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Counseling Problems of a Family Whose Child Has Muscular Dystrophy

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Is there a great need of counseling for the family with a disabled child? The answer is a loud "yes!" What is a disabled child? H Oliver Ohsberg replies,

Disabilities are deviations in body formation or function that happen as a baby comes into being. They may be caused by heredity, by disease, or by something that happens to the infant during the prenatal period, at birth, or immediately following birth. About 20 percent of the congenital anomalies have genetic causes, another 20 percent are due to environmental conditions, and the remaining 60 percent probably are due to a combination of the two factors.¹

"Out of eight families, there is a child with a disability of some kind." ² One counselor writes,

The National Foundation—March of Dimes reports that one baby in every sixteen has a serious birth defect. The term "congenital malformation" is applied to a defect that is present at birth, though not necessarily apparent. About 150,000 persons per year are born with some sort of congenital malformation.³

A disability is such an undesirable problem because it causes pain, discomfort, embarrassment, tears, confusion and the expenditure of time, energy and money. Since so many families are being affected, the need for medical, educational and spiritual counsel is obvious. Yet, Leo Buscaglia who spent six years of his professional life in counseling the disabled and their families declares,

It is appalling how little attention is given, still, by medical doctors, psychologists and educators to the counseling of disabled persons and their families. This fact becomes even more astounding when one investigates the available literature and pertinent research in this field. With the exception of a few books, mostly of dated readings, works which deal in a very general way with the field of rehabilitation counseling, some inclusive and often contradictory research, one is hard pressed to find meaningful literature in the field of counseling the disabled.⁴

It is also sad that so few pastors have had sufficient counseling training to minister effectively to families with such deep needs.

One congenital malformation is Duchenne muscular dystrophy. It was first described by the French neurologist in 1861.⁵ This muscle-wasting disorder, which affects boys almost exclusively, usually has its onset between the ages of two and five and progresses rapidly. Very few who have this disease survive their early twenties. There is no known cure, and no medication has been of great value in arresting it. Duchenne muscular dystrophy is one of forty neuromuscular diseases that the Muscular Dystrophy Association is researching to find a cure.⁶

In 1946, Steven Thornton was born healthy in appearance to the Thornton family. The author can remember the joy at his brother's birth even though the author was only four years old. It was not discovered until several years later that Steve was born with Duchenne muscular dystrophy. So the author has experienced the effects of muscular dystrophy in the life of a brother from birth to death (16 years old). Little counseling was given to his parents and no counsel was given to him, his sister and his normal brother who was born two years after Steve. What little counsel was given led to Steve's salvation decision a year before his death. Those sixteen years could have been even better than what they were for the Thornton family if thorough medical and pastoral counseling had been given. However, God's grace, Bible reading, prayer and church life sustained them through those years.

Early Knowledge by the Parents of Muscular Dystrophy in a Child

The parents may first observe that the child is not walking as soon as other children. When the child begins to walk, there are minor abnormalities in his gait: he tends to waddle and to walk on the toes and has difficulty in getting up once he has fallen. To get up from the ground, he will walk his hands up his legs. He has difficulty in raising his knees which prevents running. Stairs,

No disease comes from God.

difficult at first, eventually become impossible to climb. The arms are next affected. By early adolescence, he is unable to walk and gets around by a wheelchair. He may eventually get so weak that he cannot ride in a wheelchair.

Motivated by concern as they see these symptoms, the parents seek medical advice. An accurate diagnosis includes gathering data as to the age of onset, the distribution and severity of muscle weakness, and the family history. An examination of a muscle biopsy is the most definite procedure for confirming the existence of the disease. "Electromyography is also a valuable diagnostic tool, as is the measurement of various serum enzymes."⁷

Once the prognosis is made that the child has Duchenne muscular dystrophy, the disease and its causes are explained to the parents. This counsel includes information on the nature and progress of the disease and genetic counsel which would help the couple to know if the wife is a carrier of it. This would help the couple to decide whether to have any more children. The general information tells the parents that there are ten forms of muscular dystrophy. The Duchenne form is by far the most common childhood type. "It occurs about once in every 3000 to 4000 male births, and one-third of these cases arise from new mutations."⁸ This is a muscle-wasting disease which progresses upward from the boy's legs to the rest of his body. The muscle cells actually die. No one has any idea why or how this happens. Finally, the diaphragm muscles are affected and the child dies of respiratory failure. They usually die by their mid-20's.

In the genetic counseling, the parents are told that Duchenne muscular dystrophy comes either from inheriting an altered gene on the X chromosome in an "X-linked" (or "sex-linked") recessive pattern of inheritance or from a defective gene as a result of a spontaneous change in the particular egg cell that joined with a sperm cell to develop into the child.⁹ This new mutation happens where there is no previous family history of the disease. Sean Phipps explains the cases where the defective gene is inherited.

The gene for DMD is located on the X chromosome. Since the defective gene is recessive, a female with the DMD gene on one of her two X chromosomes will not develop muscular dystrophy. The normal gene on her second X chromosome masks the effect of the defective gene. Such a woman is called a "carrier." Male offspring, however, have only one X chromosome, and there are no equivalent genes on the Y

chromosome. Consequently, in males the X chromosome genes have no "partners." Therefore, a male with the DMD gene on his X chromosome will be affected with the condition because he has no normal gene to counteract the effect of the abnormal one.

Each time a DMD carrier mother has a child, there are four possible outcomes, each with an equal probability of happening. Thus, the chance of producing an affected son is one in four, or 25 percent. If we break down the risk further according to the sex of the child, it follows that there is a 50 percent chance that each son will be affected. All daughters will be unaffected, but each has a 50 percent chance of being a carrier like her mother.

It is important to point out that unaffected sons of carrier mothers do not have the DMD gene and, therefore, cannot transmit DMD to their offspring. The same is true for those daughters of carriers who have not inherited the DMD gene. If circumstances should allow a male affected with DMD to reproduce, and if his wife was not a carrier of DMD, then all of his sons would be unaffected and free of the gene but all of his daughters would be carriers.¹⁰

To find out if the wife is a carrier, a number of tests can be taken. The test most widely utilized measures the blood serum level of the enzyme creatine kinase (CK, sometimes referred to as CPK, or creatine phosphokinase).¹¹ Because there are variations in the CK levels, the test should be taken on three different occasions. Other types of tests include the measurement for serum enzymes other than CK, the measurement of various other substances in the blood, and an analysis of the structure and functioning of blood cells.¹² There are also tests which involve microscopic examination of muscle cells. "Already they can detect carriers with 98 percent accuracy."¹³ This is possible by these tests and recent studies of the muscular dystrophy gene. Once it is determined whether the woman is a carrier or not, the couple can be advised on having more children. Even if a wife is a definite carrier, there is a three-in-four, or 75 percent, chance that in any pregnancy the child will not be affected.¹⁴

Responses to the Medical Report and Counsel

There are normally four responses to the information provided by the medical authorities when it is a permanent disability or terminal illness. (1) There is acceptance of the child and his disability. R Murray and Shirley Thomas write,

This is the attitude we would hope for, because it typically leads to the healthiest personality development for the child. The parents have accepted the handicap in an objective way. They neither reject nor overprotect the child.¹⁵

Overprotection prevents possible development of abilities.

Leo Buscaglia states to parents,

Acceptance of other family members is achieved only through allowing them the dignity of personal strengths and limitations, always recognizing the limitless potentials, not for being what we desire them to be, but for their being what they are.¹⁶

(2) There is overprotection of the child. They may do this because of pity or guilt. This prevents the child from developing responsibility and abilities. The Thomases note,

In some cases the child becomes domineering. His parents (usually the mother) become his slaves. Sometimes the parents' oversolicitous attitude is really a disguised rejection of the child. They consider the handicap a disgrace. But because society takes a pitying attitude toward such children and because the parents have punitive consciences, they cannot outwardly reject their child. So they play the overprotective role.¹⁷

(3) There is overt rejection of the child. This parent is resentful and shows it through blameshifting and direct criticism of the child. This will hurt the child in his judgment of himself or self-esteem and could lead to despair and suicide.

(4) There is a denial of the disability. Too much is demanded of the child and can lead to frustration and depression. At least the child is permitted to try to participate in the activities of normal children.¹⁸

The Need for Spiritual Counsel

There is a great need to relate the disease to the Christian-world view. At the time of the prognosis, the family senses a loss—a healthy child. They will experience grief and may experience depression, guilt, anger, fear, rebellion and shame. They may ask such questions as, "Why did God do this to my child?" or "What have we done to be punished like this?" The parents, the disabled child and the other children will want to know the purpose in it or how it can be understood in relation to God and the world.

The counselor will want to stress God's sovereignty and goodness, the origin of diseases because of the effects of sin on the world, the way of forgiveness for actual personal sin, and the various biblical reasons for suffering.¹⁹ In correcting the thought

that such punishment comes from God, Dr C Everett Koop, the Surgeon General of the United States, says,

Although God does judge sin, he does not punish sins by taking the life of a child. He does not act austerely or capriciously. In and through all the trials and griefs of life, God is still omnipotent, omniscient, always holy, righteous and gracious.²⁰

Margaret Clarkson in "Who Is the God of the Sufferer?" declares,

Teaching that suffering comes from God is a dangerous distortion of biblical truth.

This distortion stems from an incomplete understanding of God's sovereignty. True, God is in control of His children's lives, and nothing can come to them but what He sovereignly permits. But it is not true that all that happens is God's doing, nor that all that comes to them is His gift.

Nor does God exempt His redeemed ones from their part in the common lot of human pain. He does not promise that we shall be free from trouble, but rather that He will be with us in it, will uphold and keep us, and will enable us to overcome. He promises that He will work and overrule through all things, good or bad, for our eternal gain.

Nowhere does He say He will use His sovereignty to exempt us from suffering, but He promises He will deliver us from its evil; we shall not suffer spiritual loss. Indeed, far more New Testament promises have to do with the certainty of suffering than with material good; suffering, in fact, is the badge of Christ's discipleship.²¹

The pastoral counselor will want to answer the questions of the family as they relate to God, themselves and God's world which has been affected by sin. This will give the family a foundation for their thinking, behavior and feelings. A Christian philosophy of life will enable the family to spiritually profit and grow through this experience and to turn a tragedy into a triumph. Romans 8:28 declares, "And we know that all things work together for good to them that love God, to them who are the called according to his purpose."

Prayers for and Interest in Muscular Dystrophy Research

Christian parents and family members will pray daily for the loved one who has muscular dystrophy and for the soon discovery through research of a cure for this dreadful disease. The author remembers that he prayed every night until his brother's death for healing by God directly or through a cure discovered by research. He still prays for such a discovery.

God desires parents to turn tragedy into triumph.

Research on muscular dystrophy is motivated and advanced by the Muscular Dystrophy Association which fights 40 neuro-muscular diseases. There have been given 750 research grants to investigators in the United States and abroad. At ten university-based research/clinical centers supported by MDA, teams of scientists are conducting interdisciplinary investigations into the complex problems of these diseases.²² A major breakthrough in finding the gene which causes Duchenne muscular dystrophy has been made. J Silberner in "Muscular Dystrophy Defect Located" writes,

Somewhere on a piece of one arm of the X chromosome lies an area responsible for Duchenne muscular dystrophy, the most common form of the muscle-wasting illness. Now, researchers report that they have pinpointed the area. The effort, led by Louis M Kunkel of Harvard University, makes possible more accurate carrier identification and prenatal diagnosis.

Duchenne muscular dystrophy (DMD) is carried by mothers. Girls as a rule do not get the disease, because even if one of their two X chromosomes bears the deficiency, the other one can make up for it. But women with one deficient X chromosome are "carriers." Fifty percent of their sons inherit the faulty X and suffer the disease, which generally kills its victims before they reach their early 20's.

Ten researchers, from Harvard, Brandeis University in Waltham, Mass, Duke University in Durham, NC, and the University of Pennsylvania in Philadelphia, report in the Aug 29 NATURE the discovery of an X chromosome deletion at or very near the DMD gene, changing the scale of the genetic map from the range of millions to thousands of base pairs—the "rungs" on the DNA ladder.²³

Prior to this discovery, R H Lindenbaum of Oxford University diagnosed the disease in a young girl whose X chromosome was broken at position Xp21, a dark band near the middle of the short arm. Since then, twelve girls have been discovered who have Duchenne muscular dystrophy. All have a break in their X chromosome in approximately the same area.²⁴ This is significant since this disease is not passed to girls from the mother. It must have occurred through a new mutation.

In addition to this work of geneticists, there exists a task force on drug development which is searching for drugs that will arrest or reverse the progression of muscular dystrophy and related

neuromuscular diseases. A few years ago Scottish and Spanish scientists reported that a drug called allopurinol had helped a limited number of muscular dystrophy patients, but their finds have not been confirmed.²⁵ There is evidence that the muscle degeneration underlying muscular dystrophy may be initiated by proteinases (enzymes that break down the protein). Joanna Hollenberg Sher and her colleagues at the State University of New York Downtown Medical Center in Brooklyn, New York found that the proteinase inhibitor, leupeptin, delayed muscular dystrophy in chickens and mice.²⁶ J A Treichel writes,

Sher and her team will give leupeptin to a handful of muscular dystrophy patients once the Food and Drug Administration approves their clinical trial. Leupeptin is already being tested on muscular dystrophy patients in Japan and is soon to be tested in Italy.²⁷

Although no treatment is yet known for certain which will arrest or reverse the dystrophic process, the use of orthopedic devices and physical therapy can keep patients ambulatory longer, minimize crippling contractures, and prevent or delay curvature of the spine.²⁸ With this hope from research, Christians should continue to pray for a cure for this dreadful disease.

Reorganization of Lives

As at any time of loss, there will be shock, disorganization and reorganization. After the prognosis of the problem, the acceptance of the fact that the child has muscular dystrophy and the recognition of the place of disease in a Christian-world view, the parents will need counsel in reorganizing their lives to fulfill their responsibilities to this child and their other children. Parents will want to know about community support groups, the services of the Muscular Dystrophy Association, educational opportunities for the child and public recreational facilities where wheelchairs can be used. In reorganizing their lives, the parents will want advice on their thinking and relation to the child. Leo Buscaglia speaks to such parents,

Remember that each person who is disabled is different, and no matter what label is attached for the convenience of others, is still a totally "unique" person.

Remember that the persons with disabilities are *persons* first and disabled individuals secondly.

Remember that the disabled have the same needs that you have, to love and be loved, to learn, to share, to grow and to experience, in the same world you live in. They have no separate world. There is only one world.

Remember that the disabled have the same right as you to fall, to fail, to suffer, to decry, to cry, . . . To protect them from these experiences is to keep them from life.

Remember that only those who are disabled can show or tell you *what is possible for them*. We who love them must be attentive, attuned observers.

Remember that the disabled must do for themselves. We can supply the alternatives, the possibilities, the necessary tools—but only they can put these things into action. We can only stand fast, be present to reinforce, encourage, hope and help, when we can.

Remember that the disabled, like ourselves, are entitled to life as we know it. They, too, must decide to live it fully in peace, joy and love, with what they are and what they have.

Remember that persons with disabilities, no matter how disabled, have a limitless potential for becoming—not what *we* desire them to become, but what is within *them* to become.

Remember that the disabled must find their own manner of doing things. . . . There are many ways of tying shoes, drinking from a glass, finding one's way to a bus stop. There are many ways of learning and adjusting. They must find the best way for them.

Remember that the disabled also need the world, and others, in order to learn. All learning does not take place in the protected environment of the home or in a classroom, as many people believe.

Remember that all persons with disabilities have a right to honesty about themselves, about you, and about their condition. To be dishonest with them is the most terrible disservice one can perform. Honesty forms the only solid base upon which all growth can take place. And this above all—remember that the disabled need the best *you* possible. In order for them to be themselves, growing, free, learning, changing, developing, experiencing persons—you must be all of these things.²⁹

Parents also will need to understand that a child with muscular dystrophy will tend to repress rather than express whatever his feelings may be with respect to God, his identity and the reason for the disease in his life.³⁰ Parents should discuss this openly with the child. They should present the gospel of salvation by faith in Christ to the child and assist the child in having proper self-esteem and a Christian philosophy of life.

The parents of a muscular dystrophic child must help their other children adjust to the child and the changed conditions. They should explain the disease to the child on his level of understanding and with a Christian approach. They must be aware of possible reactions by the other children.

(1) Guilt. They may, for example, feel guilty because they think they are to blame for the illness and/or death. Very young

Parents must avoid favoritism or unequal discipline.

children often do not know the difference between a wish and an act.

(2) Jealousy. Due to the necessary time, attention, and money spent on the care of the terminally ill child, the other children may become jealous.

(3) Anger. . . . Family members can find the safest and best means of expressing and dealing with anger.³¹

Parents also must not depend too heavily on the children. Ruth Kopp asserts, "Young children and adolescents should be informed, but they need to be shielded from the full impact of adult responsibilities, adult losses, and adult grief."³² Parents should express love to each other and to all the children with words, kisses and hugs. They should answer the children's questions about the disease and speak of God's relation to the child with muscular dystrophy.

There must be a balance between overinvolvement of the other children in the illness of one child and the overprotection that tries to shield them from the harsh realities of life. Parents have a tremendous task in relating to the sick child and the other children in a way which avoids favoritism and accusations of unequal discipline. Children also need to be shown how to think and respond to people's reactions toward the family with a disabled child. Many times they are ashamed and withdraw from social activities in public. Parents need to plan family outings to provide normal social development for all.

Blessings of the Christian Home with a Muscular Dystrophic Child

A Christian family with a muscular dystrophic child normally holds to a value system which agrees with God's (Matt 6:33). Health, food and covering (house and clothes), fellowship, love, eternal life, caring friends and a supportive church are greatly appreciated. New friends are made with people who have relatives with muscular dystrophy or with people who work with muscular dystrophic patients. There also develops a team spirit as the family works together to handle the responsibilities in the home and in public. Compassion and understanding develop which are shown to other disabled and handicapped people. The family with this

terminally ill child develops a deeper trust in the Lord. God is the only One who can heal the child or enable scientists to find a cure for the disease. H Oliver Ohsberg indicates some of the good which can come from suffering.

Pain and disabilities take our thoughts off the things of this world which are temporary and lead us to consider God and eternal things (II Cor 7:8-11). Disabilities bring us to rely upon God to get us through each day and hour even. Suffering can refine our faith (I Peter 1:5-7). Our disability may allow the opportunity to display the works of God (John 9:1-3). It can produce perseverance and character (Romans 5:3-5). It may also be used by God to help us to relate to others who are suffering (II Cor. 1:3-4).³³

The writer changed his value system when he saw the shortness of life with his brother, Steve, and the eternal value of a ministry for Christ.

Sweetness of Death

Muscular dystrophic people usually die because the muscles in the upper part of their body are weakening and dying. N Karle Mottet says, "Fatality, frequent during the second decade of life, is usually due to kyphoscoliosis, sudden cardiac failure, and pulmonary infection."³⁴

In the months and weeks prior to death, the pastor will discover the concerns and needs of the person and his family. Jay Adams writes, "In ministering to the dying believer, the pastor should keep in mind the possible mixes of pain, fear, sorrow, worry, weakness, helplessness, anger and guilt that may be present."³⁵ The pastor should answer the believer's questions about heaven and afterlife from God's Word.

The funeral is a difficult time for the family. They have mixed emotions. They are sad at the loss of fellowship with a son/brother, but they are happy that he does not have to suffer any more. They know that he will have a new body like Christ's at the resurrection (I John 3:2). As the writer passed the open casket of his brother, he smiled through tears as he thought of meeting Steve in heaven with a new body. Paul is correct when he writes, "Therefore we do not lose heart, but though our outer man is decaying, yet our inner man is being renewed day by day. For momentary, light affliction is producing for us an eternal weight of glory far beyond all comparison (II Cor 4:16-17).

Families should develop a team spirit to handle responsibilities together.

Notes

¹ H Oliver Ohsberg, *The Church and Persons with Handicaps* (Scottsdale, Pa: Herald Press, 1982) pp 23-24

² Helen S Arnstein, *What to Tell Your Child about Birth, Death, Illness, Divorce and Other Family Crises* (Indianapolis: Bobbs-Merrill Co, 1962) p 48

³ Ohsberg, *The Church and Persons with Handicaps*, p 21

⁴ Leo Buscaglia, *The Disabled and Their Parents* (Thorofare, NJ: Charles B Slack Inc, 1975) p 5

⁵ Sean Phipps, *Who Is at Risk? The Genetics of Duchenne Muscular Dystrophy* (New York: Muscular Dystrophy Association, 1983) p 1

⁶ Cf Appendix I, p 17

⁷ *Muscular Dystrophy* (New York: Muscular Dystrophy Association, 1985) p 3

⁸ Gina Kolata, "Closing in on the Muscular Dystrophy Gene" *Science* (Oct 18, 1985) 307

⁹ Phipps, *Who Is at Risk?* pp 1, 6

¹⁰ *Ibid*, pp 4-6

¹¹ *Ibid*, p 7

¹² *Ibid*, pp 8-9

¹³ Kolata, "Closing in on the Muscular Dystrophy Gene" p 307

¹⁴ Phipps, *Who Is at Risk?* p 10

¹⁵ R Murray and Shirley M Thomas, "Handicapped Child" *The Encyclopedia of Christian Parenting* (Old Tappan, NJ: Fleming H Revel Co, 1982) p 221

¹⁶ Buscaglia, *The Disabled and Their Parents*, p 130

¹⁷ Murray and Thomas, "Handicapped Child" p 221

¹⁸ *Ibid*, p 222

¹⁹ Cf Jay E Adams, *More Than Redemption* (Phillipsburg, NJ: Presbyterian and Reformed Publ Co, 1979) pp 274-275 and Howard E Dial, "Sufferology: Counseling Toward Adjustment in Suffering" *Journal of Pastoral Practice*, II No 2, (1979) 21

²⁰ E Everett Koop, "The Ill Child, the Family and the Physician, Part 2" *Christian Medical Society Journal* (Winter, 1973) 11.

²¹ Margaret Clarkson, "Who Is the God of the Sufferer?" *Moody Monthly* (June, 1979) 21

²² *The CPK Test* (New York: Muscular Dystrophy Association, 1981) p 7

²³ J Silberner, "Muscular Dystrophy Defect Located" *Science News*, 128 (Sept 7, 1985) 151

²⁴ Kolata, "Closing in on the Muscular Dystrophy Gene" p 307

²⁵ J A Treichel, "Muscular Dystrophy: Promising Treatment" *Science News*, 121 (Jan 16, 1982) 39

²⁶ *Ibid*

²⁷ *Ibid*

²⁸ *Muscular Dystrophy*, p 5

²⁹ Buscaglia, *The Disabled and Their Parents*

³⁰ Douglas G Cater, "Some Observations Concerning Religious Ministry to Institutionalized Physically Handicapped Children" *The Journal of Pastoral Care*, 17, No 2 (Summer, 1963) 88

³¹ Ruth Lewshenia Kopp with Stephen Sorenson, *When Someone You Love Is Dying* (Grand Rapids: Zondervan Publ House, 1980) pp 120-121

³² *Ibid*, p 122

³³ Ohsberg, *The Church and Persons with Handicaps*, p 32

³⁴ N Karle Mottet, "Muscular Dystrophy" *Encyclopedia of Science and Technology*, Vol 8 (New York: McGraw-Hill Book Co, 1971) 751

³⁵ Jay E Adams, "Questions Concerning Pastoral Visitation of the Dying" *Westminster Theological Journal*, 36, No 2 (Winter, 1974) 209

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