

2016 Iron Information Sheet for HHT

You and your doctors can find further information, and access to these papers, via <https://www.imperial.ac.uk/people/c.shovlin/page/hht-and-pavms.html>

THE HHT DIETARY STUDIES: Why people with HHT need iron:

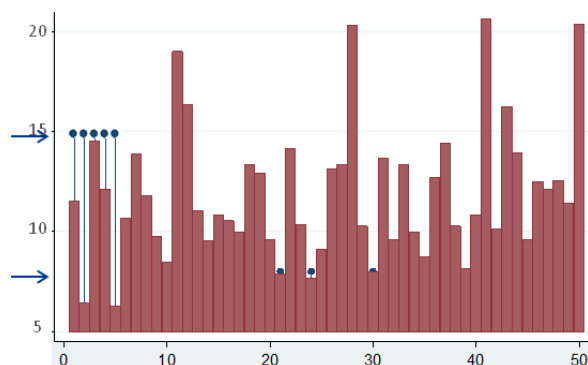
50 of you helped us with our dietary study, filling in questionnaires about what you ate, how much your noses bled, and for 25 of you, weighing your food for a week. We were able to show that the reason why most people with HHT are anaemic is simply that they do not get enough iron in to balance the iron they lose through their nosebleeds. While most of the 50 met their “normal” daily requirements, only a third were able to meet the amount needed to also replace iron lost through their nosebleeds. Fortunately, we were able to show that people with HHT usually handle iron normally- so when you are short of iron, your body absorbs more. Those who weighed their food allowed us to calculate which foods provided most iron for them– breakfast cereals were top of the list –and that vegetarians were able to get just as much iron as people who ate lots of meat.

FINNAMORE ET AL PLOS ONE 2013 Oct 16;8(10):e76516 Full papers available on line
FINNAMORE ET AL BRJ GP 2014, Apr;64(621):172-3

Iron (in mg per day):

Top blue dots: Daily intake recommended in the UK for women before the menopause. Note that this is quite difficult to meet.

Lower blue dots (most are hidden): Recommended daily intake for men or post menopausal women.

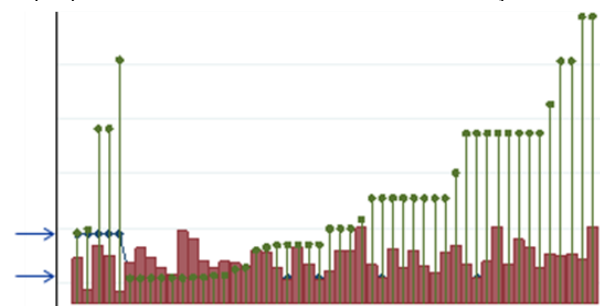


50 people with HHT: the red columns show their daily iron intakes

The same data are now shown on a different scale

Green dots: The iron needed to meet the recommended daily intake and replace the iron lost through each person's nosebleeds

The usual recommended daily intakes are shown again for comparison.



The same 50 people, in the same order. We called the green dot figure, the “haemorrhage adjusted iron requirement, or “HAIR.”

DAILY IRON REQUIREMENTS AND INTAKE: KEY POINTS

Recommended nutrient requirements (UK, RNI)

- Males/post menopausal female RNI 8.7mg/day
- Pre menopausal female RNI 14.8mg/day

Haemorrhage adjusted iron requirements (HAIR)

- Nosebleeds <every other day, usually <20mg/day
- Nosebleeds every other day, usually >20mg/day

These are VERY rough guides:

If people are short of iron, they usually absorb iron better as long as they are well, but:

- Inflammation (eg infection, arthritis) and other illness prevents iron absorption
- Drinking lots of tea also reduces iron absorption by up to 2/3.

Dietary iron:

- Individual dietary items rarely contribute >3-4mg
- The usual ‘informed’ UK dietary intake is ~8-14mg/day (see graph opposite)
- The realistic maximum daily dietary intake ~20mg/day (see graph opposite)

Iron tablets:

“Usual” dose	Iron (mg): Per tablet	Per day
Iron 7mg supplements once/day‡	7	7
Iron 14mg supplements once/day‡	14	14
Ferrous gluconate 300mg once/day	35	35
Ferracru 30 mg 2x/day	30	60
Ferrous sulphate 200mg 3x/day‡	65	195
Feospan 150mg bd	47	94
Ferrograd 325mg od	105	105
Ferrous fumarate found in:		
Fersaday 322mg 1-2x/day	100	100-200
Fersamal tab 210mg 1-2 tablets 3x/day	68	204-408
Galfer 305mg 1-2x/day	100	100-200
Pregaday (+ folic acid) 1/day	100	100

‡ Available “over the counter” without prescription

DOES IT MATTER IF I TAKE IN TOO LITTLE OR TOO MUCH IRON?

Too little iron causes anaemia, and in HHT, can increase the risks of palpitations or blood clots, stroke due to pulmonary AVMs, and/or heart failure due to liver AVMs. 1 in 3 people say taking iron tablets makes their HHT nosebleeds better**. **So check you are getting enough iron.** But iron tablets often cause constipation, diarrhoea, tummy pains or vomiting, especially at higher doses. Some people (~1 in 20 with HHT**/*), say iron treatments make nosebleeds worse; and higher iron levels/intravenous iron use can link to more infections from pulmonary AVMs^, and anaemia°. If you are struggling with any of these, talk to your doctor to see if it is sensible to alter your dosage.

*SHOVLIN ET AL LARYNGOSCOPE 2016;

**SHOVLIN, PATEL AND JACKSON ERJ OPEN RES 2016

^BOOTHER ET AL, CLIN INFECT DIS 2017 (AUG);

° THIELEMANS ET AL, HAEMATOLOGICA 2019 (APR)

Full papers available on line