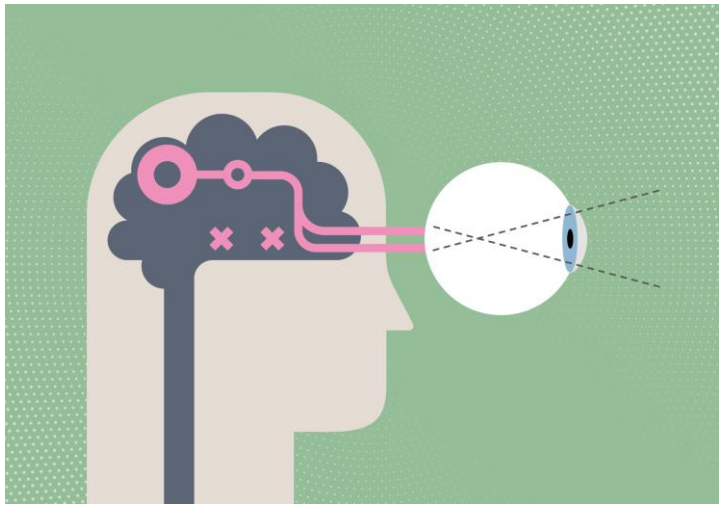
BIOS

British and Irish Orthoptic Society



Resources & Standardising care

Alis Sejourne

Lead Orthoptist for Neuro-ophthalmology and Adults with Learning Disabilities, Royal London Hospital

Member of the steering committee for BIOS Neuro-Orthoptics Clinical Advisory Group

Examples of Practice: Pathways/ Proformas

BIOS Supporting Statement on Lowering BMI Threshold for IIH Referrals

Headache Impact Test (HIT-6)

BIOS Presentation – Orthoptic-Led Idiopathic Intracranial Hypertension (IIH) Service

BIOS Idiopathic Intracranial Hypertension (IIH) Proforma

BIOS Idiopathic Intracranial Hypertension (IIH) Clinician Information Leaflet

IIHUK – The Hope Programme Poster

BIOS Idiopathic Intracranial Hypertension (IIH) Patient Information Leaflet

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Resources On Specific Conditions

+ **Multiple Sclerosis (MS)**
+ **Headaches & IIH**
+ **Neuromuscular Conditions**
+ **Brain Tumours**
+ **Degenerative Neurological Conditions**

Examples of Practice: Pathways/ Proformas

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BIOS BRITISH AND IRISH ORTHOPTIC SOCIETY

BIOS Supporting Statement on Lowering BMI Threshold for IIH Referrals

The British and Irish Orthoptic Society (BIOS) strongly advocates for the reduction of the Body Mass Index (BMI) threshold for referrals to obesity services in patients with Idiopathic Intracranial Hypertension (IIH) to 30.

IIH is a serious neurological condition that can lead to progressive visual impairment and sight loss. Evidence shows that weight management plays a crucial role in disease control, and early intervention is essential in preventing long-term disability. By lowering the BMI threshold for referral, obesity services can support earlier access to weight management strategies, improving patient outcomes and reducing the risk of irreversible sight loss.

Orthoptists, as key professionals in the early detection and management of IIH, urge obesity services to recognise IIH as a high-risk condition requiring prioritisation in weight management programmes. BIOS calls for urgent changes to referral criteria to ensure that patients receive the necessary support before significant sight loss occurs.

Examples of Practice: Pathways/ Proformas

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Headache Impact Test (HIT-6)

Headache Impact Test (HIT-6) questionnaire was designed to help you describe and communicate the way you feel and what you cannot do because of headaches.

To complete, please circle one answer for each question.

1. When you have headaches, how often is the pain severe?
   never rarely sometimes very often always

2. How often do headaches limit your ability to do usual daily activities including household work, work, school or social activities?
   never rarely sometimes very often always

3. When you have a headache, how often do you wish you could lie down?
   never rarely sometimes very often always

4. In the past four weeks, how often have you felt too tired to do work or daily activities because of your headaches?
   never rarely sometimes very often always

5. In the past four weeks, how often have you felt fed up or irritated because of your headaches?
   never rarely sometimes very often always

6. In the past four weeks, how often did headaches limit your ability to concentrate on work or daily activities?
   never rarely sometimes very often always

☐	☐	☐	☐	☐
NEVER 6 points each	RARELY 8 points each	SOMETIMES 10 points each	VERY OFTEN 11 points each	ALWAYS 13 points each

To score, add points for answers in each severity rating.

You should share your results with your doctor. Headaches that stop you from enjoying the important things in life, like family, work, school or social activities could be migraine.

Higher scores indicate a greater impact on your life

Score range 36-78

☐ TOTAL SCORE

Reference:

Yang M, Rendas-Baum R, Varon SF, Kosinski M. Validation of the Headache Impact Test (HIT-6™) across episodic and chronic migraine. *Cephalalgia*. 2011;31(3):357-367. doi:10.1177/0333102410379890.

Examples of Practice: Pathways/ Proformas

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NAME:
DOB:
MRN:

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Date of referral:	Date of onset of symptoms:	
Weight (kg):	Height (cm):	BMI (kg/m2):
Recent weight gain before diagnosis: Yes / No (delete as necessary)		

History:

- Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea are also associated with IIH.
- Medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives may also cause secondary IIH.

SYMPTOMS

Headache: Yes / No			Unilateral/ Bilateral:		
Duration of headache history:			Disabling: Yes / No		
Frequency (days/week):			Analgesic use (days/week):		
Yes/No:	Nausea/vomiting	Photophobia	Phonophobia	Throbbing	Positional
HIT-6 score:					
Pulsatile tinnitus: Yes / No					
Transient visual obscurations: Yes / No					
Other visual symptoms:					

VISUAL FUNCTION

Papilloedema: Yes / No.	Frisen Grade:	
Fundoscopy findings:		
Spontaneous venous pulsations	Pre-LP: Yes / No	Post-LP: Yes / No
BCVA for distance	RE:	LE:
Colour vision	RE:	LE:
Pupillary reflexes	RE:	LE:

Idiopathic Intracranial Hypertension (IIH) Proforma

Intraocular pressures	RE:	LE:
Visual fields	RE:	LE:
Optical Coherence Tomography	RE:	LE:

INVESTIGATIONS

Lumbar puncture	Date:	Opening and closing pressure:
CSF constituents (describe only if any abnormalities):		
CT/MRI head: Yes / No	Date:	Any abnormality:
CT/MR Venogram: Yes / No	Date:	Any abnormality:

MANAGEMENT

Acetazolamide dose:
Headache diary given: Yes / No
Advised to reduce analgesia use to max 2 days/week: Yes / No
Analgesia type + frequency:
Migraine prophylaxis name and dose:
Under neurosurgery / has neurosurgical intervention: Yes / No
If yes, please describe with approx. date of intervention:
Under obesity clinic: Yes/No
Signposted for Tier 1-2 Weight Management: Yes/No
Considered onwards referral: Yes/No ECLO, Psychological support, Headache specialists, Occupational Therapy, Gynaecology, Endocrinology
Suitable for Orthoptic-led IIH clinic: Yes/No

Clinician Name:	Sign:

Examples of Practice: Pathways/ Proformas

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Idiopathic Intracranial Hypertension – Clinician Information Leaflet

Signs and Symptoms:

- Headaches which are typically positional (worse in the mornings/when lying down).
- Nausea/vomiting.
- Pulsatile tinnitus. Often described as "whooshing" sounds.
- Transient visual obscuration's (periods of blurred vision).
- Papilledema (optic nerve swelling).
- Peripheral visual field loss, and/or enlarge blind spot, which may progress to involve central vision if untreated.
- Unilateral or bilateral sixth nerve palsies.
- Hyperopic shift - Axial length may shorten due to posterior flattening of the globe.

What you may need to test (Orthoptist):

- Best corrected visual acuity
- Colour vision
- Pupils (RAPD)
- Visual fields (GVF).
- Intraocular pressures (IOP)
- Ocular movements (abductions)

Some risk factors:

- Female aged 18-44.
- Obesity or recent weight gain
- Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea
- Medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives.

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Healthy Weight: Motivational Interviewing

This should be a brief, 5 minute conversation.
Make every contact count with SA-SA-SA!

State
State the facts.
Your weight at first diagnosis was:
Your weight today is:
Your weight loss percentage since first diagnosis is:

Ask
Could we spend a couple minutes to discuss your weight?

I want to simply ask: how do you feel about your weight?

Summarise
Summarise what they said. Encourage healthy decisions.

Advise
The risk of IIH increases with weight gain. The risk of vision loss because of IIH also increases with weight gain.

Weight loss of **6%-10%** often leads to IIH remission.

Hand out and discuss advice points on IIH Patient Information Leaflet.

Suggest
Ask the patient what they suggest they could do to help reduce their BMI?

Assist
Help the patient make achievable goals.

Make or aid referrals to Healthy Weight Programmes with your local Council, or the NHS Digital Weight Management Programme. Signpost them to further live well and better health advice from the NHS, as well as the IIHUK website. This can all be found on the IIH Patient Information Leaflet.

Examples of Practice: Pathways/ Proformas

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HOPE PROGRAMMES FOR:

ADULTS LIVING WITH IIH

PARENTS OF CHILDREN WITH IIH

FREE SELF-MANAGEMENT COURSES

IIHUK idiopathic intracranial hypertension

the hope programme

ORCHA

DO YOU OR YOUR CHILD LIVE WITH IDIOPATHIC INTRACRANIAL HYPERTENSION?

Do you want to build strategies to cope and live well?

Do you want to rediscover your strengths and meet others in the same situation?

This 6 session programme is delivered online via our platform.

- **Available 24/7 on any device**
- **Sessions released weekly**
- **Learn at a time and pace that suits you**
- **An option to remain anonymous**
- **Trained Facilitators**

TO BOOK ON
WWW.H4C.ORG.UK/COURSES
EMAIL: HOPE@H4C.ORG.UK
OR PHONE: 024 7736 0153

SCAN HERE

Examples of Practice: Pathways/ Proformas

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Idiopathic Intracranial Hypertension (IIH) – Patient Information Leaflet

Your weight at **first diagnosis** was:

Your weight **today** is:

What is IIH?

IIH is a rare condition where the fluid pressure around the brain is too high. This causes a range of symptoms such as disabling headaches, tinnitus and nausea.

What does this mean for my eyes?

The high pressure can damage the optic nerves which send vision to the brain, resulting in loss of vision. It can also damage nerves that supply eye movement, resulting in double vision.

What causes IIH?

The exact cause of IIH is unknown. However, we do know that 95% of IIH patients are overweight or experienced recent weight gain. We also know that the risk of getting IIH increases with weight gain and the risk of vision loss because of IIH also increases with weight gain.
Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea are also associated with IIH.
Medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives may also cause secondary IIH.
Speak with your doctor for further advice before discontinuing any medication.

How can IIH be treated?

Weight loss of **6%-10%** often leads to IIH remission.
Doctors may also start you on a drug, such as Acetazolamide. This works most effectively when also combined with weight loss.
In some cases, a shunt procedure may be performed to drain excess fluid from the brain and relieve pressure. However, this does not cure the underlying condition.

Ask your health professional any questions you have. We are here to support you!

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Signposting

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

Ask us how you can be referred to a suitable Healthy Weight Programme with your local Council, or the NHS Digital Weight Management Programme.
https://www.england.nhs.uk/digital-weight-management/

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

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)

Examples of Practice: Pathways/ Proformas

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Pathway for IIH patients considered medically stable in the Neuro-ophthalmology clinic

BIOS BRITISH AND IRISH ORTHOPTIC SOCIETY

Orthoptic-led Neuro-ophthalmology Clinic

Patient Information and Signposting Leaflet Given

Initiate Tier 1-4 Healthy Weight Management as suitable

Onward Referrals:

ECLO, Psychological support, Headache specialists, Occupational Therapy, Gynaecology, Endocrinology

Evaluation Metrics:

Weight, Visual acuity, colour vision, pupils, intraocular pressure, visual fields, OCT (disc and macular)

Questionnaires:

HIT-6

Improvement/Stable

Continue with current medication
Repeat review in Orthoptic-led in 3-6 months

2 consecutive visits of improvement/stability

Send email to consultant neurologist 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 *insert shared mailbox* for MDT efforts, auditing and safety-net purposes)

Worsening

Refer to clinical guidelines

Emergency

Discuss with on-call emergency clinic doctors on the same day

Non-Emergency

Discuss with consultant neurologist within a week

Referral back to Consultant-led Neuro-ophthalmologist Clinic

Examples of Practice: Pathways/ Proformas

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Orthoptic-led IIH clinical guidelines

BIOS BRITISH AND IRISH ORTHOPTIC SOCIETY

No consultant input required – for routine orthoptic-led review

Clinical Scenario	Outcome
Stable/improved clinical appearance	Continue with current/without medication and review orthoptic-led

For non-emergency virtual consultant review (emailed and reviewed within a week):

Clinical Scenario	Key Signs/Symptoms
Mild worsening of papilloedema	Frisen grade increase from 1 to 2–3, but stable fields/VA
Visual field changes without VA loss	Slow worsening of HVF or GVF over recent visits
Patient poorly compliant with treatment AND mild clinical deterioration	Mild worsening OCT/fields, or new symptoms with poor treatment compliance
New transient visual obscurations	Brief greying/dimming/vision loss episodes, stable exam
Possible medication side effects (e.g. acetazolamide intolerance)	Significant tingling or GI issues, affecting compliance
Consider reduction in medication dose	Two consecutive visits of stable/improved clinical findings with continued medication within orthoptic-led clinic
Consider for discharge	Two consecutive visits of stable/improved clinical findings without medication within orthoptic-led clinic

For emergency clinic in-person review (same day):

Clinical Scenario	Key Signs/Symptoms
Rapid vision loss	Sudden drop in visual acuity (≥2 lines or more), and colour vision, especially bilateral
Marked worsening of visual fields	Significant constriction, new enlarged blind spot, or dense scotomas
Frisen grade 4–5 papilloedema (especially new or worsening)	Swelling with blurred disc margins, haemorrhages, obscuration of vessels
New or worsening diplopia	Recent onset horizontal binocular diplopia, new 6th nerve palsy
Severe or escalating headache	Symptoms suggesting raised ICP, especially with nausea, vomiting, intense pulsatile tinnitus, or confusion/altered consciousness
Worsening papilloedema in pregnancy	Any visual symptoms or worsening swelling in a pregnant patient
New Relative Afferent Pupillary Defect (RAPD)	Suggests asymmetric optic nerve dysfunction

Examples of Practice: Pathways/ Proformas

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BIOS BRITISH AND IRISH ORTHOPTIC SOCIETY

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.

Written by Alis Sejourne – Highly Specialised Orthoptist
Approved by the Neuro-ophthalmology Clinical Advisory Group for the British and Irish Orthoptic Society

Examples of Practice: Pathways/ Proformas

BIOS Supporting Statement on Lowering BMI Threshold for IIH Referrals

Headache Impact Test (HIT-6)

BIOS Presentation – Orthoptic-Led Idiopathic Intracranial Hypertension (IIH) Service

BIOS Idiopathic Intracranial Hypertension (IIH) Proforma

BIOS Idiopathic Intracranial Hypertension (IIH) Clinician Information Leaflet

IIHUK – The Hope Programme Poster

BIOS Idiopathic Intracranial Hypertension (IIH) Patient Information Leaflet

BIOS Orthoptic-Led Clinic Flow Chart – Pathway for IIH Patients

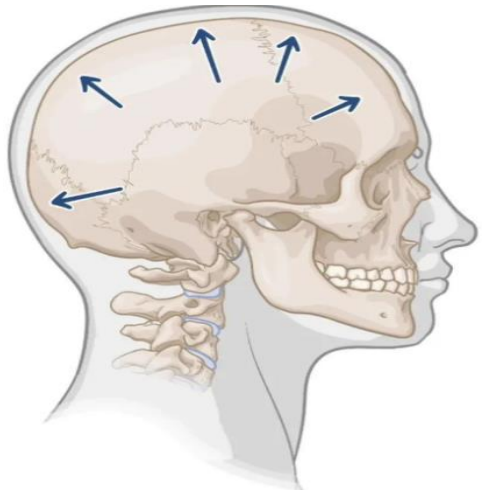
BIOS Orthoptic-Led IIH Clinical Guidelines

BIOS Orthoptic-Led Idiopathic Intracranial Hypertension (IIH) Clinic Protocol Example

Orthoptic-Led
Idiopathic Intracranial Hypertension (IIH) Service

BIOS | BRITISH AND IRISH ORTHOPTIC SOCIETY

Introduction to IIH



- Formerly called Primary/Benign Intracranial Hypertension or Pseudotumor cerebri.

- Often misdiagnosed initially due to symptom overlap with other conditions, making it a diagnostic challenge.

Not everyone with headaches who are overweight have IIH!

- IIH leads to increased intracranial pressure due to cerebrospinal fluid build-up, without an identifiable cause.

- Fulminant IIH is a severe subset of IIH with rapid progression, defined by severe papilloedema and quickly declining visual function within a month of diagnosis. It requires immediate aggressive management to prevent permanent sight loss.

- Admission rates rose by 442% between 2002 and 2014.

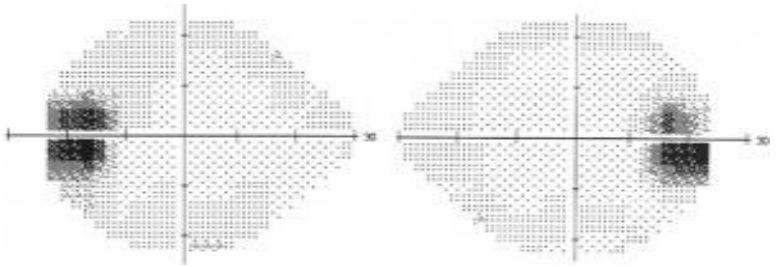
Debilitating symptoms:

- Headaches which are typically positional
  (worse in the mornings/when lying down, occurs in 95% of patients).

- Pulsatile tinnitus. Often described as "whooshing" sounds (occurs in 45% of patients).

- Papilledema (optic nerve swelling).
  Resulting in peripheral visual field loss, and/or enlarged blind spots, which may progress to involve central vision if untreated. Up to 25% of IIH patients develop permanent vision impairment.
- It is also known for IIH patients to have co-existing functional (non-organic) vision loss.

- Unilateral or bilateral sixth nerve palsies. May have double vision.



- Nausea/vomiting.

- Transient visual obscuration’s (periods of blurred vision).

- Hyperopic shift - Axial length may shorten due to posterior flattening of the globe.

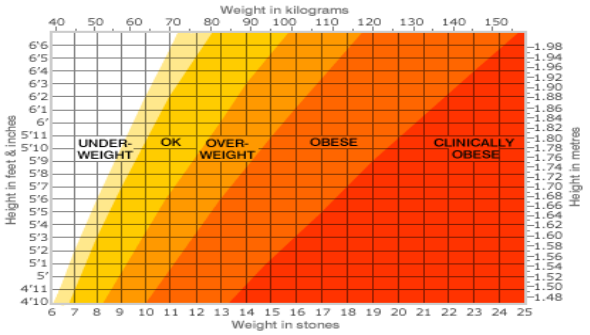
Risk Factors for IIH

- 75% of cases are women, and those assigned female at birth, aged 18-44.

- 95% of patients with IIH have high BMI (>30) or have experienced recent weight gain, significantly increasing the risk by 20 times.

- Poor mental health and low socioeconomic status.
  52% percent of IIH patients resided in the most socially deprived areas

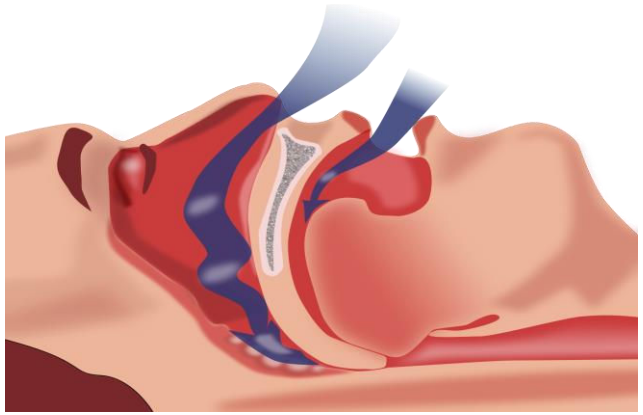
- Pregnancy-related weight gain can exacerbate IIH symptoms, and primary medications such as acetazolamide and topiramate are often discouraged in this patient group due to potential harm. It is important to inform patients of this.

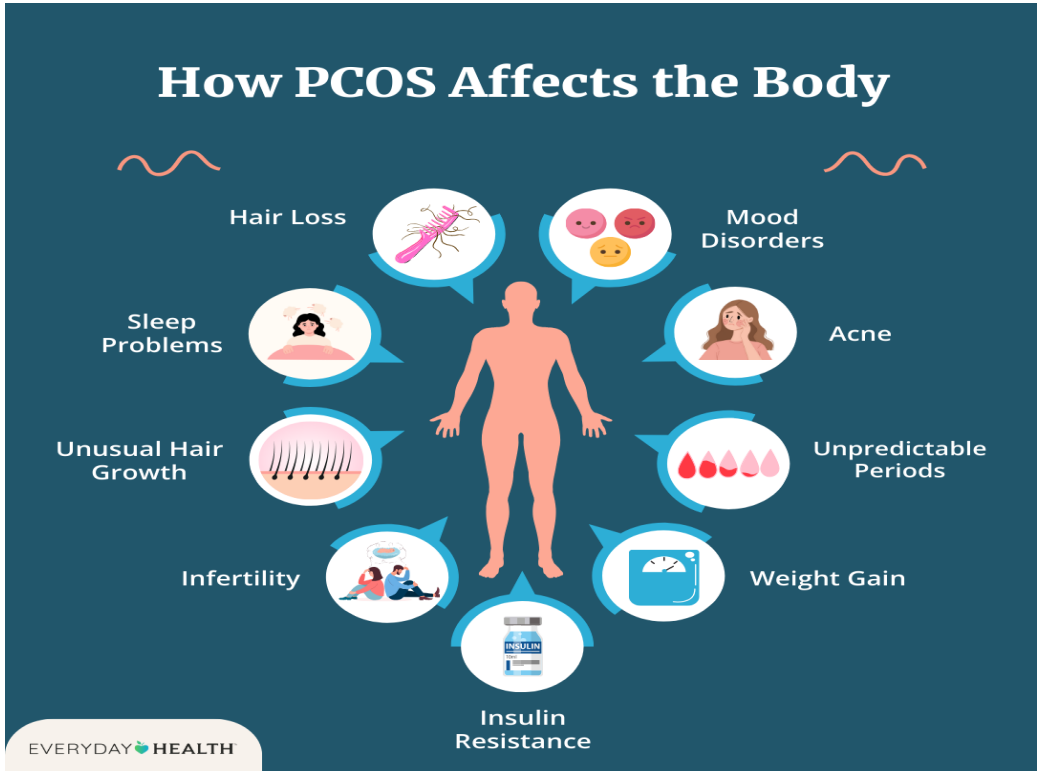


Other Risk Factors to Consider

- In those with a normal BMI, medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives.

- Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea.





Economic Impact of IIH

- The annual healthcare costs associated with IIH in the UK surged from £9.2 million in 2002 to £49.9 million in 2014, with projections reaching £462.7 million by 2030.
- The cost of hospitalisation and long-term treatment is substantial due to frequent medical visits and interventions eg. VP shunts or bariatric surgery.
- Estimated £7,016 annual cost per patient.
- A 1% reduction in eye conditions associated with IIH could save the NHS an estimated £1.5 billion over the next 5 years.
- 38% had repeated admissions in the year following diagnosis.

Frisen Grade

Grade 1

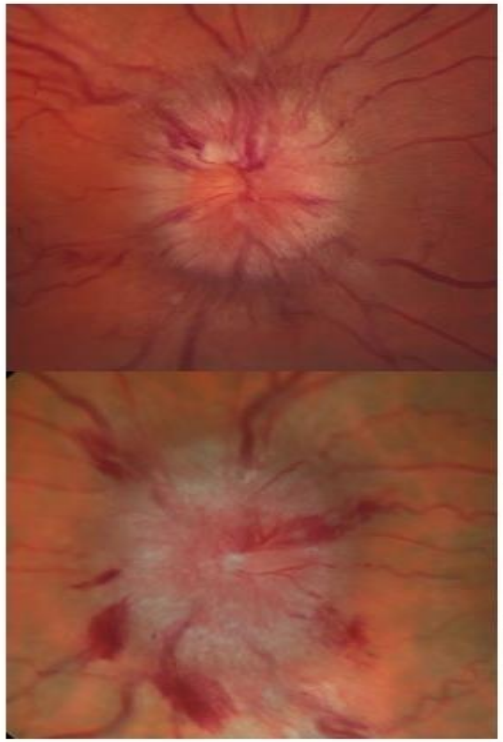
- Grayish C-shaped halo surrounding the disc*
- Sparing of the temporal disc margin
- Radial nerve fiber striation disruption

Grade 2

- Halo becomes circumferential*
- Nasal border elevation
- No major vessel obscuration

Grade 3

- Obscuration of at least one vessel *leaving the disc** (arrow)
- Elevation of all borders
- Circumferential halo



Grade 4

- Obscuration of a major vessel *on the disc**
- Complete elevation including the cup
- Circumferential halo

Grade 5

- Obscuration of all vessels on the disc *and* leaving the disc*
- All features of Grade 4

Medical Intervention

- Medication therapy (acetazolamide, topiramate) is currently our first line of treatment.

These typically reduce symptoms but does not address underlying obesity-related causes.

- Bariatric surgery is an option for patients with IIH and BMI ≥35, but it is invasive, costly, and carries postoperative risks.

- Obesity medications such as GLP-1 receptor agonists can lead to 10-15% weight loss and improve IIH symptoms.

However, obesity medications face drug shortages and adverse effects, making them currently unsuitable for primary treatment.

- Surgical options include ventriculoperitoneal shunt procedures for severe cases.

There is still no consensus on the most effective procedure. A randomised controlled trial comparing shunts and stents is due to be completed in 2027.

Weight Loss

- 6-10% weight loss is the only proven therapy for IIH remission.
- Despite evidence, less than 50% of IIH patients in the UK are offered lifestyle and weight management support
- Over 600 responses from IIH patients revealed that 84% found existing weight loss support unhelpful.
- Patients reported a clear need for specialized, evidence-based care tailored to their unique needs, which is currently lacking in many NHS services.
- Be careful of weight bias, it's not their fault!

It is important to avoid blame, weight bias or stigma – each patient has a different threshold at which weight influences their condition, meaning some develop IIH at a lower weight while others do not at higher weights. Reassure pa it's not their fault!

- Weight stigma conversations are important for compassionate care.

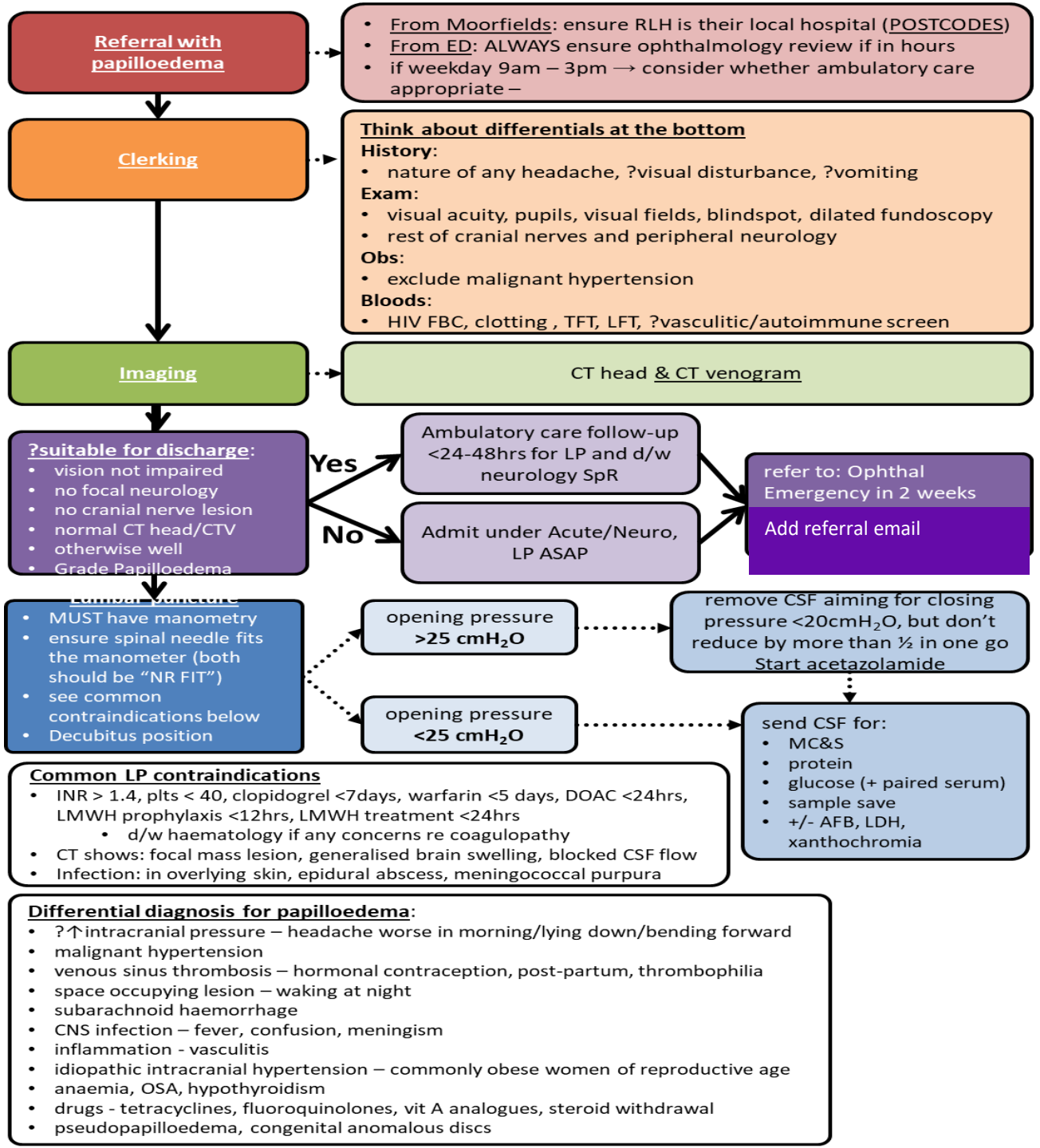
Mental Health Challenges

- Mental health support is critical, as IIH patients have a higher risk of depression, anxiety, and suicidal ideation.
- The suicide rate for patients with IIH is 4-5 times higher than the general population.
- Psychological distress is associated chronic pain, binge eating/restrictive diets and raised cortisol induced by sleep apnoea, leading to reduced quality of life.
- IIH patients are particularly vulnerable to weight sigma and a lack of support, leading to low self-esteem and decreased treatment adherence.
- Some treatments for IIH, like acetazolamide, can have mood-related side effects, including fatigue, depression, or irritability.
- Addressing mental health alongside physical symptoms is crucial for improving overall well-being and treatment outcomes in IIH patients

National Consensus Guidelines

- The 2018 national consensus guidelines for IIH provide a benchmark for improving care. They advocate for timely neuroimaging, lumbar puncture, and weight management for patients with a BMI over 30.
- Guidelines recommend integrating mental health support, acknowledging the burden of living with IIH, and providing tailored treatments for headaches.
- These guidelines also highlight the importance of interdisciplinary collaboration among healthcare providers to ensure comprehensive and effective patient care.

Example of medical papilloedema pathway



Example of Papilloedema Pathway
Internal Referral Form to Ophthalmology

Barts Health NHS
NHS Trust

Referral Form

Royal London Hospital IIH/Papilledema Service

PATIENT DETAILS

Name		D.O.B	
Address		Tel:	
		NHS/Hosp No:	

CONDITION INFORMATION

Date of Onset:		MRI/CT Scan Results: And date:	
Grade of papilledema:		Lumbar puncture opening pressure: And date:	
Clinical Diagnosis:			
General Information:			
Visual acuity:	RE LE With glasses? ☐	Fields to confrontation:	
Medication:		Analgesia:	
		Acetazolamide:	
Blood test results (FBC, U&E's, LFTs, glucose, TFT's Ca2+):			
Does the patient require an urgent assessment? (Double Vision/ Loss of Vision)?		Y ☐ N ☐	
Is an Interpreter required for the visit?		Y ☐ N ☐	

SIGNS AND SYMPTOMS

OCULAR SIGNS	OTHER SYMPTOMS
Papilledema ☐ Transient Visual Obscuration ☐ Blurred/Reduced Vision with Glasses ☐ Visual Field Loss ☐ Enlarged blind spot ☐ Abnormal Pupils (RAPD) ☐ Reduced colour vision ☐ Double Vision/6th nerve palsy ☐ Photophobia ☐ Other ☐: SPECIFY	Nausea/Vomiting ☐ Headaches (positional) ☐ Pulsatile Tinnitus ☐ Recent weight gain ☐ Hyper/Hypothyroid disease ☐ Polycystic ovarian syndrome ☐ Cushing's Syndrome ☐ Obstructive sleep apnea ☐ Other ☐:SPECIFY BMI: hh

REFERRED DETAILS

Referrer Name		Referrer Tel:	
Referrer Profession		Date:	

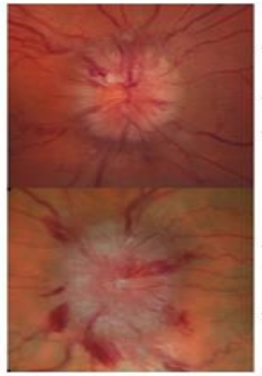
Please complete as much of this form as possible

Papilledema guide:

Grade 1
- Grayish C-shaped halo surrounding the disc*
- Sparing of the temporal disc margin
- Radial nerve fiber striation disruption

Grade 2
- Halo becomes circumferential*
- Nasal border elevation
- No major vessel obscuration

Grade 3
- Obscuration of at least one vessel *leaving the disc** (arrow)
- Elevation of all borders
- Circumferential halo



Grade 4
- Obscuration of a major vessel *on the disc**
- Complete elevation including the cup
- Circumferential halo

Grade 5
- Obscuration of all vessels on the disc *and* leaving the disc*
- All features of Grade 4

Example of IIH Eye Casualty Proforma

Idiopathic Intracranial Hypertension (IIH) Proforma

NAME:
DOB:
MRN:

NHS
Barts Health
NHS Trust

Date of referral:		Date of onset of symptoms:
Weight (kg):	Height (cm):	BMI (kg/m2):
Recent weight gain before diagnosis: Yes / No		
History taken: - Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea - Medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives.		

SYMPTOMS					
Headache: Yes / No			Unilateral/ Bilateral:		
Duration of headache history:			Disabling: Yes / No		
Frequency (days/week):			Analgesic use (days/week):		
Yes/No:	Nausea/vomiting	Photophobia	Phonophobia	Throbbing	Positional
HIT-6 score:					
Pulsatile tinnitus: Yes / No					
Transient visual obscurations: Yes / No					
Other visual symptoms:					

VISUAL FUNCTION		
Papilloedema: Yes / No.		Frisen Grade:
Fundoscopy findings:		
Spontaneous venous pulsations	Pre-LP: Yes / No	Post-LP: Yes / No
BCVA for distance	RE:	LE:
Colour vision	RE:	LE:
Pupillary reflexes	RE:	LE:
Intraocular pressures	RE:	LE:

Idiopathic Intracranial Hypertension (IIH) Proforma

Visual fields	RE:	LE:
Optical Coherence Tomography	RE:	LE:

INVESTIGATIONS		
Lumbar puncture	Date:	Opening and closing pressure:
CSF constituents (describe only if any abnormalities):		
CT/MRI head: Yes / No	Date:	Any abnormality:
CT/MR Venogram: Yes / No	Date:	Any abnormality:

MANAGEMENT
Acetazolamide dose:
Headache diary given: Yes / No
Advised to reduce analgesia use to max 2 days/week: Yes / No
Analgesia type + frequency:
Migraine prophylaxis name and dose:
Under neurosurgery / has neurosurgical intervention: Yes / No
If yes, please describe with approx. date of intervention:
Under obesity clinic: Yes/No
Signposted for Tier 1-2 Weight Management: Yes/No
Considered onwards referral: Yes/No ECLO, Psychological support, Headache specialists, Occupational Therapy, Gynaecology, Endocrinology
Suitable for Orthoptic-led IIH clinic: Yes/No

Clinician Name:	Sign:

Example of neuro-ophthalmology IIH Clinic Pathway

Consultant-led

- Patients are managed acutely and treated with medication, or surgery.
- Complex patients, those with sight threatening conditions, and those undergoing changes to their medications will stay within this clinic.
- They are referred to the orthoptic-led clinic once considered medically stable.

Orthoptic-led

- Patients medically stable are monitored in this clinic and managed holistically.
- Those raising concern or requiring support will be discussed with the consultant if required as per clinical guidelines
- Any acute concerns are discussed with the on-call emergency doctor.

Discharge

- Patients may be referred back to the consultant's clinic or discharged.
- All discharge decisions must be discussed with the consultant
- Any management decisions will be relayed back to the patient via telephone consultation and a detailed letter written to patient/GP.

Orthoptic-led IIH clinical guidelines

BIOS BRITISH AND IRISH ORTHOPTIC SOCIETY

No consultant input required – for routine orthoptic-led review

Clinical Scenario	Outcome
Stable/improved clinical appearance	Continue with current/without medication and review orthoptic-led

For non-emergency virtual consultant review (emailed and reviewed within a week):

Clinical Scenario	Key Signs/Symptoms
Mild worsening of papilloedema	Frisen grade increase from 1 to 2–3, but stable fields/VA
Visual field changes without VA loss	Slow worsening of HVF or GVF over recent visits
Patient poorly compliant with treatment AND mild clinical deterioration	Mild worsening OCT/fields, or new symptoms with poor treatment compliance
New transient visual obscurations	Brief greying/dimming/vision loss episodes, stable exam
Possible medication side effects (e.g. acetazolamide intolerance)	Significant tingling or GI issues, affecting compliance
Consider reduction in medication dose	Two consecutive visits of stable/improved clinical findings with continued medication within orthoptic-led clinic
Consider for discharge	Two consecutive visits of stable/improved clinical findings without medication within orthoptic-led clinic

For emergency clinic in-person review (same day):

Clinical Scenario	Key Signs/Symptoms
Rapid vision loss	Sudden drop in visual acuity (≥2 lines or more), and colour vision, especially bilateral
Marked worsening of visual fields	Significant constriction, new enlarged blind spot, or dense scotomas
Frisen grade 4–5 papilloedema (especially new or worsening)	Swelling with blurred disc margins, haemorrhages, obscuration of vessels
New or worsening diplopia	Recent onset horizontal binocular diplopia, new 6th nerve palsy
Severe or escalating headache	Symptoms suggesting raised ICP, especially with nausea, vomiting, intense pulsatile tinnitus, or confusion/altered consciousness
Worsening papilloedema in pregnancy	Any visual symptoms or worsening swelling in a pregnant patient
New Relative Afferent Pupillary Defect (RAPD)	Suggests asymmetric optic nerve dysfunction

Pathway for IIH patients considered medically stable in the Neuro-ophthalmology clinic

Orthoptic-led Neuro-ophthalmology Clinic

Patient Information and Signposting Leaflet Given

Initiate Tier 1-4 Healthy Weight Management as suitable

Onward Referrals:

ECLO, Psychological support, Headache specialists, Occupational Therapy, Gynaecology, Endocrinology

Evaluation Metrics:

Weight, Visual acuity, colour vision, pupils, intraocular pressure, visual fields, OCT (disc and macular)

Questionnaires:

HIT-6

Improvement/Stable

Continue with current medication
Repeat review in Orthoptic-led in 3-6 months

2 consecutive visits of improvement/stability

Send email to consultant neurologist 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 *insert shared mailbox* for MDT efforts, auditing and safety-net purposes)

Worsening

Refer to clinical guidelines

Emergency

Discuss with on-call emergency clinic doctors on the same day

Non-Emergency

Discuss with consultant neurologist within a week

Referral back to Consultant-led Neuro-ophthalmologist Clinic

Training for Orthoptists

All orthoptists involved in IIH Orthoptic-led clinics should undergo advanced training in:

- Tier 1 and 2 healthy weight signposting, coaching and motivational interviewing.
- Neuro-ophthalmology OCT interpretation module.

Motivational Interviewing

G	R	O	W
GOAL	REALITY	OPTIONS	WILL
DEFINE WHERE YOU WANT TO GET TO What do you want to achive? What does your goal look like, specifically? How would you define your goal?	AGREE PARAMETERS OF YOUR SITUATION What is happening right now? How will your situation impact your goal? What resources are available to you?	EXPLORE OPTIONS AVAILABLE TO YOU What options are available to you? How might these options play out? How would you rank your options?	COMMIT TO A PATH FORWARDS How committed are you to your goal? What are the first steps forwards? What might get in your way?

Healthy Weight: Motivational Interviewing

State

State the facts.

Your weight at first diagnosis was:

Your weight today is:

Your weight loss percentage since first diagnosis is:

Ask

Could we spend a couple minutes to discuss your weight?

I want to simply ask: how do you feel about your weight?

Make every contact count with SA-SA-SA!

Summarise

Summarise what they said. Encourage healthy decisions.

Advise

The risk of IIH increases with weight gain. The risk of vision loss because of IIH also increases with weight gain.

Weight loss of **6%-10%** often leads to IIH remission.

Hand out and discuss advice points on IIH Patient Information Leaflet.

Suggest

Ask the patient what they suggest they could do to help reduce their BMI?

Assist

Help the patient make achievable goals.

Make or aid referrals to Healthy Weight Programmes with Tower Hamlets Council, or the NHS Digital Weight Management Programme. Signpost them to further live well and better health advice from the NHS, as well as the IIHUK website. This can all be found on the IIH Patient Information Leaflet.

Example of Information leaflets

NHS
Barts Health
NHS Trust

Idiopathic Intracranial Hypertension (IIH) – Patient Information Leaflet

Your weight at **first diagnosis** was:

Your weight **today** is:

What is IIH?
IIH is a rare condition where the fluid pressure around the brain is too high. This causes a range of symptoms such as disabling headaches, tinnitus and nausea.

What does this mean for my eyes?
The high pressure can damage the optic nerves which send vision to the brain, resulting in loss of vision. It can also damage nerves that supply eye movement, resulting in double vision.

What causes IIH?
The exact cause of IIH is unknown. However, we do know that 95% of IIH patients are overweight or experienced recent weight gain. We also know that the risk of getting IIH increases with weight gain and the risk of vision loss because of IIH also increases with weight gain.
Conditions such as hyper/hypothyroid disease, polycystic ovarian syndrome (PCOS), Cushing's syndrome and sleep apnoea are also associated with IIH.
Medications such as long-term use of tetracycline, high doses of vitamin A, steroid discontinuation, and hormonal contraceptives may also cause secondary IIH. Speak with your doctor for further advice before discontinuing any medication.

How can IIH be treated?
Weight loss of **6%-10%** often leads to IIH remission.
Doctors may also start you on a drug, such as Acetazolamide. This works most effectively when also combined with weight loss.
In some cases, a shunt procedure may be performed to drain excess fluid from the brain and relieve pressure. However, this does not cure the underlying condition.

Ask your health professional any questions you have. We are here to support you!

NHS
Barts Health
NHS Trust

Signposting

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

Ask us how you can be referred to a suitable Healthy Weight Programme with Tower Hamlets Council, such as Ability Bow, or the NHS Digital Weight Management Programme.
https://www.towerhamlets.gov.uk/lgnl/health__social_care/public_health/healthy_lifestyle,_adults.aspx
https://www.england.nhs.uk/digital-weight-management/

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.
HOPE PROGRAMME — Hope For The Community CIC (h4c.org.uk)

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)

Tier 1 Signposting

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.
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https://www.nhs.uk/better-health/
Fitness Studio exercise videos - NHS (www.nhs.uk)

Holistic Support - 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.
- Available to anyone in the UK with internet, with new courses released regularly!

Encourage patients to take poster photos!

Tier 2 Programmes

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.

Tier 2 – Ability Bow (example in Tower Hamlets)

Eat Well and Move programme - YouTube

Tier 2 - NHS Digital Weight Management Programme

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.

https://youtu.be/tjQIQB3zBkc

Tier 3-4 Weight Loss Management

For patients requiring more intensive Tier 3-4 weight management support, patients need to be referred to their local obesity service.

Contact your local obesity service and suggest setting up a **streamlined referral process** and **reducing 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

Onwards Referrals

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

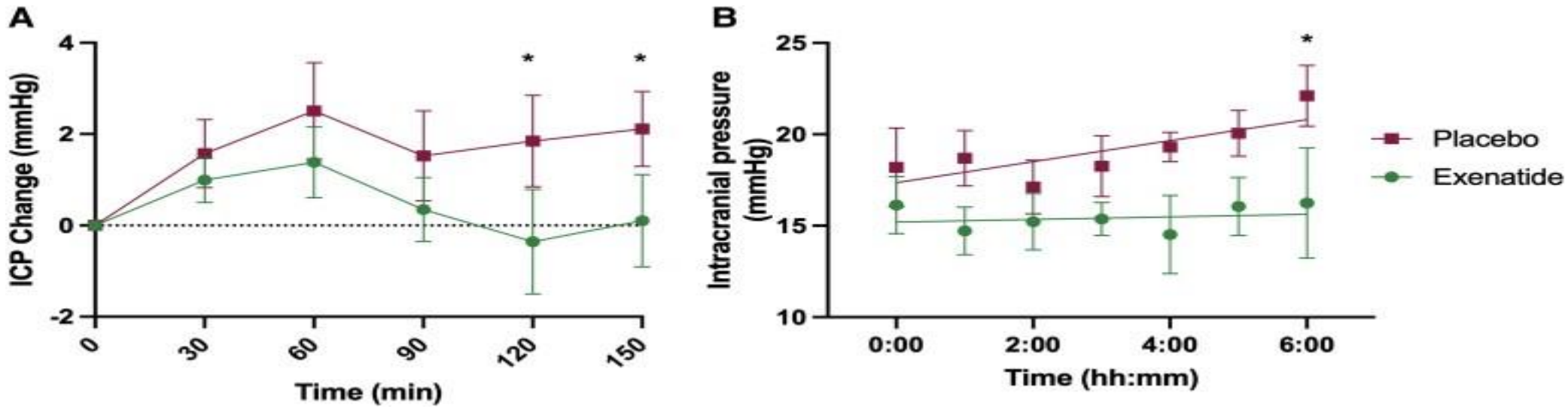
- **ECLO** for patients who have faced visual loss.
- **Psychological support** for emotional and mental health challenges.
- **Headache specialists** for ongoing management of chronic headaches and pain associated with IIH.
- **Occupational Therapy** to help manage the condition’s impact on daily activities, 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.

Early intervention and support can significantly improve patients' quality of life and overall outcomes.

The future of weight loss injections?

Case study: Our patient was taking Mounjaro injections privately and lost over 6kg in three months, reaching her target weight for IIH remission.
This is becoming more and more common.

GLP-1 injections have been studied with IIH and found to decrease ICP:



As this becomes more accessible, it may become the first line of treatment for IIH.

However, further research is needed, particularly in the long-term outcomes.

*Medical professional use only

IIH INTERVENTION

If your patient has...

1. IDIOPATHIC INTRACRANIAL HYPERTENSION (IIH)
2. RISK OF VISUAL LOSS
3. NO PREVIOUS SURGICAL INTERVENTION

...they may be eligible for the IIH Intervention trial. This randomised control trial is comparing the effectiveness of Cerebrospinal Fluid (CSF) Shunting vs Dural Venous Sinus Stenting (DVSS) to preserve vision in IIH.

CONTACT: [Fion Bremner or Ahmed Toma]

Randomisation of patients to clinical trials is the most ethical approach when there is uncertainty about routine care decisions.

IIHIntervention@trials.bham.ac.uk

Next Steps for National Initiatives

BIOS | BRITISH AND IRISH ORTHOPTIC SOCIETY

- **Neuro-Ophthalmology Clinical Advisory Group (CAG):**

BIOS Neuro-ophthalmology CAG aims to develop guidelines that promote and enhance the orthoptic role in IIH management.

- **IIH-Focused Study Day and National Audit:**

Plans are in place for an IIH study day to share best practices and develop a national audit to map services, create standardised care pathways, and strengthen the argument for establishing national protocols for IIH management. The audit will assess IIH services against consensus guidelines, supporting the push for MDT services.

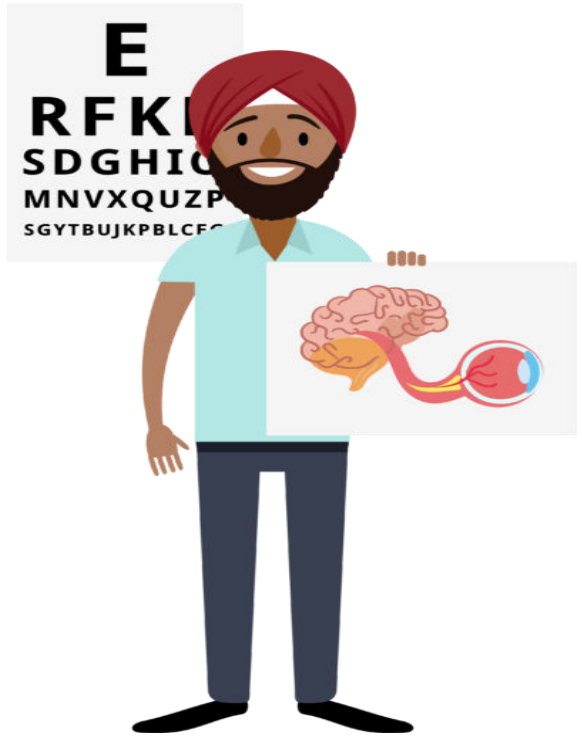
- **Resource Pack on the BIOS Website:**

A comprehensive resource pack created, including clinical guidelines on pathways and competancies, signposting and patient information leaflets, dietetic advice, standardised proformas, and a statement advocating for lowered BMI referral criteria for IIH patients to obesity services.

Thank you :)

For further information, visit:
[Neuro – Orthoptics and Ophthalmology - British and Irish Orthoptic Society]

For any questions, contact: neuroorthoptics@orthoptics.org.uk



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Edited by the Neuro-Ophthalmology Clinical Advisory Group for the British and Irish Orthoptic Society

References!

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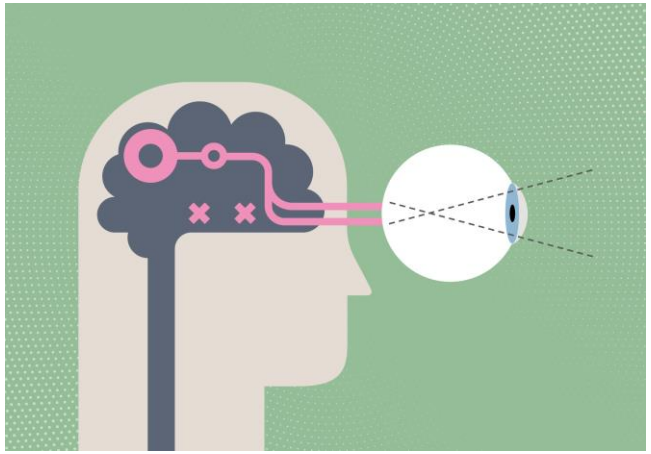

Thank you!

If you have any suggestions or questions, please reach out!
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Let’s work together to share knowledge and standardise IIH care and resources.