Liverpool University Hospitals

Patient information

Medical Treatments for Acromegaly

Diabetes and Endocrinology

Why do I need treatment?

When treating acromegaly your doctor's main concern is with controlling the disease to preserve your overall health. Sometimes, medical treatment is started soon after your diagnosis, as this may help to reduce the size of your tumour and improve surgical results.

Even if you have had surgery and / or radiotherapy, you may still need to have medical treatment if your condition remains active.

Effective medical treatment has been shown to improve or even reverse some of the early signs and symptoms of acromegaly.

Untreated or uncontrolled acromegaly is associated with a greater possibility of complications such as heart disease, bowel disease and stroke.

Why is it important to control Acromegaly?

Control of your acromegaly can make you feel better. That's why it is important to start treatment once diagnosis is confirmed. Control can also reduce the risk of complications later in life.

Most current medical treatments are designed to target growth hormone production and so reduce overall growth hormone levels. Insulin-like growth factor 1(IGF-1) is released by your liver in response to growth hormone production.

By reducing growth hormone production, the overall level of IGF-1 is reduced. IGF-1 is the marker by which we measure effective and adequate treatment.

Newer medical treatments block the action of growth hormone rather than its production, but do reduce symptoms. With this newer type of treatment, growth hormone levels can remain high.

How do the treatments work?

There are three types of medication used for treating Acromegaly. These medications act on specific receptors- structures on the surface of a cell -that selectively receive and bind growth hormone. They all work on different mechanisms.

• **Somatostatin analogues** work on somatostatin receptors to block growth hormone release from the tumour.

- Dopamine agonists work on dopamine receptors (different receptors to the somatostatin receptors) on the surface of the tumour to block growth hormone release from the tumour.
- **Growth hormone receptor antagonists.** This is a relatively new class of medication. These work by blocking the action of growth hormone on somatostatin receptors on cells throughout your body.

What are the medicines available?

Somatostatin Analogues

There are three types of somatostatin analogues available:

Octreotide - brand name Sandostatin.

Lanreotide - brand name Somatuline.

Pasireotide – brand name Signifor.

This type of treatment has to be injected. It can be given as the short acting preparation which has to be injected under the skin (subcutaneously) three times daily, or once a month by deep muscle injection (intramuscular) for the long acting version (Sandostatin LAR).

If you are to have the short acting preparation you will be taught by the endocrine nurse how to give the injection to yourself. If you are to have the long acting version, arrangements will be made for you to be given this by the nurse at your family doctor (GP) surgery.

Lanreotide can be given by injection intramuscularly every seven to 14 days (Somatuline LA), or monthly as an injection under the skin (Somatuline Autogel). Both of these preparations are usually given by a nurse, so arrangements will be made for you to be given this by the nurse at your family doctor surgery.

You can be trained by a specialist nurse to self-inject Somatuline Autogel if you wish to do so and this is the treatment prescribed for you.

Treatment with somatostatin analogues is usually very effective.

When first starting this, you may experience some gastrointestinal disturbance such as diarrhoea and flatulence but these usually settle down within about a week. This may be lessened if you do not inject within about two hours of eating. Long term, this treatment may cause gallstones in some people.

Dopamine Agonists

The most commonly used dopamine agonists are:-

Cabergoline and Bromocriptine This type of treatment is taken in tablet form.

Bromocriptine is usually taken two or three times a day.

Cabergoline is a newer, long acting dopamine agonist that may be better tolerated and causes fewer side effects than Bromocriptine and normally only needs to be taken twice weekly. Cabergoline is not licensed for the treatment of acromegaly, but it is an accepted and widely used treatment. Royal Liverpool Hospital PIF 1057 V6

Dopamine agonists can cause dizziness when you stand up, or nausea, but these often wear off with time and may be less noticeable if the medication is taken with your evening meal. Constipation can also be a problem but increasing your fibre intake may help with this. Treatment with just a dopamine agonist is not necessarily as effective as with a somatostatin analogue; sometimes both of these treatments can be used together.

Growth Hormone Receptor Antagonist

Pegvisomant is the name of this newer treatment.

Unlike the other treatments available for Acromegaly, this does not work by reducing the amount of growth hormone produced, but stops the growth hormone from sticking to receptors on the surface of cells throughout the body. This stops the growth hormone having unwanted effects on the body.

Pegvisomant is given daily as an injection under the skin. You will be taught by a specialist nurse how to give the injection to yourself. It is licensed for use in people with Acromegaly who continue to have high levels of growth hormone despite surgery and/or radiotherapy and treatment with somatostatin analogues. This treatment has similar side effects to the somatostatin analogues.

What else do I need to know?

Once you start treatment it is important to take it regularly as prescribed. You will not necessarily have to continue with the treatment for life so it is important to keep your regular follow up appointments in order for us to monitor your progress.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

Please feel free to contact the Endocrine Specialist Nurses with any questions you may have. There is an answer machine where you can leave your name and contact details. We will return all calls.

The Endocrinology Specialist Nurses Tel: 0151 706 2417 Text phone number: 18001 0151 706 2417

Related Patient information leaflet: Acromegaly (PIF 501)

There is also a very good patient support group, which offers excellent advice via leaflet and telephone contact. They also hold local area group meetings. National Support Office The Pituitary Foundation 86 Colston Street Bristol BS1 5BB Tel: 0117 370 1320 Email: helpline@pituitary.org.uk www.pituitary.org.uk

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