ORTHOPTIC LED
IDIOPATHIC INTRACRANIAL HYPERTENSION (IIH) CLINIC
PROTOCOL EXAMPLE

1. Introduction

The Neuro-Ophthalmology Service currently manages a large number of patients with complex conditions that require long term monitoring of their visual function and optic discs.
The risk of IIH is visual impairment and appropriate monitoring is required.

The IIH Ophthalmology Service consists of Orthoptist and Consultant Neurologist led clinics for the follow-up assessment of patients who require monitoring of their condition including visual function, headaches and optic discs. The role of the Orthoptist in the IIH Stable Orthoptic-led clinic is to assess and review visual function and OCT of both discs and maculae, with assistance of Consultant Neurologist or on-call emergency doctor if required.
All Orthoptists should have experience in Tier 1 and 2 healthy weight signposting, and have completed formal training on coaching and motivational interviewing, as well as an accredited module on neuro-ophthalmology OCT interpretation.
The overall responsibility for patient care remains with the Consultant Neurologist.

2. Inclusion criteria

- Patients with established IIH
- Aged 18 years old or over
- Resident in this location:
- Ensure they have an IIH referral form attached to CRS for auditing/triaging/monitoring purposes
- Ensure they have an emergency clinic proforma attached to CRS for auditing/triaging/monitoring purposes

3. Exclusion criteria

- Additional ocular problems i.e. ocular motility problems, orbital signs
- Pre-existing neurological pathology

4. Patient examination

Visual Function:

- Visual Acuity
  - best corrected visual acuity
  - pinhole acuity on all patients with less than 6/9 vision or a new change of vision
- Ishihara colour vision
- Pupil reactions
- Intraocular pressure
- Visual field assessment
    - Humphrey 24-2 – follow-up appointments and when clinically indicated

- *Goldmann Visual Fields – only when clinically indicated*

OCT:

- OCT of disc and macula (neuro)
- Patient to undergo undilated OCT assessment if possible
- Dilated with Tropicamide 1% in both eyes if required
- To be interpreted and reviewed by the orthoptist

Symptoms

Questions to be asked as outlined below.

1. Headaches? (frequency, intensity, duration, characteristic, location, positional, HIT-6 score)
2. Pulsatile tinnitus?
3. Visual symptoms? (obscurations/other)

Height and weight:

Weight is to be measured and recorded at each appointment.
This can be used to document BMI (**BMI** = kg/m^2)

General health and medications:

The patient must be asked about the following:

<u>Medications</u>

- Acetazolamide/Diamox
- Topiramate *(Patient must be advised to **avoid pregnancy** whilst taking)*
- Analgia
- Medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives.
- Other medications

<u>General Health</u>

- Other medical diagnoses/medical history
- Under neurology/neurosurgery elsewhere
- Date of last lumbar puncture and findings
- Date of last MRI/CTH and findings
- Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea

5. Review of results and outcomes

- All completed visual function and optic nerve assessments will be reviewed by the Orthoptist on the same day.
- All patients in the orthoptic-led clinic should be medically stable, with any treatment already initiated by the consultant.
- Any proposed changes to treatment and/or management plan must be discussed with and approved by the consultant neurologist.

    - Patients who have shown improvement or remain stable should continue with current medication and be scheduled for a follow-up review in the orthoptic-led IIH neuro-ophthalmology clinic in 3-6 months.
    - For those who have been stable/shown improvement for 2 consecutive visits, send an email to consultant neurologist on Tuesday PM with name, MRN, findings and management plan to confirm whether a reduction or cessation of medication is appropriate, or if discharge is suitable. (Please cc bartshealth.iihclinic@nhs.net for MDT efforts, auditing and safety-net purposes). The consultant neurologist will respond with confirmation following review. The best time to chase him is Tuesday PM. Use the 'high importance' icon so he can differentiate our requests.
    - Patients showing emergency worsening of swelling/symptoms must be discussed and seen within the emergency clinic on the same day. SEE CLINICAL GUIDELINES.
    - Patients showing non-emergency worsening of swelling/symptoms should be emailed and reviewed by the consultant neurologist within a week. SEE CLINICAL GUIDELINES.
    - All patients with worsening of swelling/symptoms should trigger referral back to the consultant clinic, where further management will be undertaken by the consultant.

6. Documentation

- All clinic findings and management plans should be communicated to the patient, their GP, and any other relevant clinicians involved in their care via a clinical letter, which must be sent within seven working days. The clinic letter should be completed after the Orthoptist has conducted a virtual review.
- If any changes are made to the treatment and/or management plan, the patient should be informed by telephone consultation where possible, in addition to receiving a clinic letter.
- Any changes to the treatment and/or management plan must be documented as follows:
  "The results from today's appointment were discussed and reviewed by XXXXX, consultant neurologist, who has advised the following changes: XXXXXXXXX."

7. Tier 1 Healthy Weight Management

See the IIH Clinician Information Leaflet for SASASA every-contact-counts guidance for Healthy Weight Motivational Interviewing.

Educate patients about their condition and signpost them to healthy weight loss resources by giving

them the IIH Patient Information Leaflet.

- See IIH.UK charity for information and support on IIH https://www.iih.org.uk/
- Use the Migraine Trust website for further information and support about living with headache Home - The Migraine Trust
- Follow further live well and better health advice and support from the NHS and British Dietetic Association.
  https://www.nhs.uk/live-well/
  https://www.bda.uk.com/food-health/food-facts.html
  https://www.nhs.uk/better-health/
  Fitness Studio exercise videos - NHS (www.nhs.uk)

- Sign up for the IIH HOPE Programme
  - Emotional support and coping strategies.
  - Guidance on managing the physical and mental health challenges of living with IIH.
  - Information on how to navigate healthcare services and support networks.
  https://www.h4c.org.uk/hope-programme

8. Tier 2 Healthy Weight Management

Local Council Weight Management Programme

Check with your local council to see what Tier 2 Weight management programme is available.

These programmes are often free and last for 12 weeks, with dietary and exercise intervention.

Referral to NHS Digital Weight Management Programme

https://www.england.nhs.uk/digital-weight-management/

The NHS Digital Weight Management Programme could help you if you are living with obesity and also have diabetes, high blood pressure or IIH. It's a free 12-week programme easily available via a smartphone, tablet, or computer and available to anyone throughout the UK.

Currently, patients can only be referred to this programme via their GP or community pharmacist.
The Orthoptist should write to their GP requesting them to complete this referral.

9. Tier 3-4 Healthy Weight Management

Referral to the Obesity Clinic

If possible, set up a streamlined internal referral process with your local obesity service and advocate for a reduced BMI threshold for IIH referrals to 30.
Use BIOS IIH supporting statement, and highlight that delayed treatment may lead to further progression of IIH symptoms and increased risk of vision loss.
MANAGE PATIENT EXPECTATIONS
Many obesity services have long waitlists, so make sure to manage patient expectations and continue with Tier 1-2 management in the meantime

10. Further Onwards Referrals to Consider

It is essential to consider the holistic health needs of IIH patients and refer them to:

- ECLO for patients who have faced visual loss.
- Psychological support for emotional and mental health challenges.
- Headache specialists for ongoing management of chronic headaches and pain associated with IIH.
- Occupational Therapy to help manage the condition's impact on daily activities, vision, pain, and overall quality of life.
- Gynaecology to manage related conditions such as PCOS.
- Endocrinology to assess hormonal factors that may influence IIH, such as insulin resistance, thyroid disorders, or elevated cortisol levels, which can affect weight and metabolic health.

11. DNA

Please refer to trust policy.

12. Discharge

A patient must only be discharged from the IIH Orthoptic lead clinic by the decision of Consultant Neurologist.

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Approved by the Neuro-ophthalmology Clinical Advisory Group for the British and Irish Orthoptic Society