

## Networking for the GHD Adult

**Please print:**

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Country \_\_\_\_\_

Home Phone ( ) \_\_\_\_\_

Work ( ) \_\_\_\_\_

E-mail address \_\_\_\_\_

Date of Birth \_\_\_\_/\_\_\_\_/\_\_\_\_ Sex : \_\_\_Female \_\_\_Male

Do you prefer calls at home or work? \_\_\_\_\_

Specify best time to call \_\_\_\_\_

Type of Disorder \_\_\_\_\_

Diagnosed as a child or adult? \_\_\_\_\_

Cause for the Disorder (i.e., tumor, injury, unknown):

\_\_\_\_\_

Please list any additional information that would be helpful in matching you with another, including current medications:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signed \_\_\_\_\_ Date \_\_\_\_\_

**By signing this networking form, I give permission to release my name, address, phone number, e-mail address and primary disorder to others in similar situations that are interested in communicating.**



## Adult Growth Hormone Deficiency

Patient Information



### The **MAGIC** Foundation

6645 W. North Avenue  
Oak Park, IL 60302  
708-383-0808/fax 708-383-0899  
800-3 MAGIC 3

[www.magicfoundation.org](http://www.magicfoundation.org)

## Membership Application

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Country \_\_\_\_\_

Home Phone (      ) \_\_\_\_\_

Work (      ) \_\_\_\_\_

E-mail address \_\_\_\_\_

Type of Disorder \_\_\_\_\_

Type of Membership (check one)       New       Renewal

\_\_\_\_\_ \$35.00      \_\_\_\_\_ \$50.00 Canada      \_\_\_\_\_ \$60.00 Overseas

\_\_\_\_\_ \$100 Professional      \_\_\_\_\_ \$1,000 Corporate

\_\_\_\_\_ \$101 - \$250 Visionary      \_\_\_\_\_ \$5,000 Lifetime

\_\_\_\_\_ \$251 - \$500 Platinum

If paying by credit card, please complete the following:

Type of Card: \_\_\_\_\_ MC \_\_\_\_\_ Visa \_\_\_\_\_ Discover      Exp Date \_\_\_\_\_

Card Number \_\_\_\_\_

Signed \_\_\_\_\_ Date \_\_\_\_\_

### Do Not Enclose Cash

Make checks payable to:

**The MAGIC Foundation**

**6645 W. North Avenue**

**Oak Park, IL 60302**

MAGIC provides educational and support services to adults with Growth Hormone Deficiency. For more information, please contact MAGIC.

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# Adult Growth Hormone Deficiency

## Adults Need Growth Hormone Too!

Most everyone understands that children need growth hormone to grow taller. Most also know that growth hormone is available for children as a medication and is necessary therapy for children who are deficient in this hormone to achieve a normal height. It has also been discovered that adults need growth hormone for a number of very important reasons. It appears that adults need growth hormone too!

## Where Does Growth Hormone Come From?

Growth Hormone is a chemical substance produced by the pituitary gland, a small dime-sized gland that extends from the base of the center of the brain located right behind the eyes. The pituitary produces a number of important hormones, including growth hormone. Part of the brain just above the pituitary called the hypothalamus controls the amount of growth hormone released by the pituitary.

The amount of growth hormone released by the pituitary over our lifetime changes with higher amounts during childhood, especially during the pubertal growth spurts, and declining amounts, as we get older.

Growth hormone is produced by the pituitary gland, which in turn, deposits this hormone into the bloodstream. This hormone can be measured in blood by taking a blood sample. The hormone normally leaves the bloodstream and enters into the tissues of the body to exert an effect. Growth hormone affects many of the tissues of the body, including bone, fat and muscles, to name a few. We need growth hormone all of our lives to maintain these tissues in proper balance.

## What Does Growth Hormone Do?

Growth hormone maintains muscle, bone and fat tissues in healthy balance. Without growth hormone, these tissues get out of balance. Deficiency of growth hormone in children is easy to recognize. Children with low levels of growth hormone grow poorly without treatment and remain short. In adults, growth hormone deficiency is not easy to spot since adults have achieved adult height and have fused their bones, thereby preventing further growth. The deficiency of growth hormone in adults can be most appreciated by looking at body composition.

An indwelling venous line (IV) will be started and baseline hormone levels drawn. You will be given a medication. Your doctor or nurse will review the medication and its effects. Growth hormone levels will be drawn intermittently from the IV at specified times for a period of two hours. If the IV stops working during the test, it is important that it be restarted so the samples may be obtained at the specified times.

The purpose of the testing is to determine if you are growth hormone deficient and/or eligible for growth hormone therapy. In order to start growth hormone treatment you will have one to two simulation tests performed. Your doctor will decide the number of tests. Adults with peak growth hormone levels less than 3-5 mcg/L are identified as Growth Hormone Deficient. Please keep in mind that these numbers are not definitive; your doctor will make the final diagnosis. It may take several weeks for your doctor to receive and review the test results. You should discuss the results and the possibility of growth hormone therapy with your doctor.

## Summary

Your doctor will prescribe hormone replacement if you are deficient in pituitary hormones. Remember that each hormone has a specific function in your body, replacement medication is very important. If you have any questions don't hesitate to call your doctor, nurse, or the MAGIC Foundation for resources.

## Evaluation/Testing

In order to confirm or determine the possibility of hormone deficiencies your doctor will perform an examination and ask you some questions. Past records may have to be reviewed. Screening blood tests will usually be done. These blood tests will check the secretion of the pituitary hormones and their target organs.

Possible tests that may be done are listed:

- T4/TSH (to test thyroid function)
- Cortisol FHS/LH (to test stimulation ability of the ovaries/testes)
- IGF-1 (an indirect measure of growth hormone)
- Electrolytes (measures water & salt balance)

You may need to have a picture of the brain; this is done by a CT Scan or MRI. A CT scan gives a detailed picture of the brain using x-rays and a computer. A MRI gives a detailed picture of the brain using a magnet, radio waves and a computer. These tests are not painful but you will have to hold still for approximately one hour during the test.

## Growth Hormone

If there is a possibility that you have growth hormone deficiency more testing will have to be performed. Growth hormone is secreted by the pituitary gland in quick bursts and does not last long in the blood, so checking a single blood sample for growth hormone will not be helpful. Deep sleep, vigorous exercise, and certain drugs are known to stimulate the secretion of growth hormone. The amount of growth hormone in the blood is measured by taking blood samples over a period of time. This is done by performing a "stimulation test." This refers to drawing baseline hormone levels, stimulating growth hormone release by giving a drug, and drawing intermittent growth hormone levels for one to three hours. Your doctor will determine the specifics of the tests, such as type of drug, length of test, and amount of the samples.

The doctor will need to make sure you are on adequate hormone replacement for other hormone deficiencies prior to stimulation testing. You will be given instructions. You should not have anything to eat or drink, except for water, after midnight the night before the test. You should have minimal activity before the test (no exercise that morning).

Growth hormone maintains a proper distribution of fat, muscle and bone. These important parts of our bodies are not nurtured properly in growth hormone deficiency, resulting in an unhealthy metabolism. With this deficiency, fat is deposited more easily, especially around the middle of the abdomen, what doctors call visceral or abdominal fat. Since growth hormone affects muscles, they also change for the worse, which means there is less muscle and less ability to exercise. Bones, too, are affected by becoming weaker (low bone density). We call this weakening osteoporosis. This combination of more fat, less muscle and less bone structure represents the body composition changes as the result of growth hormone deficiency in adults.

Adults with growth hormone deficiency also experience adverse effects on cholesterol metabolism. These changes result in a higher overall cholesterol level in blood, which is undesirable. The "good" cholesterol also changes. We want this "good" cholesterol level to be as high as possible. This good cholesterol (also referred to as HDL cholesterol) changes to a lower level as the result of growth hormone deficiency, which is the opposite of what we want to be healthy.

## What Are Some Symptoms of Growth Hormone Deficiency in Adults?

Adults who develop growth hormone deficiency often do not feel their usual selves. Most notice a decrease in their energy level and endurance for exercise. Some may avoid social contact or avoid meeting with or talking to their friends. Some may have a reduced interest in sexual activity. Other people with growth hormone deficiency think they feel normal, but do not remember the way they felt before they developed the deficiency. These people may feel a dramatic improvement only after growth hormone therapy is started.

## Causes of Growth Hormone Deficiency in Adults

Most children who develop growth hormone deficiency do so because the hypothalamus, for unknown reasons, fails to function and does not stimulate the pituitary gland to release growth hormone. There may not be a visible cause of pituitary injury in most children with growth hormone deficiency. This deficiency may continue into adulthood. Adults, however, who develop growth hormone deficiency usually do so because of some damage to the pituitary gland. This damage results in an inability to make growth hormone in sufficient quantities. The most common cause of pituitary damage in adults is a pituitary tumor. Either the tumor itself, or surgery to remove the tumor or radiation therapy of the tumor, can result from head injury or irradiation to the head for treatment of a brain tumor. Some adults may also have under active hypothalamic drive (activity) as a cause of growth hormone deficiency similar to the most common reason for children to develop low growth hormone, but this is rare.

## What Methods Are Used to Prove Growth Hormone Deficiency?

Your doctor will choose a test to prove growth hormone deficiency. Since growth hormone in blood can often be low in normal individuals, a low level in blood does not prove growth hormone deficiency. Your doctor will choose a stimulation test that will cause growth hormone to be released by your pituitary gland into your bloodstream. By measuring your blood at intervals after the stimulation has been given, your responses to the stimulus can be obtained. In normal individuals there is a rise in blood growth hormone after the stimulus. In deficient individuals there is no rise, or an insufficient rise, which will prove you are growth hormone deficient. A few of the growth hormone stimulants (growth hormone stimulation tests) include arginine, L-dopa, clonidine or insulin. Your doctor will choose one of these that best fits your situation.

## Evaluation Process of Adults with Growth Hormone Deficiency

### Introduction

You have been referred to an endocrinologist, a doctor who specializes in the diagnosis and treatment of disorders of the endocrine glands. Endocrine glands release chemicals into the blood, which tell parts of the body to do certain jobs. These chemicals are referred to as hormones. Endocrine disorders are those that involve deficiencies or excesses of hormones. A deficiency exists when there is not enough of a hormone in the body. In order for your doctor to make an accurate diagnosis, some testing may be necessary. This section was written to help you and your family understand the evaluation process of hormone deficiencies.

### Control of Hormones/Hormone Deficiency

The hypothalamus controls the pituitary gland; both are located in the brain. The pituitary gland releases or controls many hormones in the body. The hormones are released in very small amounts into the bloodstream and then travel to parts of the body (referred to as target organs) to perform a specific job. These hormones control many of the body's functions, which are the following: Thyroid Stimulating Hormone (TSH) turns the thyroid gland "on" in order to control your metabolism. Adrenocorticotrophic hormone (ACTH) stimulates cortisol production to assist your body in daily function and stress. Vasopressin assists in the salt and water regulation of the body. Gonadotropins (FSH, LH) stimulate the ovaries (in women) or testes (in men) to release "sex" hormones (estradiol or testosterone). Growth Hormone is released from the pituitary gland to cause growth in children and affects bone density, lipid metabolism, and muscle in children and adults.

Deficiencies of these hormones may occur alone or in combination with one or more other hormone deficiencies. The hormone(s) deficiency may be congenital, resulting from a defect in the brain. The deficiency may also be acquired, stemming from the damage to the brain after a severe head injury, serious illness (such as meningitis or encephalitis), brain tumor and/or radiation. Sometimes no cause for the hormone deficiency can be identified.

## Effects on Psychological Well-Being

One of the striking effects of GH therapy in GHD adults is the improvement in psychological well-being reported by these patients. Many experience a rapid improvement in their energy level. Improvements in mood and in the level of perceived psychological distress also have been documented.

## Other Considerations

Treatment with GH requires that the hormone be injected daily into the fat tissue beneath the skin. This is made relatively simple by the need for small volumes of GH and the availability of fine, small-bore needles. In the hierarchy of treatments used for patients with various illnesses, GH is relatively safe. Over 30 years of experience with GH therapy in children has uncovered few adverse effects of the hormone. In adults, who are treated with a smaller weight-related dose, edema (collection of fluid in tissue) and discomfort in the joints are sometime reported. Decreasing the dosage temporarily can relieve these. Because GH antagonizes the action of insulin, it will tend to raise blood sugar values, although this has not proven to be a significant problem in children. Individuals with prolonged excessive GH from a pituitary tumor have a tendency to develop tumors elsewhere in the body. This raises the concern that GH might promote the development or growth of tumors. This, however, has not been observed to be the case with GH therapy.

## Summary

- Adults produce and need GH.
- Adults who are deficient in GH accumulate excess fat, have deficient lean tissue, have lower bone mineral content, have an unfavorable blood lipid profile, and experience undesirable psychological effects.
- Treatment with GH reverses/attenuates many of the effects of GH deficiency-leading to better physical performance and a healthier psychological status.
- Use of GH in children for nearly 40 years indicates that it has a high degree of safety.

## How Is Growth Therapy Administered?

Growth hormone is given by injection. It is given daily underneath the skin into fat tissue. Most individuals give it in the fat in the lower abdomen. The needles and syringes used are the same used by diabetic patients. There are also many pen delivery devices available. You will need a special "sharps container" for disposal of the needles. Your doctor will calculate the dose of growth hormone. The dose may change depending upon your responses and blood tests taken to monitor therapy.

## What Symptoms Suggest Too Much Growth Hormone Therapy?

If you are receiving too much growth hormone, you may have symptoms such as swelling of the ankles, aching in your joints, or pain in your hands. Your blood pressure may also rise to a level above normal. If these symptoms occur, you should notify your physician. Most patients feel more energy and an improved sense of well being shortly after beginning therapy. You can expect to feel better in two to three weeks, but may not feel the full improvement for three to six months as your doctor slowly increases the dose to the right level for you. You should continue with the treatment for at least one year, as **you** may not see the benefits immediately.

## Summary

We need growth hormone all of our lives, not only as children for growth purposes. We need growth hormone as adults to keep our bodies in proper balance. Without growth hormone as adults, we have reduced energy and our body composition changes to more fat, less muscle and less bone. Replacement of this hormone in adults, when this hormone is deficient, will restore the body to a more normal and healthy balance. This continued, lifelong therapy should help you live a more normal and healthy life.

# Adults Who Live with Growth Hormone Deficiency (GHD)

## GHD Can Affect Your Life Quality

If you are diagnosed with GHD because of low or absent growth hormone (GH) secretion levels, you may experience a number of different physical and emotional symptoms. Patients often report feeling tired, listless, easily fatigued and having a lack of motivation. Some individuals also report feeling anxious, irritable, losing interest in sex and a pervasive sense of gloom and pessimism about their lives. Because of these effects, people with GHD may tend to avoid contact with others, show signs of stress in their marriage and experience a gradual decrease in their productivity at work. Quality of life begins to decline and the affected individual often suffers in silence. This brochure is provided to help you understand these feelings and what actions you can take to improve your life.

## How GH Can Cause Moods and Emotions to Change

Although we refer to it as “growth” hormone, GH actually has many other functions besides helping growth to occur. GH is a powerful brain hormone that is believed to play an important role in stimulating and controlling areas of the brain that regulate moods and emotions. Certain chemicals in the brain, called neurotransmitters, are dependent on the effects of GH to help them carry their messages among brain centers. If GH is not available, these functions may not occur appropriately and the result can be uncontrolled changes in psychological functioning. Individuals may feel anxious, depressed or worried for no apparent reason when this happens, and this may cause changes in behavior or a decline in social functioning. Negative and sad feelings may dominate your mood and positive or joyful feelings can be dampened. An affected individual could feel unable to enjoy life and lack the motivation to make change in their circumstance. It is important to remember that these emotional changes are not usually directly related to actual life events and therefore are difficult to anticipate. Research has shown that many GHD patients suffer these symptoms privately and do not report them to their doctors. This is unfortunate because there are several treatments available to help manage these problems.

## Treatment of the GH-Deficient Adult Who Had GH Deficiency in Childhood

Although most children who have GH deficiency will be GH deficient in adulthood, the capacity of some patients to secrete GH improves over time. Some patients, therefore, will not need GH therapy in adult life. This is why it is important that as each GH deficient child reaches adulthood, studies be done to determine need for continuing therapy. The extent and nature of testing needed for this purpose will vary from one patient to another.

If treatment is needed, a variety of beneficial effects can be anticipated:

### Effects on Body Composition

GH therapy for as little as six months causes as much as a 25% reduction in body fat, with the greatest reduction occurring in the region of the abdomen. Concurrently, the reduced lean tissue mass of the GHD patient is increased substantially by treatment with GH. This change is reflected in large part by improvement in muscle mass. Although improvements in bone mineral density would be an anticipated effect of GH replacement therapy, systematic studies have not shown that this occurs. However, long periods of observation are needed to assess changes in bone mineral density.

### Effects on Physical Performance

Probably because of its beneficial effects on skeletal muscle, heart muscle and metabolism, treatment with GH improves exercise performance, oxygen consumption and cardiac output.

Effects on blood lipid levels:

The blood lipid profile improves with GH therapy. Specifically, total cholesterol and low density lipoprotein cholesterol are reduced and high-density lipoprotein cholesterol (good cholesterol) is increased. The extent to which these changes retard the development of atherosclerosis are not yet known.

adult life.

Several findings have led to this conclusion:

- When GH therapy is stopped, the young GH-deficient adult tends to gain weight and become relatively obese. This excess of body fat tends to accumulate around the abdomen.
- This relative deficiency of muscle mass results in diminished strength and physical performance, changes that may be manifest as decreased ability to perform tasks such as lifting heavy loads or to sustain physical tasks for long periods of time. Adults with GHD have impaired ability to consume oxygen and expend their body energy, both at rest and at work.
- Adults with GHD also may have lower mineral content in their bones, predisposing them to fractures. All of us lose bone mineral and have increased tendency to fracture our bones as we age. This natural process may be accelerated by deficiency of GH. Additionally, if the GHD adult had insufficient GH during childhood, when bones normally accumulate mineral, he/she is likely to begin adult life with low bone mineral content. This, superimposed on the loss of mineral during adulthood, eventually results in lower-than-normal bone mineral content and a greater predisposition to fractures.
- Blood lipid profiles in adults with GHD are such that they are likely to be predisposed to atherosclerosis. Their blood levels of total cholesterol, low-density lipoprotein cholesterol, and triglycerides are higher than individuals who have normal GH secretion. Suggesting that these findings are significant is the observation that adults with hypopituitarism (GH deficiency associated with deficiencies of other pituitary hormones) have an increased mortality rate. Despite replacement of the thyroid, adrenal and gonadal hormones, their excess death rate is due mainly to vascular problems of the type commonly resulting from atherogenic lipid profiles.
- Young adults who were GHD during childhood may have signs and symptoms of impaired psychological well-being. These include feelings of depressed mood, emotional instability, social isolation, anxiety and reduced vitality.

## GHD in Childhood Versus Adulthood

Children who are GHD often grow up with problems related to being small, feeling unhappy with their self-image, having few friends, and, perhaps also not doing well in school. Many short children are bullied and called cruel nicknames such as "shorty" or "shrimp" which are very painful. These difficulties can have a powerful effect on self-esteem and social skills, and if these effects are carried into adulthood, quality of life may be more complex and therefore difficult to change. In contrast, adults who develop GHD later in life may be surprised by their emotional changes and psychological symptoms, but because of their previous life experience and maturity, they are better prepared to find a solution. In either case, consultation with your doctor can lead to appropriate treatment options.

## The Special Problems of Short Stature

Short stature in childhood may be corrected by GH treatment, but above average height is not achieved in all patients. Feeling "short" and therefore different from others may lead to secondary adjustment problems, which can compound the biological effects of GHD mentioned earlier. If a poor self-image develops, lowered self-esteem, anxiety, pessimism or even depression may arise. Common signs of this are: feeling isolated from others, "left out" or shunned, becoming sarcastic or cynical, being overly sensitive to criticism, or lacking ambition and drive. No one has all these symptoms at the same time, but any one of them, or a combination of such symptoms indicates you should seek help, either from a counselor or your doctor.

## What Can Be Done to Help You

You should feel entirely comfortable speaking with your doctor about any problems you have regarding your feelings or emotions. In some instances it may be that GH replacement treatment will make a significant difference in your sense of well-being, and nothing further is needed. In others, medication to control anxiety or depression can be beneficial. Certain forms of counseling also alter anxiety and depression by modifying negative and dysfunctional beliefs and thought patterns. This is called cognitive-behavior and is usually carried out by a specially trained psychologist. All these options can be discussed with your doctor who will help you make the best decisions.

## Support Groups

Many people who have chronic medical conditions find it helpful and rewarding to meet regularly in a group setting with others who have similar problems. These self-help groups are effective for patients with conditions such as diabetes, cancer, and arthritis. In a safe and supportive group you can learn to understand, accept, and manage your condition through mutual support, information sharing, and problem solving based on the experiences of others.

## Sources of Information About Psychological Counseling

Two major professional groups provide a toll-free number and web-site through which you can get the names of counselors and doctors specializing in areas which can be helpful to you.

### ***American Psychological Association***

800-374-2721

[www.apa.org](http://www.apa.org)

### ***American Psychiatric Association***

888-357-7924

[www.psych.org](http://www.psych.org)

## The Transition from Child to Adult

### Growth Hormone Therapy

Growth hormone (GH; somatotropin), a principal stimulator of body growth, is produced by the pituitary (or master) gland, a small structure located at the base of the brain. Production of too little GH (growth hormone deficiency; GHD) in children causes growth to be slow. Because GHD produces striking effects in children and has been a recognized condition for many years, we usually associate the term GHD with children and with the process of statural growth. GH, however, is also secreted in adult life, and adults need GH to maintain health. Adults who produce too little GH also are designated as GHD, or we sometimes use the term somatotropin deficiency.

### Causes of GH Deficiency

GHD in many adults is the continuation of a process that began in infancy or childhood, or it may have its onset after adulthood is reached. The most common form of GHD beginning early in life is termed "idiopathic", meaning that the cause is not determined. Known causes beginning in childhood include developmental defects in the region of the pituitary gland, genetic problems with the production of GH, damage to the pituitary area resulting from tumor, infection, irradiation, etc. The most common causes of adult-onset GHD are tumors in and around the pituitary gland. Such tumors may compress and damage the remaining pituitary gland, or the GHD may follow efforts to remove the tumor. Other causes of damage to the pituitary of adults include infection, blood vessel disease, and irradiation administered for treatment of tumors of the head or neck.

### The Adult Who Was GH Deficient During Childhood

In the many decades that GH has been used therapeutically, the emphasis has been on alleviation of the short stature of GH deficient children. For the most part, these patients have been led to believe that the only purpose of GH therapy was to stimulate their growth so that they would achieve an acceptable adult height and that therapy would not be needed once they reached their adult height. Experience, however, has led to the conclusion that many, if not most, of the adults who were GH deficient during childhood need to continue GH therapy in