

GENE - Genetic Disorders

GENE-BH BEHAVIORAL AND SOCIAL HEALTH

OUTCOME: The patient/family will understand the behavioral and social aspects of this genetic disorder.

STANDARDS:

1. Discuss that caring for special needs individuals may result in a variety of emotions and may require medical intervention or counseling.
2. Refer to community resources as appropriate.
3. Refer to a social worker for assistance with special programs.

GENE-C COMPLICATIONS

OUTCOME: The patient/family will understand complications which are more common with this genetic disorder than in the general population.

STANDARDS:

1. Discuss complications more common in persons with this genetic disorder (e.g., hypothyroidism, alantoaxial instability with Down syndrome.)

GENE-CM CASE MANAGEMENT

OUTCOME: The patient/family/caregiver will understand the importance of integrated case management in achieving optimal physical and behavioral health.

STANDARDS:

1. Discuss roles and responsibilities of each member of the care team including the patient, family/caregiver, and providers in the case management plan.
2. Explain the coordination and integration of resources and services in developing and implementing the case management plan.
3. Explain the need to obtain the appropriate releases of information necessary to support integrated case management and to maintain patient privacy and confidentiality. **Refer to AF-CON.**

GENE-EQ EQUIPMENT

OUTCOME: The patient/family will understand and demonstrate (when appropriate) the proper use and care of equipment.

STANDARDS:

1. Discuss the indications for and benefits of the prescribed medical equipment.
2. Discuss types and features of the medical equipment as appropriate.
3. Discuss and/or demonstrate the proper use, care, and cleaning of medical equipment.
4. Participate in a return demonstration by the patient/family.
5. Discuss signs of equipment malfunction and proper action in case of malfunction, as appropriate.
6. Discuss proper disposal of associated medical supplies.

GENE-FU FOLLOW-UP

OUTCOME: The patient/family will understand the importance of follow-up and make a plan to keep follow-up appointment.

STANDARDS:

1. Discuss the importance of follow-up care.
2. Discuss the procedure for obtaining follow-up appointments.
3. Emphasize that follow-up appointments should be kept.

GENE-I INFORMATION

OUTCOME: The parents/family will understand the genetic disorder that has been diagnosed or is being considered.

STANDARDS:

1. Discuss the symptoms of the genetic disorder.
2. Discuss the inheritance pattern of the genetic disorder, if known.
3. Explain implications for future pregnancies, as appropriate.
4. Refer to pre-pregnancy and/or genetic counseling, as available or appropriate.

GENE-L LITERATURE

OUTCOME: The parents/family will receive literature about the genetic disorder.

STANDARDS:

1. Provide the parents/family with literature on the genetic disorder.
2. Discuss the content of the literature.

GENE-LA LIFESTYLE ADAPTATIONS

OUTCOME: The patient/family will understand lifestyle adaptations necessary to care for a person with a genetic disorder.

STANDARDS:

1. Discuss lifestyle adaptations specific to this genetic disorder.
2. Discuss the availability of special programs and explain that parents must be advocates for their child with special needs (e.g., Birth to 3, Head Start, special school programs).
3. Refer to community services, resources, or support groups, as available.

GENE-MNT MEDICAL NUTRITION THERAPY

OUTCOME: The patient/family will understand the specific nutritional intervention(s) needed for treatment or management of this condition, illness, or injury.

STANDARDS:

1. Explain that Medical Nutrition Therapy (MNT) is a systematic nutrition care process provided by a Registered Dietitian (RD) that consists of the following:
 - a. Assessment of the nutrition related condition.
 - b. Identification of the patient's nutritional problem.
 - c. Identification of a specific nutrition intervention therapy plan.
 - d. Evaluation of the patient's nutritional care outcomes.
 - e. Reassessment as needed.
2. Review the basic nutrition recommendations for the treatment plan.
3. Discuss the benefits of nutrition and exercise to health and well-being.
4. Assist the patient/family in developing an appropriate nutrition care plan.
5. Refer to other providers or community resources as needed.

GENE-N NUTRITION

OUTCOME: The patient/family will understand the special nutritional needs of persons with this genetic disorder.

STANDARDS:

1. Discuss nutritional needs of persons with this genetic disorder (e.g., some genetic disorders cause failure to thrive while others may cause obesity).
2. Refer to a registered dietitian.

GENE-P PREVENTION

OUTCOME: The parents/family will understand any preventive measures for future occurrences of a genetic disorder, as appropriate.

STANDARDS:

1. Discuss factors that influence the occurrence of genetic disorders (e.g., older maternal age predisposes to Down syndrome).
2. Discuss genetic counseling options especially with families with previous occurrences of genetic disorders.

GENE-PA PARENTING

OUTCOME: The parent will understand the special parenting challenges of this genetic disorder.

STANDARDS:

1. Discuss that many genetic disorders render the patient incapable of independent life and that the parents will need to plan for long term care of the patient.
 - a. Discuss that many of these patients will require parenting well beyond 18 years of life.
 - b. Discuss that the parents should plan early for an alternative care plan in the event of death of the parents (e.g., designating a guardian, setting up trust funds).
 - c. Discuss the need for consistent parenting especially in children with special needs.
 - d. Discuss the need for respite care (alternative caregivers) to allow for time for the parents to have time for themselves.

GENE-PT PHYSICAL THERAPY

OUTCOME: The patient/family will understand the role that physical/occupational/speech therapies play in the functional ability of persons with genetic disorders.

STANDARDS:

1. Discuss physical/occupational/speech therapies as appropriate to this patient.
2. Refer as appropriate.

GENE-S SAFETY

OUTCOME: The patient/family will understand safety issues specific to this genetic disorder.

STANDARDS:

1. Discuss that some genetic disorders result in lower IQs and that this often makes the patient more vulnerable to many personal safety hazards including sexual abuse/assault.
2. Discuss safety and injury prevention issues as related to this genetic disorder.

GENE-SM STRESS MANAGEMENT

OUTCOME: The patient/family will understand the role of stress management in the treatment of genetic disorders.

STANDARDS:

1. Discuss that uncontrolled stress may increase alcohol and other drug use and interfere with treatment.
2. Emphasize the importance of seeking professional help as needed to reduce stress.
3. Discuss the various stress management strategies which may help maintain a healthy lifestyle. Examples may include:
 - a. Becoming aware of your own reactions to stress
 - b. Recognizing and accepting your limits
 - c. Talking with people you trust about your worries or problems
 - d. Setting realistic and meaningful goals
 - e. Getting enough sleep
 - f. Making healthy food choices
 - g. Regular physical activity
 - h. Taking vacations
 - i. Practicing meditation, self-hypnosis, and positive imagery
 - j. Practicing relaxation methods such as deep breathing or progressive muscular relaxation
 - k. Participating in spiritual or cultural activities
4. Provide referrals as appropriate.

GENE-TE TESTS

OUTCOME: The patient/family will understand the test(s) to be performed, the potential risks, the expected benefits, and the risks of non-testing.

STANDARDS:

1. Explain test(s) that have been ordered (explain as appropriate):
 - a. method of testing

- b. necessity, benefits, and risks of test(s) to be performed
 - c. any potential risk of refusal of recommended test(s)
 - d. any advance preparation and instructions required for the test(s)
 - e. how the results will be used for future medical decision-making
 - f. how to obtain the results of the test
2. Explain test results:
- a. meaning of the test results
 - b. follow-up tests may be ordered based on the results
 - c. how results will impact or effect the treatment plan
 - d. recommendations based on the test results