Acromegaly

The Pituitary Foundation Information Booklets

Working to support pituitary patients, their carers & families
The Pituitary Foundation is a charity working in the United Kingdom and Republic of Ireland supporting patients with pituitary conditions, their carers, family and friends.

Our aims are to offer support through the pituitary journey, provide information to the community, and act as the patient voice to raise awareness and improve services.

**About this booklet**
The aim of this booklet is to provide information about acromegaly. You may find that not all of the information applies to you in particular, but we hope it helps you to understand your condition better and offers you a basis for discussion with your GP and endocrinologist.

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What is acromegaly?

The name “Acromegaly” comes from the Greek words for “extremities” (acro) and “great” (megaly). Acromegaly is a hormonal disorder that results from too much Growth Hormone (GH) in the body. The pituitary, a small gland situated behind the bridge of your nose and at the base of the brain, makes GH. Acromegaly is caused by a benign (non-cancerous) tumour of the pituitary gland, which is called an adenoma and this causes the pituitary to produce too much GH.

Growth hormone-releasing hormone (GHRH) is made by the hypothalamus, a gland in the brain situated just above the pituitary, which stimulates the pituitary gland to produce GH. Secretion of GH by the pituitary into the bloodstream stimulates the liver to produce another hormone called Insulin-like Growth Factor 1 (IGF-1). IGF-1 is what actually causes tissue growth in the body. Growth hormone has effects on many different parts of the body; in adults it is important to maintain normal energy levels and to keep body tissues, such as muscle and bone, healthy. In children, of course, it is essential to reach normal growth.

Acromegaly usually develops in adults between the ages of 30 and 50, but symptoms can appear at any age. If acromegaly develops before you have stopped growing (which usually occurs between the ages of 15 to 17) it can cause gigantism, where people are very tall, because GH promotes growth of legs and arms. As the growth of bones stops after puberty, excessive GH in adults won’t result in increased height, but may cause various other changes outlined on the next page. Acromegaly is a rare condition with only around 4 - 6 new cases per million of the population being diagnosed each year. The diagnosis is often delayed as the symptoms develop gradually over time, but may also be attributed to other conditions, or are viewed in isolation of each other, and patients and families may not notice the changes. Patients may have had acromegaly for several years before the condition is recognised.
What are the symptoms of acromegaly?

Early symptoms may involve tiredness and sleep disturbances, headaches and swelling of the hands and feet. Patients may notice a change in ring or shoe size, and particularly the width of their feet. Gradually, bone changes alter the patient’s facial features with the brow and lower jaw protruding. The nasal bone enlarges and lower teeth may be spaced out. An overgrowth of bone and cartilage can lead to arthritis and when tissue thickens it may trap nerves, causing carpal tunnel syndrome which results in weakness, numbness or pain in the hands. Organs in the body, such as the heart may enlarge. Symptoms can vary and not all mentioned may apply to everyone.

Other symptoms of acromegaly can include:

- Enlarged lips, nose and tongue
- Deepening of the voice due to enlarged vocal cords and sinuses
- Thicker, coarse, oily skin
- Joint aches
- Excessive sweating and skin odour
- Skin tags - tiny flesh-coloured finger-like projections on the skin
- Loss, or lack of libido
- Erectile dysfunction in men
- Abnormalities of the menstrual cycle and sometimes breast discharge in women
- Headaches
- Fatigue and weakness
- Impaired vision
- Sleep apnoea - breaks in breathing during sleep due to obstruction of the airway
- High blood pressure

How is acromegaly diagnosed?

If your doctor suspects acromegaly, the Growth Hormone (GH) level in your blood would be measured. However, a single blood test of an elevated GH level is not sufficient to diagnose acromegaly, as GH is secreted by the pituitary in spurts and results can vary widely from minute to minute.

A suppression test, or oral glucose tolerance test, is a more accurate way to measure GH. This involves drinking a glucose solution which in healthy people should lower GH levels, but in those with acromegaly this suppression of GH levels does not occur.

IGF-1 levels can also be used in diagnosis, as high levels are a sign of excess GH activity, which is the hallmark of acromegaly.

After acromegaly has been diagnosed by the above testing, a Magnetic Resonance Imaging (MRI) Scan of the pituitary is used to locate and detect the size of the tumour causing excessive GH production. Usually an area of pituitary abnormality is seen on the MRI scan but occasionally the tumour is too small to be seen. Very rarely, a tumour elsewhere in the body may produce GH releasing hormone which stimulates the pituitary to produce excessive GH. Such tumours will be identified with additional CT or MRI scans.

Further tests such as field of vision tests may be carried out to assess whether the tumour is causing any pressure on the optic nerves, (eye nerve). as these nerves pass very close to the pituitary gland.

Other blood tests may be taken to check if other pituitary hormones are affected such as as cortisol, (adrenal), thyroid and sex hormones.
How is acromegaly treated?

Treatment options include surgery, medical therapy and radiotherapy. The goals of treatment are to:

- Reduce excess GH to normal levels
- Relieve any pressure that the growing tumour may be exerting
- Preserve normal pituitary function, or to treat any hormone deficiencies
- Improve the symptoms of acromegaly

Studies show that untreated acromegalic patients are more likely to suffer from diabetes, high blood pressure and heart problems with a reduced life expectancy compared to the normal population. These can be improved after the successful treatment of acromegaly.

Acromegaly may be treated by surgery to the pituitary gland to remove or reduce the size of the tumour, by radiotherapy, by drug treatment, or a combination of these. Nowadays, for many patients the first treatment is surgery, although in some centres drug treatment to reduce the size of the tumour is given first. The aim of all treatments is to reduce growth hormone and IGF-1 levels to normal, in order to improve the specific symptoms of acromegaly in addition to general well-being.

Surgery

The operation is usually carried out by making a small cut in front of the upper teeth behind the upper lip, or through the nose. This is called Trans-sphenoidal surgery. By going behind the nose like this, the surgeon can see your pituitary gland without having to operate on the main part of your head. In some centres an Endoscopic approach is used - fine tubes called endoscopes are pushed through the back of the nose, involving a small incision.

Most patients can be treated very successfully this way, although results are usually better if your tumour is small. The operation takes about an hour and a half. You will normally be in hospital for about five days. For the best results it is important to be referred to an experienced pituitary surgeon and your endocrinologist will be able to advise whom you should see.

See our booklet entitled Pituitary Surgery and Radiotherapy for further details about the operation.

Surgery will normally lower your growth hormone levels considerably, but in some instances the acromegaly is not cured. In such cases, consideration will be given to treating you further with radiotherapy and/or drug therapy.

Drug Treatment

There are three types of drugs for treating acromegaly - each acts by different mechanisms:

- **Somatostatin Analogues** work on specialist markers (somatostatin receptors) to inhibit GH release from the tumour.
  - **Octreotide** (brand name Sandostatin, manufactured by Novartis).
  - **Lanreotide** (brand name Somatuline, manufactured by Ipsen).
  - **Signifor** (Pasireotide)
  - **Octreolin** This is an investigational new oral drug being developed for use in acromegaly.
Introduction: Living with Infertility

Octreolin is an oral formulation of injectable Octreotide, a somatostatin analog with proven efficacy and safety that is commercially available only by injection. Dopamine Agonists work on alternative markers (dopamine receptors) on the surface of the tumour to inhibit GH release from the tumour by a different mechanism. Pegvisomant A drug which works differently and blocks the action of GH and reduces IGF-1 levels. Please see more treatment information at https://www.pituitary.org.uk/information/treating-a-pituitary-condition/drugs-information-library/

Somatostatin Analogues

Somatostatin analogues require injections. Octreotide can be given once a month deep into muscle (intramuscularly) for the long-acting preparation (Sandostatin LAR, Novartis), or, occasionally, three times a day under the skin (subcutaneously). The short-acting preparation of octreotide is provided as ampoules or vials, which can be used for several doses. It is normally kept in the fridge, but must be removed and come naturally to room temperature before use. The long-acting preparation is usually given by a nurse at your GP surgery.

Lanreotide (Somatuline Autogel, Ipsen) is available as a once per month depot injection. A depot injection means it is a slow release medication injected. Often, a patient can give this injection to him or herself.

Octreotide and Lanreotide help the symptoms of acromegaly by reducing growth hormone levels. When you first start taking somatostatin analogues, it may give you stomach colic or diarrhoea, but these effects usually wear off within a few days. Some patients find that stomach problems improve if they do not inject for about two hours after eating. In the longer term both may cause gallstones, but these very seldom cause problems.

In general, the effectiveness and side-effects of long-acting somatostatin preparations are similar to the three times daily octreotide but you may prefer the convenience of only having to have an injection once a fortnight or once a month. The injection is into a muscle.

Dopamine agonists

There are several dopamine agonists available, all are taken by mouth but only two are widely used: Cabergoline (brand name Dostinex, manufactured by Pfizer) Bromocriptine (brand name Parlodel, manufactured by Novartis) Cabergoline, a newer long-acting dopamine agonist that causes fewer side-effects than bromocriptine, appears to be more effective in lowering GH and IGF-I levels, and needs to be taken only twice weekly. It is not licensed for the treatment of acromegaly but is an accepted and widely used treatment. Dopamine agonists used in very high doses to treat Parkinson’s disease have been shown to cause heart valve changes in some patients but studies in patients receiving cabergoline for acromegaly have been reassuring in this respect.

Therefore, patients using Cabergoline for pituitary conditions will need to have regular echocardiograms (heart scans). Your endocrinologist or GP will arrange this for you. Bromocriptine
Treatment of acromegaly

usually needs to be taken two or three times a day.

Unfortunately, although dopamine agonists are taken by mouth, they are often less effective than somatostatin analogues which have to be injected. They may cause you to be constipated, although this can be alleviated by increasing the fibre in your diet. At the beginning of treatment, you may also suffer nausea or dizziness when you first stand up. These effects also tend to wear off with time.

Pegvisomant

Pegvisomant (Somavert, Pfizer) is a completely different way of treating acromegaly. All current forms of treatment attempt to lower the amount of GH released by the pituitary gland. Pegvisomant is a blocker of the action of GH. It does not try to inhibit the release of GH from the pituitary into the blood but instead stops the GH leaving the blood to stick to cells throughout the body. This should block all the unwanted effects of GH and studies in patients with acromegaly suggest it is very effective. It is given as a daily subcutaneous (under the skin) injection. It is currently used for patients in whom the more traditional treatments have not been successful.

Radiotherapy

Radiotherapy (treatment with radiation) might be needed if your surgery has not been completely successful (not all the tumour could be removed) or if it was not possible for you to have an operation. The most common reason for incomplete tumour removal is proximity to the important blood vessel supplying the brain (internal carotid artery). In this situation, the surgeon may decide that it is safer to leave some of the tumour behind and rely on other ways of lowering GH. If you are given radiotherapy, it will be planned and carried out with extreme care. Using the images from your MRI or CT scans; the radiotherapy team will spend time planning exactly where the X-rays will be aimed.

You will attend the clinic on two or three occasions to have a special mask or fixation device made. This is a clear plastic mask or device which is used to hold your head still and ensure the radiation beams are correctly aligned. Treatment - very low doses of radiation - is usually given through three parts of the head - one on top of your scalp, and one area just beside each ear. The treatment itself usually comprises 5 - 6 weeks of daily treatment (Monday to Friday). It may take several months, or even years, after the treatment for the effects of radiotherapy to be complete. While you are waiting for this, you may be given drug treatment to improve control of GH levels.

Improvements in pituitary scanning and computerised control of radiotherapy mean that new forms of finely focused, high dose radiotherapy (stereotactic) are being developed. This treatment is not suitable for all pituitary tumours and its benefit is being evaluated. Stereotactic radiotherapy allows much higher doses of radiation to be given to a part, or occasionally the whole, of the tumour often in a single session. The larger dose of radiation means that your GH levels come under control much more quickly, maybe months rather than years. Gamma Knife is the best-known form of stereotactic radiotherapy, is currently not widely available in the UK.

For more information about radiotherapy, see our booklet entitled Pituitary Surgery and Radiotherapy.
What effects will I see from my treatment?

**Effects of treatment**

Once treatment is successful, you should notice that the soft tissue in your hands and feet decrease in size and patients often notice that their facial features gradually return towards normal. This may take some time, but do not despair - improvements will happen once treatment is successful.

If you were suffering from excess sweating this should decrease and if you had sugar diabetes, it should improve, or disappear altogether. Your headaches will usually improve and so will any visual disturbances that may have been present beforehand. If you snored, it should be improved. Main bone growth (for example: hands, feet and jaw) will remain the same.

**How is my progress monitored?**

All patients with acromegaly should be looked after by a specialist in this condition (an endocrinologist). Ideally your endocrinologist will have access to specialist nurses and radiology plus access to a neurosurgeon specialising in pituitary disease.

The success of the treatment of your acromegaly needs to be monitored. The aim of treatment is to lower your average GH level to less than 1 mcg/L and have your IGF-1 level in the normal range for your age.

Your endocrinologist will ask you how your symptoms have changed, in particular whether there has been any change in your ring size and facial appearance. It is also important for you to have regular blood tests to check your GH and IGF-1 levels, as well as the function of the rest of the pituitary gland. GH can be measured either during a glucose tolerance test (see above) or by means of tests known as a “day curve” when blood samples are taken several times during a single day. In order to determine its effect, these blood tests will need repeating when there has been any change in your treatment.

**Aftercare**

It is likely that your condition will require long-term monitoring with regular blood tests and this will be shared by your endocrinologist and GP. Because acromegaly is relatively rare, you may find that you are the only patient with this condition in your GP’s surgery, and the practice may find it helpful to have a copy of our Pituitary Disease Fact File for General Practitioners.

People with acromegaly have an increased chance of developing bowel polyps (small benign growths) and bowel cancer. You will normally be offered a routine colonoscopy, and usually every 3 to 5 years if you are over 40. A colonoscopy is a test where a doctor looks into your colon (large bowel) using a flexible telescope; this test can diagnose bowel problems and is carried out to ensure earliest detection, even before symptoms develop, so that the chance of a complete cure is high. However, always tell your doctor if you develop any new symptoms from your bowel, such as persistent diarrhoea, passing mucus, passing blood or abdominal pain.

NB: If you are taking hydrocortisone, it is important to tell the doctor before the colonoscopy procedure. Double your usual dose as soon as the preparatory laxatives take effect.
A 100mg injection 30 minutes before procedure to be given by doctor. Take usual dose on morning of procedure.

NB: Some centres may want to admit you to hospital the night before to give the bowel prep and provide hydrocortisone cover but it is recommended you drink lots of water to prevent dehydration. For more information, see our *Hydrocortisone, Advice for the Pituitary Patient leaflet*.

Coping with acromegaly

In addition to physical changes in patients with acromegaly, many find their illness emotionally challenging - particularly if they were unwell for some time before a correct diagnosis was made. There may be stress caused either by specific physical aspects (for example: loss of libido, exhaustion, joint pain) or by factors such as changes to your bodily appearance, face and anxiety. In addition, both the fear of anticipated surgery, so close to the brain and the fact that for some people recovery can take quite a while, can be stressful. All of these issues can be just as difficult for family and close friends as for the patients themselves.

Your GP will be able to arrange counselling if this is required. You may also find it useful to make contact with The Foundation Helpline on **0117 370 1320** and/or with your nearest local support group (details from our website) where you will find many people who are keen to help and support you. If you wish to speak to a fellow acromegalic who has had similar experiences, we have trained Telephone Buddies available to support you. There is a UK Acromegaly Support Facebook Group too.

The University of the West of England (UWE), in partnership with The Pituitary Foundation, has conducted research which has identified several psychosocial issues related to pituitary disease. These include: increased levels of depression, anxiety; appearance-related concerns; a reduced quality-of-life and well-being. These are associated with impact of diagnosis, treatment, and the realisation that their condition is a long-term condition. Please see our *Psychological Booklet Series*. 
How will acromegaly affect my lifestyle?

### Employment

For your stay in hospital if you have had surgery, the ward staff will give you a certificate for your employer and advise you how long you will be expected to remain off work. Your GP can issue further certificates if you require these.

If you are experiencing any difficulties in retaining or returning to your employment, at any stage of your pituitary condition we suggest that you contact The Foundation’s Helpline or your local Citizens Advice Bureau for the most up-to-date information about employment rights and where to get advice about benefits. If you need extra employment support because of a disability your local Jobcentre Plus can put you in touch with one of their Disability Employment Advisers. Our website forum has a section where you can read about employment queries and receive other patients’ experiences if you wish to register and post your own messages.

### Prescriptions

Prescriptions for drug treatment of acromegaly are not free-of-charge unless you need replacement therapy because your pituitary gland has become under active - see exempt medication below.

If you have to take any of the following: hydrocortisone, thyroxine, testosterone, oestrogen/progesterone, or desmopressin permanently you will receive free prescriptions for all medicines. Ask at your GP’s, pharmacist or endocrine clinic for form FP92.

The form (which will need to be signed by your doctor) tells you what to do to apply for exemption and you will receive an exemption certificate. These certificates need to be renewed and you should receive an application when this is due for renewal. The full list of medical conditions and information about free prescriptions can be found in leaflet HC11, available from pharmacies and main post offices or on [www.dh.gov.uk](http://www.dh.gov.uk).

If you aren’t sure whether you are entitled to free prescriptions, you must pay for your prescription and ask for a NHS receipt (form FP57 in England) when you pay; you can’t get this at a later date. The above form will explain how to claim your money back and must be within three months of paying.

If you don’t qualify for free prescriptions and need more than five prescription items in four months, or more than 14 in a year, ask your pharmacist about a pre-payment certificate, which is more economical for you.

**For Wales:** All patients registered with a Welsh GP, who get their prescriptions from a Welsh pharmacist, will be entitled to free prescriptions.

**For Scotland:** all prescriptions are free and no form needs to be completed.
Insurance & pensions
Your current insurance provider will require medical reports and each case will be assessed individually to make any adjustments found to be necessary on your premiums. Company policies do vary widely and you may need to shop around. Don’t be disheartened if the first response is disappointing.

Please call The Foundation or see our website for up-to-date insurers contact information (other patients have used, and told us about these companies) also for travel information we can provide.

Driving
You have a legal obligation to advise the Driver and Vehicle Licensing Agency (DVLA) if there is any reason why you should not drive. Many patients with acromegaly will find there are no restrictions on their driving, but you should check with your GP. The only condition likely to affect patients is having a problem with your eyesight.

Trans-sphenoidal surgery does not in itself limit your entitlement to drive and your doctor or specialist will give you full advice. DVLA say that patients with a pituitary tumour should tick the ‘brain tumour’ box and put a note at the side of the form, stating ‘pituitary tumour’. DVLA will accept any extra brief notes with the form (or at side of form) regarding the patient’s condition, such as stating ‘pituitary tumour’ etc. and that DVLA should contact their specialist endocrinologist for further information if required.

You may also seek further advice from the DVLA by consulting for England, Scotland and Wales: Drivers’ Medical Enquiries DVLA Swansea SA99 1TU or phone
DVLA Medical Enquiries
Telephone: 0300 790 6806
Monday to Friday, 8am to 7pm
Saturdays, 8am to 2pm
Tel: 01792 782337 (medical professionals only)
mailto: medadviser@dvla.gsi.gov.uk (medical professionals only) For Northern Ireland: Driver and Vehicle Licensing Northern Ireland, Castlerock Road, Coleraine, BT51 3TB. Tel: 028 4703 41369

Personal medical identification
If you are taking hormone replacement medication, such as hydrocortisone or desmopressin, it is a good idea to wear a medical information bracelet or equivalent as the information will help doctors if you have an accident and are unconscious.

There are various medical emblems available; our website includes contact details for several organisations.
Common questions

Q: What happens if my octreotide/lanreotide has been left out of the fridge?
A: These preparations can be left out of the fridge for up to 2 weeks, provided they have been kept away from direct sunlight and excessive heat. However you should keep them in the fridge as much as possible.

Q: What should I do if I can’t remember whether I have taken my medication?
A: Don’t risk taking a double dose (except in the case of any hydrocortisone replacement) wait until your next dose is due and carry on as normal.

Q: Is it safe to take other prescribed medicines alongside octreotide/lanreotide?
A: Octreotide can interact with other medicines; make sure your doctor knows you are taking octreotide.

Q: How do I keep my octreotide cool during the journey?
A: As mentioned earlier, it is not a problem if your octreotide is kept out of the fridge for a while. However, many patients like to keep their supply in a cool bag whilst travelling.

Q: Can I drink alcohol?
A: Moderate alcohol intake should not cause problems, but you should speak to your consultant for advice.

Q: My lifestyle means that it is inconvenient for me to take octreotide/lanreotide at the prescribed times. What can I do?
A: You should not alter the times that you take drugs, or their dose, without speaking to your consultant first. If you would like further advice about issues you may have due to work or lifestyle, please call The Pituitary Foundation Helpline.

Q: After I have injected my octreotide/lanreotide, I tend to get a stinging feeling and redness around the injection area for about 15 minutes. Can anything be done about this?
A: If you take care to ensure your injection has reached room temperature before injecting, this effect should be minimised.

Q: How do I obtain syringes and needles?
A: This varies from area-to-area. In many cases your doctor will provide these when prescribing octreotide. If not, contact your consultant.
Useful addresses

**Tall Persons Club**
This is a club which provides its members with advice and information on practical matters such as clothing, beds, cars etc. and medical and social matters.
They can be contacted at [www.tallclub.co.uk](http://www.tallclub.co.uk)

**Long Tall Sally**
Specialises in women’s clothing for ladies of 5’8” and above, with sizes ranging from 10 to 20. Mail order catalogue and branches available.
Contact details are: [www.longtallsally.com](http://www.longtallsally.com)

**Walk Tall**
Big size footwear
Contact details: [www.walktall.co.uk](http://www.walktall.co.uk)

**Changing Faces**
Is a charity offering counselling advice and information for those who have facial changes. Their specialist team can provide practical and sensitive counselling and advice to help you handle your emotions, experiences and any social situations with knowledge and confidence. Contact details: [www.changingfaces.org.uk](http://www.changingfaces.org.uk)
Support Information & Advice
0300 012 0275
support@changingfaces.org.uk

If you’d like to read patient experiences of acromegaly, please see [https://www.pituitary.org.uk/news/?category=14063](https://www.pituitary.org.uk/news/?category=14063)
Please support The Pituitary Foundation

Join the The Pituitary Foundation today and enjoy the benefits of membership!

✔ Receive our members’ magazine, *Pituitary Life*, three times a year full of the latest information, updates and patient stories, to help you better understand, or manage your pituitary condition.
✔ Our monthly e-bulletin, which includes the latest pituitary news, information and ways to get involved.
✔ Become an important part of the only charity in the UK providing support to pituitary patients.
✔ Receive a welcome pack and a membership card and enjoy discounts to Pituitary Foundation events, such as our conferences.
✔ Give us a stronger voice to raise awareness, and understanding, of pituitary disorders.

Individual membership costs **£25.00** for a full year, which is only **£2.08** a month!
(Family, concessionary and life membership rates are also available). To become a member, please complete the form below and return to us with your payment (cheques made payable to *The Pituitary Foundation*) to:

**The Pituitary Foundation,**
86 Colston Street,
Bristol, BS1 5BB

If you would like to pay for your membership by standing order, please contact 0117 370 1333 or to join online visit [www.pituitary.org.uk](http://www.pituitary.org.uk)

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I wish to become a Member of **THE PITUITARY FOUNDATION**

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**Please tick (✔) the type of Membership you require:**

| Individual | £25.00 (annual) | Joint | £35.00 (annual) |
| Life Membership | £350.00 | Concessionary* | £15.00 (annual) |

*(Concessionary rate for people on a state pension, in receipt of state benefits, on low income, students, and under 18s only).*  
☐ Yes! I want to Gift Aid any donations I have made in the past, present and future to The Pituitary Foundation. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify The Foundation if you want to cancel this declaration, change your name or full address, or no longer pay sufficient tax on your Income or Capital Gains.

| Signature: | Date: |

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More Information
The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues. For more information please visit our website, or call our Helpline.

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Disclaimer: All information is general. If you or your carer, have any concern about your treatment or any side effects please read the Patient Information booklet enclosed with your medication or consult your GP or endocrinologist.

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