Symptoms

The causes are unclear. However, always present are:

• an abnormality in absorption or excess production of, cerebrospinal fluid (CSF) leading to a build-up of this fluid in the brain;

• increased blood volume in the vessels around the brain;

• swelling of the brain.

The symptoms reported are those usually associated with raised intracranial pressure (ICP): these will commonly include headache, visual disturbances, photophobia, vomiting, problems with balance and spatial awareness, disorientation, loss of short-term memory (sometimes long-term memory loss), “pins and needles” or loss of sensation in hands. In some cases, CSF leaks down the nose. It is important to exclude cerebral tumour as a cause of the...
symptoms. People with raised ICP may find it difficult to cope with previously learnt everyday tasks, eg handling money or using the telephone. They may be unable to find their way around a previously familiar town: traffic is confusing, they can be unaware of kerb height (sometimes afraid to step off the kerb in case they step “into space”); crossing the road can be a nightmare.

Intracranial Hypertension

Diagnosis

Diagnosis of IH is by scan and measurement of the CSF pressure. On CT scan, the ventricles (chambers in the brain) will usually appear normal or small. The CSF pressure should always be measured despite the “normal” scan results. It will be found to be raised on lumbar puncture. On examining the eyes, papilloedema (swelling of the optic disc) may be present. This in itself is often an indication for surgical intervention.

As most people with IH appear perfectly normal, they often do not receive the recognition they deserve. But IH can be very disabling. Relationships suffer. Headache can be constant, thus disturbing normal sleep patterns. Depression is not uncommon.

Monitoring

Some 11 - 35% of people recover spontaneously; in others, management is variable. Some people do very well on a regime of diuretics and steroids but must be monitored symptomatically, and by CSF pressure measurement to protect the eyesight.

There is little evidence that drug therapy improves the long-term outcome, although a short (two week) course of steroids may be enough to re-open venous pathways so that the IH resolves.

Where sight is affected, it may be necessary to fenestrate the optic nerve (slit the sheath surrounding the nerve): everyone should be under the care of an ophthalmic surgeon.

Some people need repeated lumbar punctures to remove excess CSF, or the excess CSF may need to be diverted by means of a surgically inserted shunt. In theory, a lumbar peritoneal shunt is the shunt of choice. In practice, the patient may
and may need to be treated with combinations of various painkillers. Complementary therapies such as cranial osteopathy, Indian head massage and reflexology are often very helpful, but should only be used if the neurologist or neurosurgeon is in agreement.

Life with Benign Intracranial Hypertension

What’s in a name? (a poem by an adult with IH)

I’m angry, cross, annoyed
At a very misguided man
The one who names diseases
With inappropriate, ill suited titles.
Benign Intracranial Hypertension is the label
That doctors place on me.
If I met that man face to face
I would demand that he justify that name.
And tell me what’s benign:
I find the word an insult to my suffering.
It implies it’s OK, harmless, curable,
Slight, superficial, easily treatable.
I know it’s not life-threatening
In a mortal sense,
But it’s killing my living.
I haven’t worked for months
In the job I love,
Had countless lumbar punctures
And needles in other parts.
Operations with tubing and valves
Inserted in unsymmetrical patterns
around my body.
Symptoms too numerous to list.
My marriage is under constant strain
And my children suffer,
That really hurts.
Will I be home next week or not?
I want to get on with living,
Have a routine or normality.
Yes, I’m angry all right.
What right did he have to label all
this benign.
I have a right to be exasperated,
infuriated
With his lack of imagination and understanding.

Surely he could have come up with something,
Something just a little more grand,
Something to portray my distress,
To evoke a little understanding in
people standing near,
To induce a little sympathy for me.
Come on someone please,
Start now with this disease
Let’s have a renaming ceremony,
But please, remember, invite me.

L.G.

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