,10</sup>; and precipitation by a disturbing psychological event.<sup>11</sup> In our experience, underlying psychological explanations cannot always be identified, consistent with a case series which showed that in a study of five children diagnosed with conversion disorder, none had major psychopathology.<sup>12</sup> By the time children with conversion disorder are seen by our team, they usually have entrenched patterns of pain and/or disability that are not removed by purely psychosocial interventions, and exclusive focus on the psychological may prove ineffective and cause resentment of the therapist by the patient. Conversely the exclusive application of a medical model may escalate symptoms, and increase the utilisation and expense of medical services.<sup>3</sup> Available literature supports the use of physical rehabilitation, although there is a lack of high quality evidence.<sup>2,12</sup> A rehabilitation programme can legitimise a patient's condition and help to provide a dignified exit from the illness or presenting state.<sup>8</sup>

There is no agreed label for the clinical presentation of a patient who displays physical symptoms of uncertain origin. Common terminology includes conversion disorder/reaction, hysterical paralysis, psychosomatic presentation, somatisation disorder, and functional pain. For the purposes of this paper, the term conversion disorder will be used to describe cases where no physiological explanation for symptoms is found in the course of an appropriate medical assessment.

There is no consensus regarding the prevalence of conversion disorder.<sup>1</sup> Conversion disorder is more common in adolescents than in either children (rare under 8) or adults,<sup>2</sup> and is identified in females more than males.<sup>3,4</sup> Developmental differences between adults and children lead to different injury and pain presentations,<sup>5</sup> so that the adult conversion disorder literature is of limited usefulness in the assessment and management of a paediatric population. The variability of physical presentations is wide. The experience at the Women's and Children's Hospital, Adelaide (WCH) is consistent with published presentations in the paediatric population, which include paralysis, gait disturbance, visual disturbance, pain syndromes, and speech disorder.<sup>2,6</sup>

Most authors accept that symptoms of pain or dysfunction in conversion disorder are psychological or emotional in origin,<sup>1,3,7</sup> but this does not form an essential part of our working definition. The diversity of views about aetiology suggests that there may be no single explanation for conversion disorder. We therefore remain open to the importance of factors such as: psychological

The treatment model utilised at WCH is an integration of effective interventions described in the literature. There are five elements: management of the medical system; pain management; identification and resolution of predicament; management of emotional feelings; and restrained rehabilitation. The programme is implemented at a case discussion between the managing medical team, and allied health and Department of Psychological Medicine staff, followed by a joint meeting with the family. The aim is to implement all five elements. Sometimes families are resistant to certain elements, or no focus for intervention is found. For example, in some cases, no predicament can be identified, or if a predicament is identified, it is not judged as suitable for intervention. The cornerstone of the WCH approach is functional rehabilitation, which is the element to be described in detail in this paper, but we will first briefly outline the other four elements.

## MANAGEMENT OF THE MEDICAL SYSTEM

Patients with chronic illness are frequently managed by multiple health professionals, often without all of them being informed of the roles and interventions of others. A multidisciplinary approach is important to ensure that all parties involved in the treatment of a patient are projecting the same language and methods.<sup>2</sup> The

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mainstay of managing the health system is the facilitation of case conferences with health professionals from within and outside the hospital to facilitate communication between the patient, their carers, and health professionals. Where the family rejects the rehabilitation model, the health system can still respond in a way that minimises harm. We have found that successful management of conversion disorder requires that everyone involved, including the family, achieve enough of a working consensus about the problem to be able to reach a workable treatment package. Most often, the consensus is that “nobody knows” what is causing the pain or disability.

### **PAIN MANAGEMENT**

Staff speculation and scepticism regarding pain that has no clear explanation may have negative effects.<sup>3</sup> In those cases where there is significant pain, our pain management is aggressive, encompassing chemical analgesia, hypnotherapy, and physical remedies, so that patients are convinced of the commitment to reducing their pain. Against this background, patients and their families are informed that pain will not determine the pace and structure of the rehabilitation programme. We explicitly contradict the view that function can return when pain eases, pointing out that pain is often slower to respond to the rehabilitation programme than is function. Our patients and families have mostly accepted this approach.

### **IDENTIFICATION OF PREDICAMENT**

Taylor has argued that childhood conversion disorder is often the manifestation of some otherwise insoluble predicament in which children find themselves.<sup>13, 14</sup> Pretending to be sick is part of every child’s repertoire,<sup>15</sup> and family or other predicaments (loyalty issues in relation to marital conflict, compromised parental functioning) can lead to the unwitting exercise of this way of coping in cases of conversion disorder in children. When a predicament is identified, its management facilitates the rehabilitation process.

### **MANAGEMENT OF EMOTIONAL FEELINGS**

There is a high prevalence of anxiety and depression in chronic illness, and outcomes are improved if these symptoms are addressed. Furthermore, there is some evidence that enhanced discrimination and expression of emotional feelings enhances quality of life in the face of chronic illness.<sup>16</sup> Clinically, we commonly see that chronically ill patients can misperceive emotional feelings, such as anxiety, as manifestations of their physical illness. Furthermore, unrecognised unresolved feelings interfere with treatment adherence. Therefore enhancing emotional literacy is an essential element of the rehabilitation approach.

### **RESTRAINED REHABILITATION**

The central aim of management is to restore function, and our view is that this task should be led by a professional skilled in the management of the primary disability: physiotherapists for patients with musculoskeletal and neurological presentations; occupational therapists for difficulties where activities of daily living are compromised by, for example, dizziness; and speech pathologists for functional coughs, aphonias, and dysphagias. The rehabilitation programme should occupy and structure the whole day, and clear requirements for adherence to set goals are essential. Before the week is commenced, the patient and physiotherapist chart an agreement as to what will be required of all players, which is then displayed in the patient notes and in the patient’s room. All professional staff are responsible for encouraging the child to stick to this programme. The written expectation of the patient’s activities mean that there is less likelihood of confusion or resistance from the patient. It is useful to allow adolescents to participate

in setting goals and milestones to enhance feelings of mastery. Although the programme is restrictive, we are often able to engage adolescents as partners in its development, promoting compliance and enthusiasm.

Jane (14) was admitted to hospital four weeks after an injury at gymnastics. A previous referral to a local physiotherapist had been declined by the family for fear that it would cause Jane too much pain. Pain was located across both shoulders, cervical spine, and low back. All movements aggravated pain, which was unresponsive to analgesia. Jane was mostly confined to bed at home. She was barely able to transfer from bed to chair alone and was only able to walk 10 metres unaided. Neurological assessment, plain x ray and computed tomography scan were normal. The child psychiatrist and physiotherapist met with the orthopaedic registrar, whose initial interpretation of the negative findings was that Jane was “putting it on”. After some discussion, the registrar accepted that none of us really knew what was causing the pain. This view was then put to the family as the medical consensus, along with reassurance that dangerous causes of back pain had been excluded. The family were told that the orthopaedic surgical team would remain involved, but would now be working in partnership with psychological medicine and the physiotherapist, who would provide a rehabilitation programme. We explained to the parents and patient that an initial injury can lead to muscle weakness and joint stiffness because of inactivity. The main goal was to slowly increase functional ability through a highly structured rehabilitation programme guided by functional goals. We explained that, any acute inflammation having settled, pain was no longer a good indication of the need for rest, so that while we would manage pain aggressively, we would want rehabilitation activities to go ahead as planned. This approach was acceptable to the family.

Jane’s predicament seemed fairly clear. She was an only child of socially isolated parents, who both spent much time taking Jane to her 10 gym classes a week, and were invested in her gymnastic career at the expense of their own interaction and peer activities. It seemed there might be little left in their lives once Jane grew up. There also seemed to be difficulties for all three in the expression of any disagreement or strong feelings. Only limited progress was made in dealing with these psychological issues during Jane’s inpatient stay, so that the focus was on the physical rehabilitation process.

This rehabilitation approach, influenced by the King’s College Hospital management of chronic fatigue syndrome,<sup>17</sup> is described as “restrained” for several reasons: it is slow; favoured activities are often prohibited until unfavoured activities are achieved; there are clear injunctions against exceeding the targets set by the rehabilitation programme on “good days”; and children remain in hospital until the agreed level of functional competence is restored.

### **Slowly graded increase in exercise**

Graded exercise can reduce incapacity and symptoms in many chronic and painful conditions.<sup>18</sup> Demands for rapid progress can compromise recovery, while limiting expectations for improvement can negate the damage to self esteem that failure could bring to the patient. Our patients even feel that they

**Table 1** Jane’s exercise programme, week 1

	Mon/Tues	Wed/Thurs	Fri/Sat	Sun/Mon
Walk	10 metres	25 metres	20 metres twice	50 metres
Throw & catch ball	2 minutes	4 minutes	6 minutes	8 minutes
Physio exercises	1 set × 5	1 set × 7	1 set × 9	2 sets × 6

are being held back by the programme, and this restraint seems sometimes to lead to more rapid improvement. Table 1 presents Jane’s exercise programme.

**Restraint from engaging in favoured activities**

The patient’s rehabilitation is restrained through the establishment of a hierarchy of activities according to the objective difficulty that each activity presents, given the apparent disability. The patient cannot proceed to the next functional step until the current level has been mastered. The hierarchy means that favoured activities, which are often more demanding, are proscribed until more mundane ones are accomplished. This can serve as an incentive for the patient to achieve functional improvement in tasks that may not appeal to them, such as return to school.

The treating physiotherapist spent a session with Jane and elicited as an overall goal being able to actively participate in sport without pain. He then asked her to identify five physical activities that she enjoyed and thought she may be able to manage now or in the next days. These activities were then incorporated into a programme for the coming week, guided by the physiotherapist to ensure that it was in keeping with the hierarchical approach, as well as addressing muscular imbalance through stretching and truncl stability exercises. The result was a programme that Jane felt was her own, and through which she would achieve important intermediate goals (such as return to school) on her way to resuming favoured activities.

**Good day/bad day**

Patients with any disability often experience good and bad days,<sup>17</sup> feeling that they can manage a greater level of activity or exercise than prescribed on the good days, and feeling unable to achieve goals on the bad days. Both over- and underactivity can stall progress. Excessive unaccustomed use of the musculoskeletal system may result in delayed onset muscle soreness that may take up to 48 hours to resolve. Conversely, rest on a bad day will delay recovery in strength and functioning, and can increase fatigue, interfering with

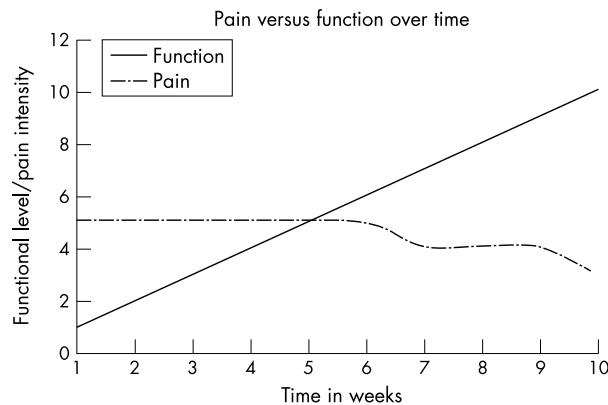
achievement of the next day’s goals. A vicious cycle of attempt at exercise, increased pain, and rest may develop. The firm insistence on strict adherence to set goals in spite of discomfort is accompanied by positive encouragement, promotion of self management skills such as relaxation and positive imagery, and various motivational techniques, such as externalising language and hypnotherapy.

Importantly, pain levels should be expected to fluctuate, and will not improve at the same pace as functional abilities. All staff need to reinforce that while pain may not be getting better, functional improvements show that good progress is being made. Figure 1 shows Jane’s course of recovery, and has proved useful in showing families, when they first embark on the programme, what to expect.

**Remain in hospital until functional independence is achieved**

In most cases, patients are in hospital at the time of referral. When a diagnosis of conversion disorder is made, medical and nursing staff often advocate for immediate discharge or transfer to the psychiatric ward. We have not found psychiatric admission optimal for our patients. Nor have we had success when children are discharged from hospital before they are sufficiently mobile to allow attendance at school free of any mobility aids (crutches, etc). Our view is that the level of disability caused by conversion disorder is usually sufficient to warrant intensive inpatient (or day patient) intervention. Except in the most severe cases, the inpatient phase is rarely longer than 10 days. The inpatient setting also maximises potential for successful control of the environment and for the interdisciplinary structure to adhere to a common treatment philosophy.<sup>8</sup> Unless all team members are very experienced, there is a danger that they may lose enthusiasm for directing rehabilitation services towards patients that they may not be convinced are “really” ill, or even begin to worry that they are being deliberately manipulated. Staff are able to respond more positively with the extra support that is available when a child is being treated in an inpatient setting.

After a three week admission, Jane had progressed to independent mobility, and was spending full days at the hospital school, even though she had no diminution of her pain experience. She had progressed sufficiently far along her activity hierarchy to be able to engage in some of her favoured leisure activities, and was considered able to cope at her ordinary school and therefore ready for discharge. Initially outpatient physiotherapy appointments were made for 2–3 times per week with the same principles of goal setting; functional improvement was maintained. Gradually pain levels diminished, and Jane stopped taking analgesics about two months after discharge. The family was seen fortnightly by the child psychiatrist, and after several sessions, Jane herself was able to articulate her frustration that her parents “don’t have a life of their own”.



**Figure 1** Graph showing Jane’s course of recovery.

**CONCLUSION**

In the absence of any clear evidence for any overall approach to the management of conversion disorders in childhood, we

have sought to develop an approach that is supported by what literature is available, and is clear, explicit, and open to evaluation. We recognise the importance of addressing family and psychological factors, and the role of the health system. It has been our experience that when these factors are appropriately addressed, positive outcomes can be readily achieved through an intensive and well coordinated physical rehabilitation programme that is tailored to the needs and emotional maturity of children and adolescents. The approach that we have labelled "restrained rehabilitation" awaits further evaluation.

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## ARCHIVIST .....

### Fryns syndrome

**H**ere's a syndrome to bear in mind when you see a newborn baby with congenital diaphragmatic hernia. In 1979 JP Fryns and colleagues described two siblings who were stillborn and had craniofacial anomalies (coarse facies, large nose with flat bridge, large mouth, narrow palpebral fissures, low set ears, and cleft palate), hyperplasia of distal phalanges, short, webbed neck, and bilateral diaphragmatic hernias. It is an autosomal recessive condition but the chromosomal location is unknown. There is considerable variation in phenotype but the four most consistent features are distal digital hypoplasia, coarse facies, abnormal ears, and congenital diaphragmatic hernia. The latter is said to be a feature in some 75% to 90% of cases. About 14% of reported cases have survived the neonatal period. Between 1995 and 2001 details of 1833 children with congenital diaphragmatic hernia were entered into the database of a Congenital Diaphragmatic Hernia Study Group including data from 83 US hospitals. (The Congenital Diaphragmatic Hernia Study Group. *Journal of Pediatric Surgery* 2002;**37**:1685-7) Twenty-three (1.3%) of these children were given a diagnosis of Fryns syndrome. (Previous estimates had put Fryns syndrome as the cause of some 4% to 10% of all cases of congenital diaphragmatic hernia.) Eight of the 23 had cardiac defects including a variety of individual anomalies. One had an omphalocele and one a neural tube defect. The diaphragmatic hernia was on the left in 15, on the right in 3, and bilateral in 2 (side unspecified in 3). Four children underwent extracorporeal membrane oxygenation. The 23 children did badly. Sixteen were not operated upon for their diaphragmatic hernias and all of these died at an average age of 2.25 days (30 minutes to 11 days). Seven underwent surgical repair between 6 hours and 14 days after birth and four survived to go home at between 32 and 129 days. Two of these four needed further surgery. Three had marked developmental delay and the fourth was thought to have delayed development but had not yet been assessed formally. Three died after 6, 15, and 168 days.

Fryns syndrome is an apparently rare, autosomal recessive disorder with a high rate of stillbirth and early neonatal mortality. Estimates of mortality and of the contribution of the syndrome to the total number of children with congenital diaphragmatic hernia will of course, depend on ascertainment and rates of referral to specialist surgical centres. Of the 19 children in this series who died six had care withdrawn with the agreement of their parents.