cognitive impairment, to be referred for reevaluation of his or her condition as a possible genetic disorder that might not have been diagnosable a few years earlier, such as microdeletion disorders or single-gene mutations. If a genetic diagnosis is made, the patient is usually referred back to the primary care physician with recommendations for routine management.

Providing Education, Care, and Support

Maintaining contact with the family or making a referral to a health care practice or an agency that can provide a sustained relationship is critical. It is becoming more common for genetics health care professionals to provide regular follow up and management, particularly for children with rare genetic disorders. However, some families choose not to have follow-up visits with genetic experts.

Regardless of whether families choose to receive continued care with a genetics center, clinic, or professional, nurses can help patients and families process and clarify the information they receive during a genetics visit. Misunderstanding of this information can have many causes, including cultural differences, the disparity of knowledge between the counselor and the family, and the heightened emotion surrounding genetic counseling. Family members have difficulty absorbing all of the information presented during a genetics evaluation and counseling session. Knowing this, genetics professionals write and send clinic summary letters to families. The nurse may need to help the family understand terminology in the letter, help them identify and articulate remaining questions or areas of clarification, and coach them through the process of accessing genetics health professionals to get remaining questions and concerns answered. Information often needs to be repeated several times before the family understands the content and its implications.

Nurses must assess for and address parents' feelings of guilt about carrying “bad genes” or having “made my child sick.” Depending on the type of cytogenetic disorder, the nurse may be able to absolve the parents of guilt by explaining the random nature of segregation during both gamete formation and fertilization. If the condition is a Mendelian-inherited or mitochondrial disorder, it is important to assess parents' understanding of recurrence risk, help