› series: parents

For Parents:

Your pituitary child, 5 to 11 years

The Pituitary Foundation Information Booklets

The Pituitary Foundation

Working to support pituitary patients, their carers & families

The Pituitary FOUNDATION

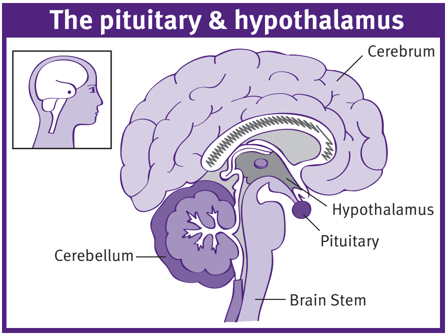
About this booklet

The aim of this booklet is to provide information for parents who have a primary school-age child with a pituitary condition. You may find that not all of the information applies to your child in particular, but we hope it helps you to understand the condition better, and offers you a basis for discussion with your child's GP, their paediatric endocrinologist, and primary school staff.

The pituitary gland

The pituitary gland is about the size of a pea and is situated in a bony hollow, just behind the bridge of the nose. It is attached to the base of the brain by a thin stalk. The hypothalamus, which controls the pituitary by sending messages, is situated immediately above the pituitary gland.

The pituitary gland is often called the master gland because it controls several other hormone glands in the body, including the thyroid, adrenals and ovaries or testicles. It secretes hormones from both the front part (anterior) and the back part (posterior) of the gland. Hormones are chemicals that carry messages from one cell to another through the bloodstream. Hormones are important for growth, puberty, energy levels and day-to-day normal life. If the pituitary gland is not producing sufficient amounts of one or more hormones, this is called hypopituitarism. Occasionally, too much hormones may also be produced.



The pituitary & hypothalamus

The hypothalamus

The hypothalamus serves as a communications centre for the pituitary gland, by sending messages or signals to the pituitary in the form of hormones, which travel via the bloodstream and nerves down the pituitary stalk. These signals, in turn, control the production and release of further hormones from the pituitary gland, which signal other glands and organs in the body. The hypothalamus also influences temperature regulation, food and water intake, sleep and wake patterns.

Conditions

Underactivity of the pituitary gland or hypopituitarism may result from several different causes. There may be a congenital (present from birth) abnormality in the formation of the gland. Sometimes hypopituitarism is due to a slow-growing tumour called a craniopharyngioma, in the brain above the gland.

Various diseases may damage the gland and cause hypopituitarism. Pituitary problems can occur after a severe head injury or as a side-effect of treatment with radiotherapy to the head, which may be needed for brain tumours. Infection in the brain can also result in hypopituitarism.

A number of genetic causes have now been found to cause hypopituitarism in children. Many of these genes are important to help develop the pituitary gland when your child is in the womb. The eye nerves and pituitary develop together in early life; sometimes if the process is faulty, hypopituitarism occurs in association with problems with vision in one or both eyes. This is called septo-optic dysplasia.

Diagnosis

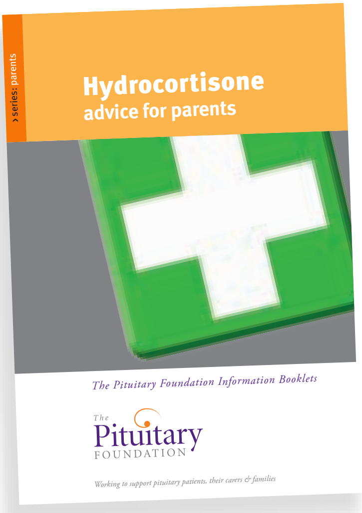
Your child might have been diagnosed with a pituitary condition as a baby or later in childhood. For all children, The Foundation recommends that referral is made to a paediatric endocrinologist in a centre of excellence, for testing and diagnosis of pituitary problems. A centre of excellence will have the expertise and experience of managing pituitary conditions in babies and young children, by a multi-disciplinary team (MDT).

Diagnosis depends on the measurement of pituitary hormones in the blood, either as a one-off, or after stimulation tests over several hours to show more clearly how the gland works. Scanning of the head, usually with an MRI (magnetic resonance imaging) scan can show the structure of the gland and surrounding structures. An assessment of your child's eyes may be needed by an ophthalmologist.

Treatment and ongoing care

Treatment consists of replacing either the missing pituitary hormones themselves, or of the hormones produced by the target glands. The most important of these hormones are:

Hydrocortisone which replaces the stress hormone, cortisol produced from the adrenal glands. Cortisol is important in maintaining blood sugar levels and protecting against stress and illness such as infection. Current replacement of hydrocortisone is by tablets, which are taken in split doses several times daily, as advised by your child's paediatric endocrinologist. Hydrocortisone tablets are usually provided as 10 mg tablets; a tablet may need to be cut into smaller pieces to give a smaller dose. For example, a dose of 2.5 mg is a quarter of a 10 mg tablet. In young children who are not able to swallow tablets, hydrocortisone may be dissolved in a small amount of water at room temperature and then swallowed. Your doctor will advise you on the dose and how many times to give in a day.



› series: parents

Hydrocortisone
advice for parents

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There is a new form of hydrocortisone which presents as granules in capsules for opening. Hydrocortisone granules are available in 0.5 mg, 1 mg, 2 mg and 5 mg capsules which may offer more precise dosing.

You'll be given 'sick day rules' information in the event your child needs increased hydrocortisone or an injection in emergency situations. Please see pages 10 for sick day rules and our ***Hydrocortisone Advice leaflet for parents*** at **www.pituitary.org.uk/information/publications/essential-free-publications/hydrocortisone-advice-for-parents-leaflet/**

Levothyroxine is the replacement for thyroxine which is made by the thyroid gland. Thyroxine is a hormone which is critical to brain development in early life, and also helps with several bodily functions including growth. Levothyroxine is usually in the form of tablets which are taken early morning, half an hour before breakfast. A liquid preparation of levothyroxine is also available.

The dose of levothyroxine will vary according to need and will be instructed by your child's paediatric endocrinologist.

Desmopressin (DDAVP) is the replacement treatment for anti-diuretic hormone (ADH) which is produced in the back part of the pituitary gland. This hormone circulates in the bloodstream and acts on the kidneys to control the amount of water passed out of the body as urine. If ADH is deficient, it will cause the condition called diabetes insipidus (water diabetes). Desmopressin is given usually two to three times a day, as tablets that need to be swallowed, tablets that melt in the mouth and nasal sprays.

Recombinant human growth hormone (GH) is the replacement treatment for growth hormone that is responsible for growth throughout childhood. Replacement consists of single injections under the skin every day. Most growth hormone devices are needle devices which deliver a small dose of the treatment through a small sharp needle. A needle free device, called a transjector, is also available.

Sex hormones: testosterone in boys, and oestrogen in girls, may be needed around the usual puberty age to help children with hypopituitarism to progress in puberty and to maintain sexual development in adults. Replacements are available in the form of gels, tablets, creams, patches and injections.

Hormone deficiencies in hypopituitarism can be very variable. In some children, only GH needs to be replaced, whereas in others, all the hormones need to be replaced. In some children, puberty can be late if the puberty hormones are deficient. In children with septo-optic dysplasia and children who have been treated with radiotherapy, puberty may develop early. Once growth is complete, adolescents are usually re-tested to check if they have growth hormone deficiency as young adults. In young people with growth hormone deficiency, growth hormone is not required for growth but is used at lower doses for its beneficial effects on body composition and bone mineral density. Please see more about puberty on page 13.

Monitoring your child at clinic

In the early days, appointments with your child's paediatric endocrinology team could happen fairly often, and once your child is more stable, these could occur at three, or six monthly intervals.

At your first clinic appointment clinic, you and your child will normally see a consultant. If you are seen by a junior doctor first, a consultant will always review and discuss your child's condition and care. First appointments usually last between 20 and 40 minutes.

At the clinic, they will carry out a number of assessments and tests to help them build a picture of your child's growth and development. They will usually measure your child's height and they may measure the parents' heights too.

They may take blood and urine samples or carry out x-rays. All of these tests are usually carried out on the same day as your clinic appointment. If they take a blood sample, your child would be given a 'numbing' cream or spray to reduce pain. Sometimes one-off blood samples are not adequate to find out if your child's pituitary hormones are deficient. In that case, your child may need a stimulation test, also called a dynamic function test, which may last for up to three hours.

After your child's appointment, a letter will be sent to your GP or the doctor who referred you to the clinic. A copy of the letter will also be sent to you, other doctors and health professionals involved in your child's care. The letter will contain contact details in case you have any questions. If your child needs a follow-up appointment, this will be arranged before you leave the clinic.

Questions to ask their paediatric endocrine team

- What should I watch out for and what do I do if it happens?
- How do I contact the ward or department?
- Is there a fast access to medical help if my child is unwell – what is this?
- School support – how do I approach this?
- Medicines my child needs; how does she/he take these
- Repeat prescriptions, does my GP provide these?
- Future outpatient appointments – will I receive these by post?

Your child's file

It can help if you store all the information about your child in one place. This makes it easier to find key pieces of information and share them with your child's health care team and GP. Suggestions to include in this file:

- Track changes in your child's treatment and his/her height and weight
- Note contact details for everyone involved in your child's care
- Prepare for appointments and admissions
- Write down any questions and answers
- File copies of clinic letters and leaflets
- Emergency details

Provide information to other people looking after your child, such as grandparents, relatives, and school.

Starting **school**

[1]Parents of children with medical conditions are often concerned that their child's health will deteriorate when they attend school. This is because pupils with long-term and complex medical conditions may require ongoing support, medicines or care while at school to help them manage their condition and keep them well. Others may require monitoring and interventions in emergency circumstances. It is also the case that children's health needs may change over time, in ways that cannot always be predicted, sometimes resulting in extended absences. It is therefore important that parents feel confident that schools will provide effective support for their child's medical condition and that pupils feel safe. In making decisions about the support they provide, schools should establish relationships with relevant local health services to help them. It is crucial that schools receive and fully consider advice from healthcare professionals and listen to and value the views of parents and pupils.

[1]Ref: The Department of Education (December 2015 / reviewed 2017) *Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*

All schools should have a medical conditions policy which states how the school will care for any child with medical conditions, the procedures for getting the right care and training in place and who is responsible for making sure the policy is carried out.

The policy should recognise health conditions can be life threatening and that they can also affect how a child learns. Schools must regularly review and audit their policy to make sure the arrangements for children with medical conditions are working. Schools in England are required by law to have a medical conditions policy.

This policy statement should be developed with pupils, parents, school nurse, school staff, governors, the school employer and relevant local health services. This policy statement should be made publicly available on the school's website. Also see ***Medical conditions policy*** **www.medicalconditionsatschool.org.uk/**

Advising teachers and staff

Plan a meeting with the head teacher and their class teacher, before your child starts school, or if your child's condition is diagnosed after starting school, arrange this meeting before your child returns to school. Take along your child's individual health plan (IHP) – you can use either of these templates to form your child's plan:

- The Pituitary Foundation's ***Hydrocortisone Care Guide for schools*** **www.pituitary.org.uk/information/publications/essential-free-publications/hydrocortisone-care-guide-for-schools/.**
- Medical conditions at school **www.medicalconditionsatschool.org.uk/documents/Individual%20Healthcare%20plan__Part%202.pdf**

Your child's specialist endocrine nurse can liaise with, or visit, your child's school to provide expert guidance and teaching of adrenal insufficiency and crisis management. Also, they can provide letters during examination periods requesting extra time if this is needed.

One parent says:

"We made a point of having a meeting with the head of the school and went armed with information from hospital regarding the condition. We also took a copy of our own medical sheet we hold showing current dosages, contacts and what to do if there is an adrenal crisis. I know that you (The Foundation) have provided us with some wonderful leaflets and we keep all of this in a folder - a copy for us and one in school. Emergency injection should be sited at school, as well as relevant forms to allow ambulance crew to administer hydrocortisone should the need arise.

It is important that all staff that your child comes into contact with are made aware of the condition especially where there is more risk - for example at PE lessons. Good contact is vital for peace of mind and also to give your child some normality."

A full explanation of sick day rules is on page10.

Preparing your child

Making the transition from home to primary school is a significant event for any child and the family. When your child has a long term health condition that may affect them at times and/or their appearance, you might also have the additional challenge of managing any curiosity and concern from school staff, classmates and other parents. It is useful to start preparing early to give your child a successful start at their new school. Providing your child with something to say when people are curious about their condition, and teaching them how to move the conversation on will get any curiosity out of the way and enable your child to get on with the business of making friends. Your child will hear the simple explanations you are using to describe their condition. For example:

"I'm Ellie, I have to take tablets at lunchtimes. They make me feel better but make my face round, but you can't catch it. What's your name?"

"Hi, I'm James, will you be my friend and help me if I'm not feeling well?"

A parent's experience: *"We have always been determined for Jack to have a normal life despite the seriousness of his illness. Without going into major details we made sure that Jack knew that he had a serious condition and that he knew it was OK to take medicines every day. We got him involved with the packing of his tablets pot in his bag and got him to take the tablets into the school office each morning.*

We explained his need to tell someone if he felt unwell and to find a special friend who he could rely on if he needed help."

Sick day rules

When to increase a child's hydrocortisone dose

If a child with cortisol deficiency becomes unwell due to another illness, he/she is unable to increase the production of cortisol, which is needed to help the body cope with the illness.

In these circumstances, the amount of hydrocortisone given needs to be increased to mimic the body's normal extra hormone production in time of need. In most cases, the usual hydrocortisone is doubled and given 4 times a day for 2 days. If your child is very unwell and is unable to keep food or fluids down, then it is best to give an intramuscular dose of hydrocortisone. Your specialist nurse will teach you how to do this. Emergency intramuscular hydrocortisone injections can be life-saving.

You may wonder when to give double dose hydrocortisone, especially if your child is reasonably well with minor viral infections such as coughs and colds. As a parent, you will be able to judge if your child is more ill than usual with the illness. It is worth noting that an extra dose will not do any harm. So, if in doubt it is better to give the additional hydrocortisone than not. The same also applies for intramuscular hydrocortisone. If your child is unwell enough to require double dosing of hydrocortisone, ensure that the morning doubled dose is given early morning and is not delayed. If your child has been given a hydrocortisone injection, he/she must be admitted to hospital afterwards to be monitored. The monitoring should be for 12 hours or longer. This is because the effects of the injection only last about 6 to 8 hours, and it is important to check that the child is stable on oral dose before going home.

Diarrhoea and/or vomiting

It is important not to ignore diarrhoea and/or vomiting, especially if your child is also taking tablets such as desmopressin (DDAVP). Diarrhoea and/or vomiting can cause your child to become dehydrated with imbalance of salt and water levels in the body.

Coughs and colds

If the child has a minor head cold with snuffles, runny nose and a cough but is otherwise well, there is usually no need to increase the oral hydrocortisone. However, if you feel your child is more lethargic than usual, there is no harm in giving hydrocortisone as per sick day rules.

Temperatures

If your child has a raised temperature (fever), he or she may require hydrocortisone as per sick day rules. However, if your child is well despite fever, you may wish to give him/her usual dose hydrocortisone.

Antibiotics

If your child has been prescribed antibiotics for an infection, e.g. a chest infection, tonsillitis or middle ear infection, it is best to give hydrocortisone as per sick day rules. In most cases, double dose hydrocortisone is required for two days, but if the infection persists, you may give double dose until the infection resolves. Please note that for chest infections, the cough may last for more than a few days. It is not necessary to give double dose hydrocortisone for the duration of the cough.

Dentists

- If your child has a dental appointment for a check-up or cleaning, he/she should not need any extra hydrocortisone.
- If your child has an appointment for fillings or other treatments which require a pain relieving injection, you should give them double the dose of oral hydrocortisone for the 24-hour period around the appointment.
- If your child unexpectedly needs an injection for filling or other treatment for broken teeth for example, give them double the dose of oral hydrocortisone as soon as possible, and continue for the next 24 hours.
- Major dental work, such as having teeth removed, should only be carried out in hospital. Please call your specialist treatment centre for advice before the appointment. If your child is being put to sleep (general anaesthesia) for teeth extraction, your paediatric endocrinology team will advise the surgical team to give additional intravenous hydrocortisone as per local protocol.

General anaesthesia

If your child needs general anaesthesia for any reason, extra hydrocortisone given intravenously (IV) will be needed as they go to sleep. The endocrine team your child sees would be available to advise your local hospital on the dose needed and can be contacted.

Your child could have an alert attached to his/her file to remind staff that he/she is on hydrocortisone. It is still important to remind staff in all centres that your child needs medication regularly and that doses should not be omitted unless hydrocortisone is given intravenously.

Immunisations for childhood illnesses

Immunisations are not contraindicated while on replacement hydrocortisone therapy. All children on hydrocortisone are encouraged to complete all routine immunisations.

- If your child is taking medications other than hydrocortisone, you should ask your specialist treatment centre for advice.

After the injection of immunisation, you may consider giving double dose hydrocortisone, particularly if your child is distressed or in pain. Some children develop a fever and rash a few days after the injection. You should follow the advice under ‘temperature’ if this happens. If your child is well after the injection, you may continue usual dose hydrocortisone.

Accidents and injuries

If your child has a fall, bump or bruise, but immediately recovers and carries on as normal, there is no need to give double dose hydrocortisone. If you are worried, it is best to contact your specialist treatment centre.

However, if your child has a serious injury, for example, bumps his/her head and becomes unresponsive and unconscious, then you will need to give him/her an intramuscular injection of hydrocortisone and call an ambulance to take them to hospital immediately. In hospital, alert staff attending to your child that he/she has hydrocortisone and that you had given him/her an intramuscular dose of hydrocortisone at home.

Unresponsive child/hypoglycaemia

If your child runs short of cortisol, he/she may have low blood sugar levels (hypoglycaemia). The signs of hypoglycaemia are:

- pale
- sweaty
- drowsy
- confused
- eyes appear glazed
- not responding

If you think your child has hypoglycaemia, you should give your child an intramuscular injection of hydrocortisone and call an ambulance to take him/her to hospital immediately. While waiting for the ambulance, if your child is conscious, give him/her glucose gel that you should have in your emergency pack. Give this by squirting the gel in the mouth between the gums and the inside of the cheek and then rub the cheek gently to help the gel become absorbed. If your child is unconscious, do not give him/her anything to eat or drink, including glucose gel.

Special note for children with diabetes insipidus who are taking desmopressin (DDAVP)

If your child needs extra oral hydrocortisone for vomiting and/or diarrhoea:

- Do not give them any more desmopressin
- Allow them to drink if thirsty
- Ensure that you child is passing urine
- If passing less urine or vomiting, you should consider taking your child to hospital.
- If vomiting and not keeping down medication, give an intramuscular injection of hydrocortisone

Emergency kits

Your specialist treatment centre will give you an emergency medication kit, which should be with your child at all times. You may ask for more than one kit to be kept elsewhere, for example at school. Emergency kits have a one year expiry date; do check from time-to-time if your kits and medication supplies are in date. It is a good idea to video your emergency injection training session by the endocrine team, on your phone as a refresher for any future need.

Each kit should contain:

- 1 x vial of 100mg/1ml of hydrocortisone for intravenous/intramuscular injection. Some preparations require reconstitution using water for injection
- A filter needle for drawing up liquid from a glass ampule
- 1 x 2ml syringe
- 2 x blue needles (or orange needles, depending on age)
- 1 x tube of glucose gel with instructions for use
- 1 x leaflet ‘How to give an emergency injection of hydrocortisone’
- 1 x steroid card filled in with your child’s details

Puberty

In females

The timing of puberty can be variable. Sometimes in young people with conditions affecting the hypothalamus and pituitary gland, puberty can happen at the right age, while sometimes it can happen a little too early or sometimes a little later than usual. In some cases, puberty may not happen at all and then hormones are needed to help your child go through puberty.

The main puberty hormones made in the pituitary gland are called gonadotrophins, Luteinizing hormone and Follicle stimulating hormone (FSH). In girls, these hormones drive the ovaries to make the girl hormone oestrogen which helps in the development of the breast and womb.

If the pituitary gland starts producing the puberty hormones too early, the ovaries make oestrogen early and cause early puberty. On the other hand if the pituitary gland cannot produce the puberty hormones the ovaries cannot make oestrogen (or testosterone), and puberty is late.

Mostly, the ovaries are healthy, but it is the hormones from the pituitary gland that are not working. One possible exception to this is in young people who have had treatment for leukaemia or a tumour with radiation treatment or chemotherapy which might have damaged the ovaries as well as the hypothalamus and the pituitary gland.

Girls go into puberty at different times, so you may notice that other girls in your child's class start developing even from age nine years. The first sign is starting to develop breasts. If breasts do develop before the age eight years, then that is too early. Most girls have changes in puberty by age 12 years; if there are no signs in your child by age 12 years, blood tests may be required to investigate further.

You may wish to consider pausing puberty if it starts too early. Your child will be developing faster than other girls at school. She may even start her periods before the end of primary school. If puberty happens very early, your child may stop growing and end up being short. The easiest way to pause puberty is to have an injection that puts the puberty hormones (LH and FSH) from your pituitary gland back to sleep until the right time, which is usually just before your child becomes a teenager.

If puberty is late, your child may need some help. The easiest way to progress in puberty is to replace the oestrogen that the ovaries are not making. This is often a small tablet that has to be taken every day, or maybe a patch that is changed twice a week. Your doctors will try and mimic what the body normally does, i.e. start at low doses and increase them very gradually over approximately two years to ensure puberty changes are adequate and periods happen regularly.

At some point on a higher dose of oestrogen, progesterone will be added (another hormone also normally made by the ovaries). This may be in the form of a tablet that has both oestrogen and progesterone. This will start periods. The tablet with both hormones might either be an oral contraceptive pill or hormone replacement therapy (HRT). Sometimes tablets could be replaced by a patch.

In addition to producing puberty changes, oestrogen is also important for keeping bones healthy and helping you feel well. If puberty hormones are damaged and ovaries do not make oestrogen, some form of oestrogen medication would be advised to continue until at least age 50 years. This is the age that most women stop producing as much oestrogen and their periods stop (called the menopause). It makes sense for oestrogen medication to be stopped then too.

In males

The main puberty hormones made in the pituitary gland are called gonadotrophins, Luteinizing hormone (LH) and Follicle stimulating hormone (FSH). In boys, these hormones drive the testicles to make the boy hormone testosterone, which helps boys change in their physical appearance, for example in growing facial hair and in their voice breaking.

If the pituitary gland starts producing the puberty hormones too early, the testicles make testosterone early, causing early puberty. On the other hand, if the pituitary gland is slow to produce testosterone or cannot produce testosterone, puberty will be late or may not occur.

Mostly, the testicles are healthy, it is just the hormones from the pituitary gland that aren't working. One possible exception to this is in young people who have had treatment for leukaemia or a tumour with radiation treatment or chemotherapy which might have damaged the testicles as well as the hypothalamus and the pituitary gland.

Boys go into puberty at different times. You may notice that other boys in your child's class growing quickly, even from age 10 years. The first sign in boys is testicles getting larger, and hairs around the penis but these are not easily noted. Often, you may find your child to be growing quickly as the first sign of puberty. If any of these signs occur before age 9 years, this is too early. Most boys develop in puberty by age 13 years. If there are no signs of puberty by age 13 years, blood tests may be needed to investigate further.

You may wish to consider pausing puberty if it starts too early. Your child will be developing faster than other boys at school and may have a deep voice before leaving primary school. If puberty happens very early, your child may stop growing and end up being short. The easiest way to pause puberty is to have an injection that puts the puberty hormones (LH and FSH) from your pituitary gland back to sleep until the right time, which is usually just before your child becomes a teenager.

If your child is late in puberty, he may need help. The easiest way to progress in puberty is to replace the testosterone that the testicles are not making. This is often a single injection in the muscles once a month. Often these injections contain peanut oil. It is best to discuss the matter with your paediatric endocrinologist if your child has severe peanut allergy. Your doctors will try and mimic what the body normally does, i.e. start at low doses and increase them very gradually over approximately two years to ensure puberty changes are adequate

Testosterone is not only useful for physical development, it is also important for keeping bones strong and healthy. If the testicles do not make testosterone, some form of testosterone medication should be started and continued, probably for life. Once on a higher dose of testosterone, the doctors may offer different ways of taking it - like an injection that lasts three months or a gel that is put on every day.

Transition

Transition means moving from paediatric endocrinology to adult endocrine care. It is a gradual process and should start for your child around age 11 years, so that he/she is ready for transferring to adult care between ages 16 to 19 years.

From age 11 years onwards, your doctor or nurse may begin to talk to you and your child about transition. Gradually they will encourage your child to be more involved to find out more about his/her condition and make the right decisions. As your child grows up to be a young person, he/she will be encouraged to become more independent in managing his/her hormone condition. For example, he/she might begin having part, or all of their hospital appointments without parents being present.

When your child is ready for transition, the children's doctors will introduce them to the adult team and often see your child (and you) together for some time. There are specific 'transition clinics' where your child will be seen until he/she is ready to transfer completely to the adult clinic, usually by age 25 years. There may be option to have their care closer to home, which can be discussed with his/her doctor.

Transition comes at a time when other big things in your child's life are also happening:

- doing exams, leaving school, making choices about college, university and jobs
- spending more time with friends, finding a partner, making choices about where to live

You may think of transition as a journey. It may be a long journey or it may be a short one. Whatever the length, transition is a process to help those people whose journey involves crossing boundaries between paediatric and adult services. It's about looking up and looking ahead, but not too far and not too quickly. Transition involves preparation and planning for the future. It's also about building relationships between individuals and services, and to provide age-appropriate clinical care to:

- Equip young adults with skills, knowledge and attitudes they require to take an active role in managing their condition as an adult.

- Provide an appropriate clinical setting and appointment system that meets the needs of young people.

To help with the process of transition, a *'My Healthcare Passport'* is available; most paediatric endocrine units will have a version of this, so do ask.

Practical advice

Signposting hydrocortisone use

All children on steroid replacement therapy should carry some identification stating cortisol insufficiency. This could be by wearing a medical identity bracelet or necklace. One alternative is to keep a steroid card stating information about hydrocortisone dosage. Another alternative is to store the health data in your mobile phone (or your child's if he/she has one). Further information about these can be obtained from the paediatric endocrine specialist nurses.

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App for your mobile phone

My Cortisol is a free app available for ***Android*** and ***Apple devices*** to help with emergency care of children with cortisol deficiency.

Travel

When travelling there are a few things to consider:

Book in the child's travel vaccines with the GP and follow the immunisations advice as necessary. Discuss your travel programme with your paediatric endocrine specialist nurses. If travelling abroad, you will need a customs letter (or letter from their peadiatric endocrinologist for travel). You will need to carry your emergency kit on board a plane. Your customs letter will state that your hand luggage will contain sharps, needles and fluids. You may have to take more than 100 ml that is normally allowed. Ensure there is enough medication for the holiday, including doses of hydrocortisone for the entire duration of your stay. When changing time zones, it is safest to give the normal morning dose then repeat eight-hourly (if on three times a day) or six-hourly (if on four times a day) until the morning of your destination's time zone and then commence at normal times and doses from that point.

- If your child is also on DDAVP, please call the endocrine specialist nurses for advice.
- Ensure your travel insurance company is aware of your child's cortisol deficiency as this will need to be registered as a pre-existing condition.
- Find out how to contact an ambulance and where the local hospital is located near your destination before you travel. If your child is unwell, you do not want to be finding out this information at that point.

Support for parents

Our website has a section of information and signposting for parents here **www.pituitary.org.uk/support-for-you/carers-and-parents/**

The Pituitary Foundation has a group specifically supporting younger patients and their parents, and the group covers the UK. Our informal support groups differ from other local support groups in that they mainly have an online presence and offer telephone support instead of regular face-to-face meetings as they are not location specific. The four Co-ordinators of the group are Richard Jackman and George Marriott, and their mothers Alice Jackman and Rachel Marriott. They are there to offer peer support and information so do please get in touch.

Occasionally the younger people's group represents The Pituitary Foundation at events where the subject of younger pituitary patients is prominent. The group also helps run the sessions for younger people at Pituitary Foundation Conferences. The co-ordinators also help The Foundation to maintain and keep up to date our support information for younger patients.

We also have informal support offered from other parents with younger children and please contact us if you want to be put in touch with them, via **helpline@pituitary.org.uk**

Useful links

Contact (family support)

Freephone: 0808 808 3555
9.30am-5pm, Monday-Friday; free from UK landlines and UK mobiles
www.contact.org.uk

Turn 2 us (Benefits advice etc.)

www.turn2us.org.uk/

A parent's story

As a parent of a child with pan hypopituitarism, I was understandably quite nervous about my first child, Isabella, starting school. She had only been left before with close family, and attended a small pre-school, located a couple of doors away from my parents.

I had applied for a school which was next door to my parents (to allow me to work without worry.) This wasn't the closest school to my house, but I wrote to the school governors and cited Isabella's condition, and about the school's good reputation. Shortly after we received confirmation I had a meeting with the head teacher and with Isabella's new teacher. The pre-school also arranged an extra meeting to talk with the Early Years team about their experiences of Isabella's condition. After a great deal of persuasion, my daughter's endocrine nurse agreed to train Isabella's new school in how to administer the emergency injection of hydrocortisone. All staff were invited to attend training, including lunchtime supervisors, office staff, learning

A parent's story

support assistants, breakfast and after school club staff. I attended, and talked through everything alongside the nurse. At the end of the training, the head teacher asked for the staff members who were willing to administer the injection to sign a list, so that if needed, one of these adults could be found quickly. The staff at school were confident and put my mind at ease. The school nurse and I wrote Isabella's health care plan, which was approved by Isabella's endocrine nurse.

Isabella has her own cupboard in the class containing her daily hydrocortisone, 2 kits of her emergency injection, her healthcare plan and additional carb snacks if she's hungry. There are also photographs of Isabella and basic instructions if she feels unwell at various places around school. The class teacher also explained to the children that if Isabella feels poorly or hurts herself, it is very important that they tell an adult straight away. They were told that Isabella has to have her medicine so that she doesn't get poorly.

Isabella takes her hydrocortisone at 12 noon daily and one named adult in school has an alarm set on her phone to remind her. Isabella also has a bottle of Calpol in the cupboard at school, with a thermometer. They have a letter from me giving permission to give her medication if needed. As you cannot overdose hydrocortisone, I have been extremely clear that they should err on the side of caution and always give extra hydrocortisone if they are unsure. Luckily, the staff have always been vigilant and on occasions have done this. For example, when Isabella has had a bad fall and broken the skin on her legs, or had a knock to the head whilst swinging on the metal bars!

School staff have always been very good at contacting me or my parents, should they be concerned about Isabella presenting differently from her usual bubbly self or being pale, hot or sweaty. Isabella joins in with after school sports clubs and the heath care plan is given to the sports coach and a conversation with the teacher. The teacher gives Isabella her 3.30pm dose of HC and a quick snack. During school trips, myself or my parents have gone along as an extra adult helper, but on one occasion we couldn't go, so they sent an extra member of staff for additional care of Isabella.

After a year or so, Isabella's school went through a turbulent time which involved every teacher in the school leaving, along with the head teacher. Unfortunately, when I asked Isabella's endocrine nurse to train the new school staff she refused as it wasn't normal practice and school should just call an ambulance. However, she agreed with me that if Isabella broke a bone, (which given the fact that she is constantly in the accident book) and was not given the injection straight away, her life would be in danger. I took things further. In the end, the chief commissioner for medication in schools agreed to train the school herself, which I am extremely grateful for.

Having good regular communication with school staff, and knowing they are trained willingly and confidently to save my daughter's life should they need to, has alleviated much anxiety for me and allows Isabella to enjoy school and to take part in everything just like any other child.

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**

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

Title:		First Name:		Surname:	
Home Address:					
Postcode:					
Telephone No:				Email:	

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

Individual	☐ £25.00 (annual)	Joint	☐ £35.00 (annual)
Life Membership	☐ £350.00	Concessionary*	☐ £15.00 (annual)
Additional donation (optional) £			

**(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:	

Helpline
Monday - Friday 10:00am-4:00pm
0117 370 1320

Endocrine Nurse Helpline
available scheduled hours
0117 370 1317

Website: www.pituitary.org.uk

Email: helpline@pituitary.org.uk

Text: 07786 202 249

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.

The Pituitary Foundation
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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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Working to support pituitary patients, their carers & families