



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



Thyroid Conditions Entry

Organisations who wrote / approved the information

Thyroid Australia

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*Chronic Illness Alliance
www.chronicillness.org.au
03 9805 9126*

THYROID CONDITIONS

A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

What is the thyroid?

The thyroid is a butterfly-shaped endocrine gland situated in the front part of the neck, just below the Adam's apple. It produces two hormones which are essential for normal metabolism. There are a range of thyroid disorders that can afflict children.

What are thyroid disorders?

Hypothyroidism occurs when the body's metabolism is too slow due to an absence or deficiency of thyroid hormone. This can be due to either an abnormal thyroid gland, taking an inadequate level of thyroid hormone replacement (the treatment for hypothyroidism), iodine deficiency disorder (IDD - remedied by the use of iodised salt), having an absent message from the pituitary gland to the thyroid, or treatment for hyperthyroidism, thyroid nodules or thyroid cancer. The most common cause of hypothyroidism in Australia is Hashimoto's thyroiditis, an autoimmune condition which destroys the thyroid.

Symptoms of hypothyroidism can include:

- poor memory and concentration
- tiredness & fatigue
- depression
- irritability
- weight gain
- muscle weakness and cramps
- intolerance to cold weather
- deteriorating or slowing growth rate
- constipation
- dry, coarse, itchy skin
- brittle hair
- a croaky, hoarse voice
- slow reflexes
- slow heart rate
- delayed as well as precocious sexual development
- high cholesterol levels
- girls may suffer from increased menstrual flow

NB: children and adolescents with underactivity of the thyroid may have almost no symptoms or signs other than weight gain or slowing growth.

Congenital hypothyroidism is a predominantly non inherited disorder where the thyroid gland is usually either small and in the wrong position, or is completely absent. Rarer causes include an inherited enzyme defect leading to deficient hormone production and deafness, and a brain pituitary gland abnormality (secondary hypothyroidism) also occurs rarely. If left untreated congenital hypothyroidism can lead to cretinism (irreversible mental retardation and stunted growth), however in Australia it is detected as part of the 'heel prick' test soon after birth and treatment is begun immediately.

Hyperthyroidism occurs when an excess in thyroid hormone produces the symptoms of abnormally high metabolism, either due to an overactive thyroid gland, "hot" nodule, or taking too much thyroid hormone replacement. The most common cause of hyperthyroidism in Australia is Graves' disease, an autoimmune condition which overstimulates the thyroid. Most hyperthyroid patients eventually become hypothyroid, over many years. Remission of the disorder is less common in children than adults.

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Symptoms of hyperthyroidism can include:

- intolerance to hot weather
- more frequent bowel movements
- weight loss (despite a good appetite)
- tiredness & fatigue
- anxiety
- irritability
- hot, moist velvety skin
- excessive sweating
- fine brittle hair
- muscle weakness (especially the upper arms and thighs)
- increased heart rate
- high blood pressure
- poor concentration
- fine tremors of the fingers
- accelerated growth
- girls may have lighter and less frequent menstrual periods

Many people with autoimmune thyroid disease (Graves or, in a few cases, Hashimoto's) develop Thyroid Eye Disease (TED). This is an autoimmune disease of the orbit (eye socket) and eye muscles, characterised by inflammation, swelling and possible scarring (rare/occasional), with swollen eyelids and "poppy" eyes. TED, however, is usually mild when it occurs in young children.

Thyroid nodules are lumps or abnormal growths on the thyroid, whether benign (non-cancerous) or malignant (cancerous). These are generally asymptomatic, however some people experience tenderness and pain in their thyroid. They can be associated with overactivity, where the person also has symptoms outlined above.

Goitre: This is an enlarged thyroid gland. It can sometimes be quite large and uncomfortable. All people suffering from thyroid disorders can develop a goitre.

Thyroid cancer: There are different types of thyroid cancer (papillary, follicular, anaplastic, medullary, and lymphoma), the vast majority of which are readily treatable.

How common are they?

Hypothyroidism: Hashimoto's thyroiditis is more common in children with a family history of the autoimmune thyroid conditions or other autoimmune conditions. Hypothyroidism affects around 10 boys per 10,000 and 60 girls per 10,000.

Congenital hypothyroidism affects about one in every 4,000 births.

Hyperthyroidism: Graves' disease is more common in children with a family history of the autoimmune thyroid conditions or other autoimmune conditions. Hyperthyroidism affects around 2 boys per 10,000, and 4 girls per 10,000.

Thyroid nodules: More common in females than males. However, a nodule in a child or teenager under the age of 20 is more likely to be malignant (cancerous) than a nodule in an adult..

Thyroid cancer: In Victoria, for children under 20, there are around 3 new cases of thyroid cancer per year - 1 boy and 2 girls. Thyroid cancer is now recognised with increased frequency in children, adolescents and young adults who have previously been treated with spinal radiation as part of treatment for other different cancers. It is also seen in children who have been exposed to accidental ionising radiation in other countries. All these children should be regularly screened every 2 years with a thyroid ultrasound. Medullary thyroid cancer is an inherited and difficult to treat form of the disease. All family members of a person diagnosed with medullary thyroid cancer should be screened genetically. If this test is positive, the affected person will need to have a preventive thyroidectomy (surgical removal of the thyroid gland).

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2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

Treatment regimes for thyroid disorders are normally determined by regular blood tests and through clinical observation.

Hypothyroidism is treated with thyroid hormone replacement (thyroxine) tablets with very few side effects or allergic reactions. This is usually taken first thing in the morning. It can take many months to find the correct dose of thyroxine, as too much thyroid hormone causes symptoms of hyperthyroidism, whereas too little causes symptoms of hypothyroidism to persist. The effect of treatment also takes some time (weeks to months) to become apparent, as thyroid hormone is relatively slow-acting.

Hyperthyroidism is commonly treated in one of three ways:

1. Anti-thyroid drugs work to decrease the excessive thyroid hormone production. These tablets often take a few weeks to produce effects. Anti-thyroid drugs can occasionally have side-effects. Rarely they may stop production of white blood cells (part of the immune system) or blood platelets (needed to form clots). Sore throats, mouth ulcers, excessive bruising or skin rashes can be indicative of this. Patients should stop taking their medication and see their doctor the same day they develop these symptoms for tests. Of course, sore throats, mouth ulcers, and skin rashes are common and it is most likely that they are not due to carbimazole or PTU. However, the only safe action is to stop the medication until after the result of the blood test is received (usually 1 day). Most children require years of antithyroid drug treatment with only about 40% remission rate.
2. Thyroidectomy (surgical removal of the thyroid), Grave's disease in childhood and adolescence is sometimes treated by surgery, particularly if a patient is allergic to the anti-thyroid drugs. About 5/6 of the gland is removed, the remnant being usually sufficient for normal thyroid function. Similar surgery is used for multinodular goitre. A total thyroidectomy is only used for cancer or occasionally for a huge goitre.
3. Radioactive iodine (RAI) reduces the amount of functioning thyroid tissue and hence reduces thyroid hormone production. RAI is rarely used in patients under 17 years of age, for treatment of overactivity. but is recommended by WHO as safe over the age of 17. RAI is an intrinsic part of thyroid cancer management at any age. RAI treatment normally results in the patient becoming hypothyroid over 2-10 years, replacement treatment being given with thyroxine.

Thyroid nodules are removed in patients who have been exposed to radiation, where the nodules are multiple or large. A nodule, if small is sometimes observed and followed with serial ultrasound. Some nodules may be amenable to fine needle aspiration for diagnosis but this is not always suitable for children. If a nodule is associated with overactivity of the gland, simple removal cures the condition. Removal of a nodule does not cause underactivity of the gland.

Thyroid cancer is usually treated by the surgical removal of the thyroid gland, followed by radioactive iodine ablation of any remaining thyroid tissue. Hypothyroidism follows and is treated with thyroxine replacement. In contrast to other cancers, most forms of thyroid cancer are potentially curable.

Which health professionals are involved?

Children with thyroid disorders are normally treated by a paediatric endocrinologist or a paediatrician in consultation with a paediatric endocrinologist. Endocrine surgeons normally perform thyroid surgery.

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B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

Thyroid conditions affect every aspect of an individual: mental and emotional health, behaviour, academic performance, physical appearance and development, including sporting prowess. This can be extremely frustrating for the affected individual. The underlying frustration relating to the condition can be exacerbated by taking some time to be diagnosed, the length of time it takes for treatment to take effect (up to many months), and medication dosages needing to constantly be revised to meet the demands of a growing body.

After their treatment has stabilised (which can take some time, in some cases over a year) people with thyroid conditions can generally function like a healthy individual. However, medication does not replicate the functioning of a healthy thyroid. This means there will be some days (or weeks) where the person's symptoms return. This is additionally frustrating as there are no short-term remedies for these symptoms.

Children with thyroid conditions can be ostracised by their classmates. Their conditions can cause physical symptoms (such as weight gain or dry, itchy skin). and behavioural problems (such as hyperactivity). Frequently these children also struggle to keep up in both academic and social situations while the thyroid is not treated, although the academic skills return to normal as hormone levels normalize. This can cause them to be labelled (as well as feel) 'stupid' or 'slow'.

2. Effects on those close to the child/young person

Before diagnosis, the first thing parents, siblings and friends of a hypo- or hyperthyroid child may notice is a change in the child's personality or activity levels. Hypothyroid children can be labelled as "lazy", and hyperthyroid children can seem hyperactive. These changes in personality can be confusing to the child and to those who know the child. These personality changes can also cause friction between siblings. Parents may sometimes struggle to ensure that their child takes their prescribed medication.

3. "In Their Shoes" - stories from children/young people with the condition

"It's hard to say at what stage having a chronic illness was most socially difficult to bear. For a long time I didn't know that I was sick, and this made things bad for me because no one - including myself - could understand just why I had problems with things that they found so easy, like PE. Kids are always trying to label you as something, so when I did find out that I had Graves' Disease, people seemed to nod understandingly and turn their heads away. I always got queer looks. My friends didn't like hearing about it, and I couldn't comprehend why they were so discomforted by it. Most people don't like to be reminded of the mortality of human beings, and so in a way I guess they were kind of scared by it. I mean, if it could happen to me, why couldn't it happen to them?"

For the most part people understood, once they were told, why I couldn't do things like PE and sport and why I had to take tablets when everyone else didn't. But they still didn't want to know about it. I learnt that the best thing to do was keep my mouth shut. Sometimes I felt that my friends thought I was faking, or making it into something bigger than it actually was, because they couldn't actually see just how sick I was. It wasn't like I had a plaster on my arm or use a wheelchair, the battle was an inner struggle. I remember telling my friends that I was going to have surgery, and the only thing they could think to say was, "really?" as though they weren't really interested. Maybe that says a lot about my relationship with my friends at that stage, but maybe it says a lot more about how people of that age react when confronted with disease.

When I had my surgery I was pretty sick for a long time. One of the things that hurt me most was that only two of my friends came in to see me. I didn't actually want to see them, because I was too sick, but it was the thought that counted. I had about two weeks off school, and then went back for half the day a few days a week. For a while my friends were quite understanding and they did things like waiting for me when I had trouble finding the energy to get up stairs. People I didn't often talk to would come up to me and ask me how I was doing. But after a while the novelty wore off and after about a month my friends were telling me things like, 'You're such a slackass, you could come to school on time, really, if you felt like it.' I couldn't, but they didn't want to listen to that. Teachers were sometimes just as bad, not really believing how sick I was. Nevertheless, as time went on I got better, and by that time I had long become used to dealing with people who didn't want to have to face reality."

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C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

Both hypo- and hyperthyroidism can affect children quite markedly at school, in that they suffer from fatigue and behavioural problems. Fatigue (which can be extreme) is one of the most debilitating symptoms of both thyroid conditions. However, hyperthyroid children are also hyperactive, leading them to be labelled disruptive. Often thyroid patients feel that their personalities have been adversely affected, and others complain of their "laziness" or hyperactivity, and emotional instability. Their schoolwork can be adversely affected by their lack of concentration or poor memory. Following treatment, hypothyroid patients can have an increase in energy which can also lead to a decreased attention span and concentration in school, leading to further behavioural problems. As with sufferers of other conditions, thyroid patients also have to deal with the following issues:

- People's lack of knowledge and understanding of thyroid disorders
- The fact that, even though their thyroid condition is being treated, they will probably not feel well for some time as it takes a long time to control a thyroid condition, and it takes time for the body to adjust to the treatment
- Restrictions on lifestyle, due to fatigue and other symptoms
- Potential social isolation
- The severity of thyroid conditions vary from patient to patient. Some, therefore, respond to treatment more quickly than others
- Over-protectiveness on the part of others
- Missed schooling
- Impact on learning
- The need to take daily medication
- Medication side effects (especially for hyperthyroid patients)
- And, just the fact that they are "different" from their peers
- There are also anecdotal reports which suggest that some older children and teenagers, in an effort to fit in with their peers, do not always comply with their medication regimes, and so may revert to the symptoms of their diagnosed thyroid condition

Schools need to be sensitive of the child's potential problems with concentration and learning and with sport. Do not expect immediate and permanent resolution of symptoms once treatment is commenced - thyroid conditions take time to resolve. However, ongoing problems may indicate that the child is not taking their medication regularly or that their medication is not being managed adequately.

School staff should seek precise written information from the child's endocrinologist (via the parent) as to the severity of an individual situation, whether sport is advisable, duration of restrictions on activity and a time line expected for recovery of normal concentration. For adolescents in years 11 and 12, overactivity of the thyroid can be triggered by stress, careful monitoring is required and the educational examinations board in the state must be notified to seek special consideration, should sudden changes take place.

2. Link(s) to useful other online resources for schools on strategies in responding to a child/young person with this condition

American Association of Clinical Endocrinologists, *Thyroid through the ages: Birth and early childhood* (Growth) - www.aace.com/pub/tam2001/tam-birth.php

JS Dallas, *Congenital hypothyroidism* (The Thyroid Foundation for Education and Research, & Thyroid Australia) - www.thyroid.org.au/ThySoc/ThySocCH.html

S Dowshen, *Thyroid disorders* (Nemours Foundation) - http://kidshealth.org/kid/health_problems/gland/thyroid.html

S Dowshen, *Thyroid disease and teens* (Nemours Foundation) - http://kidshealth.org/teen/diseases_conditions/growth/thyroid.html

R Koumourou, *Thyroid disease in children* (Thyroid Australia) - www.thyroid.org.au/Information/CTC.html

R Levy, *Hypothyroidism in infancy and childhood* (Thyroid Foundation of Canada) - www.thyroid.ca/Articles/EngE11E.html

ML Mitchell, *Congenital hypothyroidism* (Thyroid Foundation of America) - www.allthyroid.org/disorders/pregnancy/newborns/1

SR Salisbury, *Thyroid disease in childhood* (Thyroid Foundation of Canada Health Guide #9) - www.thyroid.ca/Guides/HG09.html

Anon, Over to you: Diagnosed with Graves' at fourteen (Thyroid Australia) - www.thyroid.org.au/Stories/Graves14.html

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D: FURTHER INFORMATION

1. Organisations, including services and resources available

Thyroid Australia aims to provide information, education, and support to people living with or affected by thyroid disorders. Services include information, community education, support groups, and (eventually) research.

Thyroid Australia Ltd
PO Box 2575
Fitzroy Delivery Centre VIC 3065

Phone: (03) 9561 2483 (10am - 3pm Mon-Fri)
Fax: (03) 9561 4798 (10am - 3pm Mon-Fri)

Email Address: support@thyroid.org.au

Internet Address: <http://www.thyroid.org.au>

2. Reading, including links to downloadable documents

Ridha Arem MD, *The Thyroid Solution: A Mind-Body Program for Beating Depression and Regaining Your Emotional and Physical Health* (Ballantine Books, New York) 1999. (ISBN 0 345 42919 2.)

H Jack Baskin MD, *How Your Thyroid Works*, 4th ed. (Adams Press, Chicago) 1995. -
<http://www.thyrolink.com/patients/infoeng/baskin.html>

RIS Bayliss KCVO MD FRCP & WMG Tunbridge MD FRCP, *Thyroid Disease: The Facts*, 3rd ed. (OUP, Oxford) 1999. (ISBN 0 1926 2946 8)

Jake George & Nancy Patterson, PhD, *Graves' Disease: In Our Own Words* (National Graves' Disease Foundation; Blue Note Publications, Cocoa Beach FL) 2002. (ISBN 1 878398 20 2)

Elaine A Moore, *Graves' Disease: A Practical Guide* (McFarland & Co., Jefferson, NC) 2001. (ISBN 0 7864 1011 6)

M Sara Rosenthal, *The Thyroid Sourcebook: Everything You Need to Know*, 3rd ed. (Lowell House, Los Angeles) 1998. (ISBN 0 7373 0014 0)

Alan L Rubin, MD, *Thyroid for Dummies®* (Wiley Publishing, New York) 2001. (ISBN 0 7645 5385 2)

Mary J Shomon, *Living Well with Hypothyroidism: What Your Doctor Doesn't Tell You ... That You Need to Know*, (Avon Books, New York), 2000. (ISBN 0 380 80898 6)

Dr Anthony Toft, *Home Medical Guide to Thyroid Disorders*, consulting ed. Prof Bruce Robinson, (Dorling Kindersley; Australian Medical Association, London), 2000. (ISBN 1 86466 282 4)

Lawrence C Wood MD FACP, David S Cooper MD FACP, & E Chester Ridgway MD FACP, *Your Thyroid: A Home Reference*, 3rd ed. (Ballantine Books, New York) 1995. (ISBN 0 345 39170 5)

Websites

Thyroid Australia - www.thyroid.org.au

British Thyroid Foundation - www.btf-thyroid.org

Hypoparathyroidism Association (USA) - www.hypoparathyroidism.org/

The MAGIC Foundation for Children's Growth (USA) - www.magicfoundation.org/

National Graves' Disease Foundation (USA) - www.ngdf.org

ThyCa: The Thyroid Cancer Survivor's Association (USA) - www.thyca.org

Thyroid Federation International - www.thyroid-fed.org/home.html

Thyroid Foundation of America - www.allthyroid.org

Thyroid Foundation of Canada - www.thyroid.ca