



The child with multiple impairments

The World Health Organization defines a child with multiple impairments as a child with a significant physical disability combined with a sensory and/or cognitive disability (1). Such a child may place tremendous stress on a family because of the many associated issues and the fact that, in most cases, the child has a chronic condition with no cure.

The objective of this statement is to address the role of the paediatrician or family physician in caring for children with multiple impairments and their families. This role includes:

- interpreting the diagnostic findings of the multidisciplinary team to the family;
- responding to the child's changing needs as he or she ages;
- providing continuity of care in a family-centred context;
- collaborating with the entire family;
- delivering care in the community;
- coordinating care between the members of the multidisciplinary team and community-based services; and
- empowering family members to become active partners with professionals so that parents can act as decision-makers, and problem solvers who are able to make informed and appropriate choices.

Comprehensive care begins with a thorough evaluation of the child and family. The child's etiological and secondary conditions, as well as contributing environmental factors, should be identified through a history taking, medical examination and pertinent laboratory analyses. The medical assessment should include a standardized evaluation of development to identify the child's functional status in the areas of general intelligence, gross and fine motor skills, language, and social adaptation. Many children with multiple impairments experience 'comorbidity' with behavioural or psychological problems (2).

The diagnosis should be explained to the family, with the understanding that family members may grieve for the loss of the 'ideal' child. Initial parental reactions may include denial, sadness, anger and guilt. Gaining the confidence and active participation of the family in the child's medical care is a long process, and it is essential to foster this involvement. Medical information often needs to be delivered repetitively because family members may not hear or absorb it all at the time of diagnosis.

Ongoing support is crucial to these families; they incur increased expenses, which are aggravated frequently by the loss of income. Family life becomes more isolated. The physician should acknowledge that the parents of a child with multiple impairments face a recurring series of stresses and, at times, may see a doctor when they are unable to cope any longer. Families affected by chronic poverty, low educational levels, parental psychopathology, prolonged separation from an infant in the first year of life, marital discord and divorce, remarriage and step-parenting, a lack of family and community supports, and the lack of structure and rules in the household are at risk for maladaptive adjustment, and will require extra services to foster coping abilities (3).

Comprehensive care of the child and family should focus on three main areas (4):

- anticipatory guidance with an overall tracking plan to be used throughout the child's infancy, and toddler, preschool and school years until adolescence, and transition to adulthood vocational training and employment;

- prevention of secondary problems; and
- preservation of family function through the adequate use of resources.

The above areas should be addressed at the first visit and updated when appropriate during each follow-up visit. During subsequent visits, the physician should make every effort to identify the accomplishments of the child and parents, and to deliver praise and encouragement, acknowledging that parents are the most knowledgeable individuals about their child's abilities and impairments. These steps not only help to develop a good relationship between the physician and the family, but they also help to create a relaxed atmosphere where the medical visit is not viewed as a 'fault finding' venture.

ANTICIPATORY GUIDANCE

Overall planning for each age-dependent cluster of goals

Some of the issues that require anticipatory guidance from the physician at various developmental stages are as follows:

- **The first two years:** sitting and mobility with or without special equipment and technology, the transition in feeding from liquids to solid foods, early stimulation and the acquisition of early developmental skills.
- **The preschool years:** communication skills, feeding, toilet habits, child care, recreational activities, special equipment and adapted technology.
- **The school years:** special education classes, social skills, recreational activities and camp.
- **Adolescence:** menses, masturbation, sexual activity, contraception, prevention of sexually transmitted disease and vocational training (5).
- **The transition to adulthood:** vocational placement and outside placement in a group home.

Nutrition

Although a complete discussion of nutrition is beyond the scope of this paper, important nutritional issues, such as weight gain (either insufficient [6] or excessive [7]), fat stores, a special diet in cases of metabolic disorders, the 'nutriceutical' role of high doses of vitamins (8), feeding problems (including difficult deglutition) (9), gastroesophageal reflux (10), possible aspiration (11), and constipation (12) should be addressed by the physician on a regular basis.

Safety issues

The physician and parents should discuss standard safety issues, such as smoke detectors, the appropriate temperature of tap water, keeping small objects out of the child's reach, window locks, storage of dangerous household products and medications, stair gates and adapted

car restraints. Parents should be made aware that children with multiple impairments are at increased risk of physical and sexual abuse, particularly when other caregivers are involved.

Immunization

The child with multiple impairments should receive regular immunizations that follow the routine schedule as closely as possible. Hepatitis B immunization should be included because of the increased risk of transmission in specialized child care centres. Pertussis immunization of children with neurological disorders is now appropriate because of the availability of the new acellular pertussis vaccine (13). Influenza vaccine should be given each year, where appropriate.

Positioning

Anticipatory guidance about positioning should begin during the first days of the child's life by teaching caregivers how to promote a 'physiological' posture that reproduces the posture of a term newborn with normal neurological status (14). For a child who is unable to maintain an active sitting position, an adapted seat will allow better positioning of the head, and facilitate eating, the use of the upper limbs and interaction with the caregiver and the environment. A child who can sit should use a seat that holds him or her in a correct sitting position (with a physiological lordosis) and prevents the kyphotic position with retroversion of the pelvis. Promoting the sit to stand progression is also important. When standing with the help of an appropriate aid, the child can interact with the rest of the family at eye level (15).

Mobility

Mobility is a crucial issue that must be discussed in the child's first year of life. Because parents perceive walking to be a very important milestone, it is essential that the physician help parents realize that their child may not walk. Assisted mobility allows the child to exert some control over his or her environment, to learn autonomy and social skills, and to develop self-esteem, competence and his or her cognitive potential. Some children will develop the ability to ambulate at home, but they will use a wheelchair or another device for mobility outside of the home (16).

Dental hygiene

Fluoride supplementation in communities where water is not fluoridated is important (17), as is good dental hygiene, beginning as soon as teeth are present. Because many syndromes present with disorders of the teeth (eg, hypodontia or extra teeth), it is essential to promote the health of gums and teeth. Moreover, some anticonvulsive medications, such as phenytoin, cause hypertrophy of the gums. Early dental referral is essential.

Elimination

Physicians should explain bladder- and bowel-related conditions, such as a neurogenic bladder, and the various therapeutic options available (18). Parents should also receive anticipatory guidance about constipation, combined with appropriate diet counselling and treatment (12).

Vision and hearing screening

Vision and hearing screening will help to correct any treatable deficit that the child may experience. Professionals (eg, from the Canadian National Institute for the Blind) who are appropriately trained in stimulation programs should be included in the screening process.

Screening specific to the disease

Appropriate screening measures specific to the child's disease should be undertaken. For example, the child with trisomy 21 would benefit from the following measures (19):

- screening at birth for malformations of the heart and the gastrointestinal tract;
- screening at birth for cataracts;
- screening at birth for hypothyroidism;
- an auditory brain stem response test in the child's first six months of life, and annual evaluations of hearing until three years of age, and then every other year;
- annual vision assessment;
- growth monitoring;
- annual screening for thyroid dysfunction;
- routine dental care every six months;
- routine immunizations;
- cervical spine radiographs at three, 12 and 18 years of age; and
- annual physical and neurological examinations.

Early stimulation

Infants with multiple impairments are often difficult to arouse, and their responses to the same stimulus vary over time. The physician should provide early developmental intervention appropriate to the child's condition and level of development. Overstimulation is as counterproductive as hypostimulation, and the child should always be spoken to slowly. Families should be referred to early intervention programs and rehabilitation services, such as occupational therapy, physiotherapy, speech therapy and infant-parent programs.

Attachment

Various aspects of the child's impairments may affect the parents' attachment to the child. Bonding may be tenuous if the child is particularly fragile or remains dependent on equipment in a hospital for a long period of time. On the other hand, some parents may develop an excessively close attachment to the child. Attachment difficulties may lead to great disappointments and psychological maladjustment (20).

Sleep problems

The causes of sleep problems are extremely variable, and few empirically validated treatment options are available. Several behavioural strategies have been studied, including the following (21):

- Graduated extinction is a strategy where parents respond to the child's bedtime problem after increasingly longer time intervals.
- Chronotherapy refers to delaying or shifting scheduled bedtimes and wake times by 2 h per day until the desired hours of sleep are achieved.
- Bedtime fading implies that the child is sent to bed at a relatively late time and then, gradually, at an earlier time.
- Response cost allows the child to be removed from bed for a specified period if he or she fails to fall asleep within a preset time after going to bed.
- Melatonin treatment seems promising, especially if the child experiences blindness, mental retardation and other central nervous system diseases (22).

Pain

Although children with neurological impairments generally do not display typical pain behaviours, they may experience pain caused by activities of daily living, spasticity, medical procedures and surgery. Pain assessment is quite challenging in the presence of cognitive and communication impairments. While there is no tool that is known to be valid and reliable for assessing pain in neurologically impaired children, baseline information of child-specific patterns of behaviours can be obtained from parents. Ongoing comparative use of this information over time can provide useful measures (23). Everyday pain should be treated with a graduated analgesical approach, according to the World Health Organization's analgesic ladder, with steps ranging from the use of nonopioids to opioids, plus adjuvant medications for increasing or persistent pain (24). Spasticity should be approached with a treatment plan specific to the underlying condition, including physical and occupational therapy, and antispasticity medications such as baclofen and botulinum toxin (25). Opioids, with or without benzodiazepine adjuvants, should be used for acute or procedural pain. Epidural analgesia is particularly valuable during orthopedic procedures, and postoperative pain can be treated with patient-controlled and regional analgesic techniques, and appropriate monitoring (26).

Behavioural and psychological issues

Children with mild or moderate retardation may exhibit disruptive behaviours (eg, aggression, impulsivity), attention deficit hyperactivity disorder, anxiety disorders, and obsessive-compulsive disorder. In cases of a severe developmental delay, some children may exhibit stereo-

typical or self-destructive behaviours. As children get older, other psychiatric disorders may occur, including depression, mania and bipolar disorder. Children with 'comorbidity' may benefit from counselling, special support, and psychopharmacological medications, which reduce arousal symptoms and improve affect, behaviour and general functioning (4).

PREVENTION OF SECONDARY PROBLEMS

Nutritional status

Undernutrition: Undernutrition is an important risk factor for infections and impaired immunity. Children with cerebral palsy often have a significant impairment of their chewing and swallowing mechanisms, which leads to decreased food intake and increased eating time. The problem is made worse by gastroesophageal reflux and aspiration. Treatment should provide high-energy supplementation, given either orally, with tube feeding or through enterostomy. Formulas used should have higher ratios of nutrients to energy. To maintain oral-motor skills, enterostomy should be supplemented with an oral stimulation program (27).

Obesity: Children with certain conditions, such as trisomy 21, have a tendency to become obese (19). Some children are less active, have reduced muscle mass and decreased energy needs; they are at risk for adult-onset diabetes. Physicians should also consider the role of excessive exposure to television in the development of obesity and encourage appropriate exercise programs.

Orthopedic problems

Multidisciplinary intervention is often required to minimize orthopedic complications. Children with spasticity are at risk of developing contractures. Initiating an in-home, physiotherapy program as soon as the child is sent home from the hospital helps to maximize joint range of motion and delays difficulties arising from contractures. Therapies, such as casting and orthotics, can help to reduce the possibility that contractures will develop.

Other strategies for orthopedic problems that may be considered for some children include oral medications, injection of botulinum toxin and dorsal root rhizotomy.

Monitoring is very important because the development of scoliosis is a significant risk factor in some children (28).

Recurrent infections

Aspiration pneumonia: Aspiration during feeding can be detected by radiological swallowing studies. Gastroesophageal reflux must be considered in cases of recurrent aspiration pneumonia. If medical treatment of the reflux fails to prevent recurrent pneumonia, a surgical approach with gastrostomy should be considered.

Decubitus ulcers: Care should be taken to prevent decubitus ulcers. In cases where procedures of general hygiene

might become painful, the child must receive appropriate local anaesthesia.

Urinary tract infections: Preventing urinary tract infections is very important when managing patients with a neurogenic bladder. Clean intermittent catheterization can usually be performed from the time of birth, and many children are able to learn the technique. Despite antibiotic prophylaxis, some children will have positive urine cultures at some point, but unless there is evidence of clinical infection, it seems that a better management technique is to postpone broad-spectrum antibiotics to prevent the emergence of resistant strains (18).

Communication skills

Children with multiple impairments are at very high risk of developing speech and communication difficulties. Speech and language can be affected by dysarthrias, oral-motor apraxias or dyspraxias, which make expressive language very difficult to elicit. Speech and language therapy should be integrated in the child's program. Augmentative communication modalities, such as communication boards or electronic devices, should be implemented, if necessary (29).

Educational issues

Children with multiple impairments require individualized education programs and the involvement of a multidisciplinary education team.

Psychosocial status

Children with multiple impairments are at risk of developing low self-esteem and depression, which are more common when parental expectations are unrealistic and exceed the abilities of the child.

Quality of life

Social readiness is essential for vocational training and employment. Many communities have employment opportunities ranging from competitive employment, such as work as an office clerk or messenger, to the traditional sheltered workshop.

PRESERVATION OF FAMILY FUNCTION

It is important to preserve both the interests of the child and the family when planning the care of a child with multiple impairments. A nurturing home environment will maximize the child's capabilities, minimize the effects of the impairments and prevent or reduce the length of hospitalization. A comprehensive plan for the home care of a child with multiple impairments should take into account the following (30):

- the medical stability of the child, and the capacity for backup and emergency care;
- the ability of family members to perform required medical and nursing tasks;

Table 1: Selected Internet web sites related to children with multiple impairments

Topic	Internet web site
Children & families	<ul style="list-style-type: none"> • <i>Child & Family Canada</i> <www.cfc-efc.ca/index.htm> provides quality, credible resources on children and families. Visit the site and click on Special Needs
Disabilities	<ul style="list-style-type: none"> • The Family Village Library <www.familyvillage.wisc.edu/library.htm> is a good source of information about disabilities. Visit the site and click on Card Catalog of Specific Diagnoses
Trisomy 21	<ul style="list-style-type: none"> • <i>Health Care Guidelines for Individuals with Down Syndrome</i> <www.nas.com/downsyn/dshh.html> • <i>Ups and Downs, Calgary Down Syndrome Association</i> <www.cadvision.com/upsdowns>
Cerebral palsy	<ul style="list-style-type: none"> • <i>Cerebral Palsy Canada</i> <www.cerebralpalsycanada.com>
Support groups	<ul style="list-style-type: none"> • <i>Canadian Directory of Genetic Support Groups</i> <www.lhsc.on.ca/programs/medgenet/support.htm>

- the home situation, especially the physical environment, safety and geographic location;
- the availability of respite and emergency services;
- the availability of specialized child care and special education;
- the availability of recreational programs;
- the involvement of a paediatrician to provide primary care, and communicate with other physicians and health care professionals involved in providing care;
- the availability of necessary equipment and supplies; and
- financial reimbursement for transportation from home to hospital or specialized clinics, specialized daycare or school, equipment and sitters.

The development of advanced technologies has saved the lives of many severely handicapped children who would have died in the past. These medically fragile, technology-dependent children pose additional stresses on the already challenging situation of caring for a child with multiple impairments at home (31). One significant source of stress is the chronic nature of the medical crisis, which is associated with the physical burden of care and the time demands of home care. Another source of tension is the disruption of normal family life, with its impact on family dynamics, activities and schedules, including work-related responsibilities and the effect on siblings. Some studies report an increase in marital discord (32), while other studies show that this is not the case (33).

The coordination of care is essential and must address the following areas (34):

- medical services for planning treatment strategies, coordinating visits with subspecialists, avoiding duplication of tests and services, sharing information with the multidisciplinary team and the family,

facilitating access to services, training caregivers, educating local emergency medical services, and ongoing reassessment and refinement of the care plan;

- educational services to identify the need for individualized testing, special education and therapy services, gaining access to appropriate transportation and acquiring assistive technology devices;
- social and public health services for locating, and accessing financial assistance programs and public health services; and
- services in the home setting for organizing home nursing and therapy services, respite care, and adapting the home to support special technology.

The coordination of services is very important because families need adequate follow-up from nursing agencies, insurance carriers and durable medical equipment suppliers. All aspects, including financial considerations, must be discussed with family members, who should feel comfortable with the choices that they make.

Support networks are an important supplement to medical services. They are generally devoted to promoting the proper diagnosis, treatment and prevention of a specific condition, with an emphasis on nutrition, physical fitness and stress management. The networks provide written information, such as newsletters, updates about disease diagnosis, management and prevention, and a list of local support groups for sharing knowledge, ideas and emotional support with other parents (35). Table 1 outlines selected Internet web sites, which may provide additional information.

In addition to coordinating medical care, the role of the family physician or paediatrician is to act as an advocate in the community on behalf of the child and family, while empowering the caregivers to be active, knowledgeable decision-makers.

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PSYCHOSOCIAL PAEDIATRICS COMMITTEE

Members: Drs Anne C Bernard-Bonnin, Département de pédiatrie, Hôpital Sainte-Justine, Montréal, Québec (principal author); T Emmett Francoeur, Westmount, Québec (director responsible); Sally Longstaffe, Child Development Clinic, Children's Hospital, Winnipeg, Manitoba; William J Mahoney, Children's Hospital – Hamilton Health Sciences Centre, Hamilton, Ontario (chair); Peter Nieman, Calgary, Alberta; Sarah Emerson Shea, IWK-Grace Health Centre, Halifax, Nova Scotia

Consultants: Drs Katerina Haka-Ikse, Toronto, Ontario; Rose Geist, The Hospital for Sick Children, Toronto, Ontario (representing the Canadian Academy of Child Psychiatry)

Liaisons: Drs Diane Moddemann, Child Development Clinic, Children's Hospital, Winnipeg, Manitoba (representing the Canadian Paediatric Society Developmental Paediatrics Section); Mark Wolraich, Vanderbilt Child Development Center, Nashville, Tennessee (representing the American Academy of Pediatrics, Committee on Psychosocial Aspects of Child & Family)

The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.

Internet addresses are current at the time of publication.