

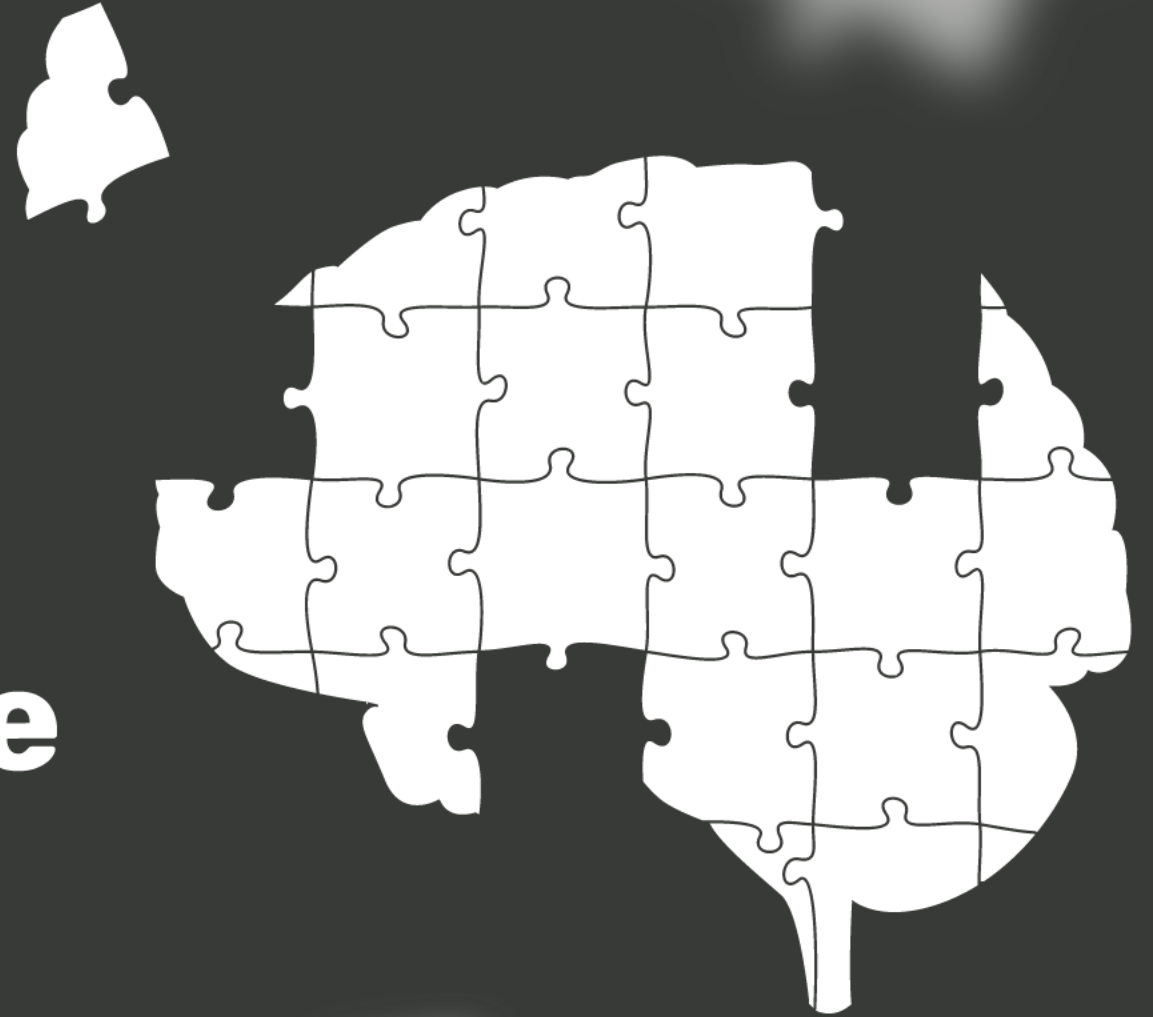
THE BRAIN TUMOUR CHARITY

HEADSMART GP

Dr Victoria McBride
Clinical Lead

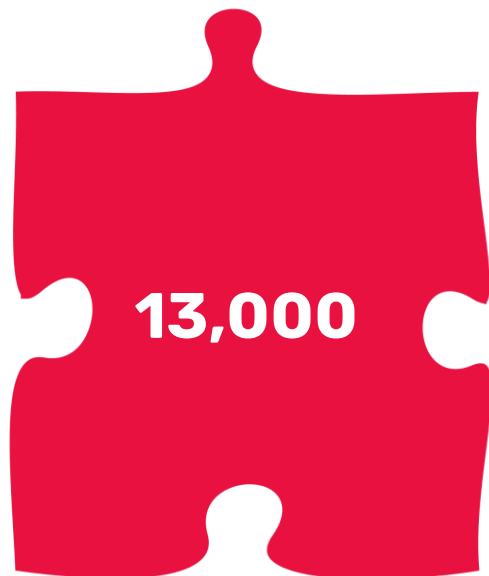


Many brain
tumour puzzles
are solved **too late**

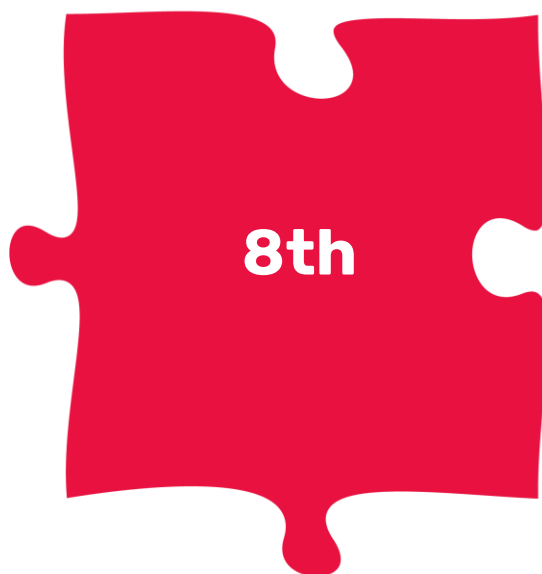


Brain tumours

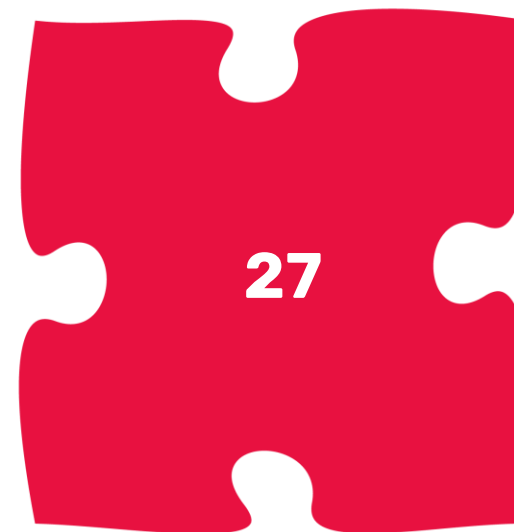
may be more common than you think



Diagnosis
per year



Most common
cancer



Average years of life
lost – the highest of
any cancer

High rates of **emergency diagnosis** and poorer outcomes



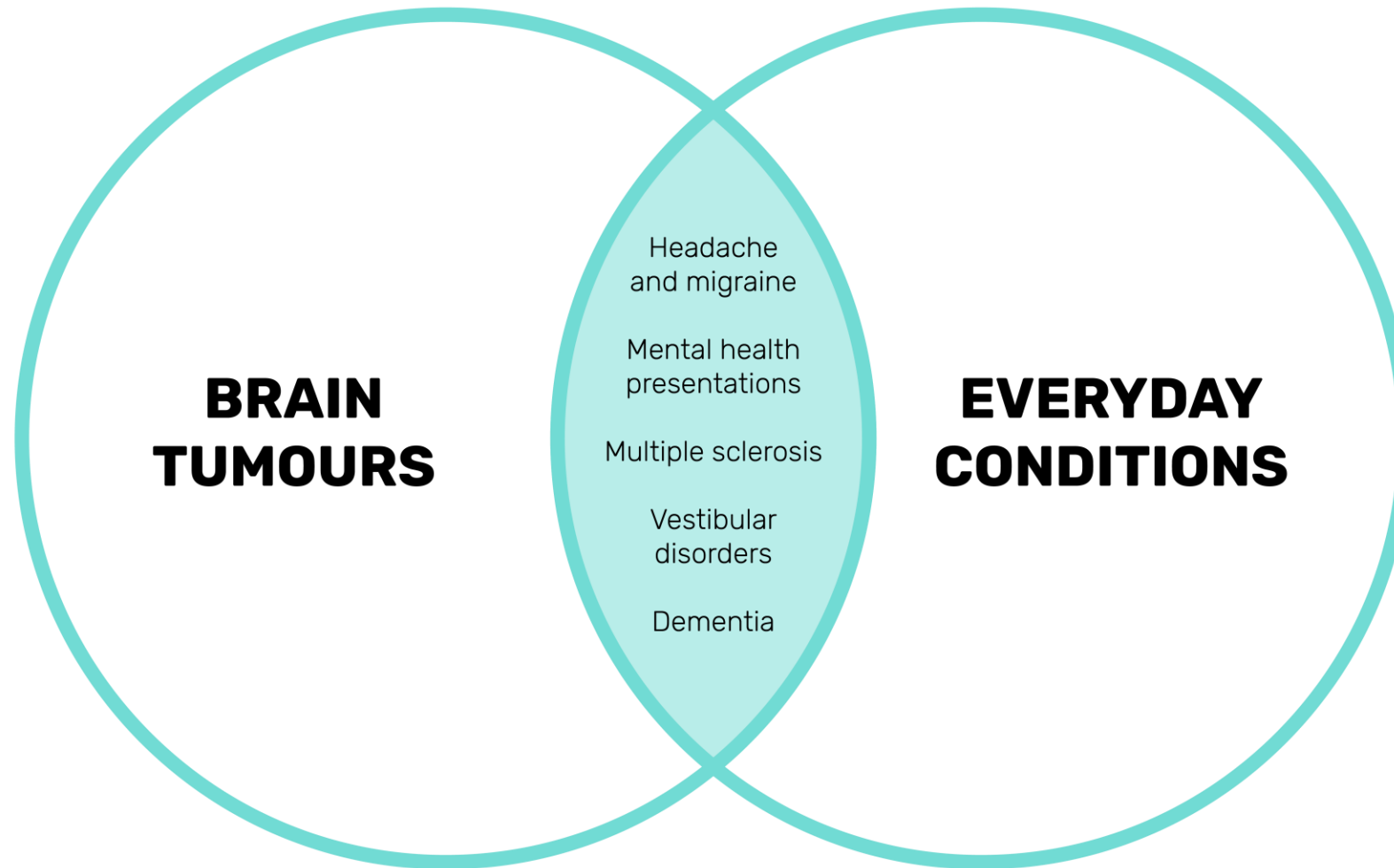
Brain tumour/cancer diagnosis in an emergency setting



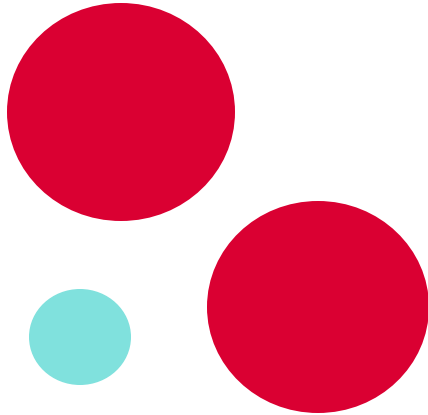
All cancer diagnosis in an emergency setting

| Country | Latest data available | Brain tumour/cancer diagnosis in an emergency setting | All cancer diagnosis in an emergency setting |
|------------------|-----------------------|---|--|
| England | 2020 | 45% (brain tumours) | 22.5% |
| Northern Ireland | 2018-2021 | 62% (brain cancer) | 23% |
| Scotland | 2022 | 74% (brain cancer) | 23% |
| Wales | Data not available | - | - |

Brain tumours compete with **everything** we see



Emergency diagnosis is the **norm**



A large percentage of brain tumours are diagnosed in emergency settings



Emergency presentations are associated with lower 1-year relative survival and increased risk of morbidity



A proportion of brain tumours could only ever be diagnosed in emergency care, but the current number is too high

(Pursehouse et al, 2024)

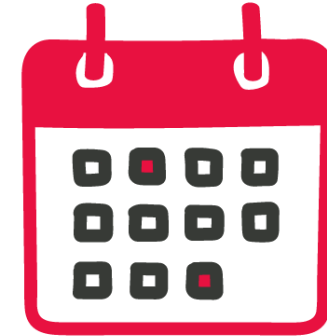
Why earlier diagnosis **matters**



- A clearer, less frightening diagnostic pathway
- Fewer crisis presentations
- Less neurological damage at diagnosis and beyond
- More time to process what's happening.



- Reduced caring burden
- Less sudden disruption to work, finances and home life.



- Shorter hospital admissions
- Fewer emergency bed days
- Reduced long-term care costs.

GP practice teams have an opportunity to **change** this

- Brain tumour patients see their GP team on average **three or more times** before diagnosis
- Primary care teams are uniquely placed to:
 - **Notice patterns**
 - **Recognise change over time**
 - **Connect subtle dots**
 - **And safety net well**

When patients aren't here: **Joe's story**



Persistent concerns

"I kept being told it was **anxiety.**"



Escalating symptoms

"I felt like I wasn't being **taken seriously.**"



A family who knew something wasn't right

"By the time someone listened, it was an **emergency.**"



Introducing the
Headsmart GP Toolkit
for faster diagnosis



We're **committed** to supporting GP teams

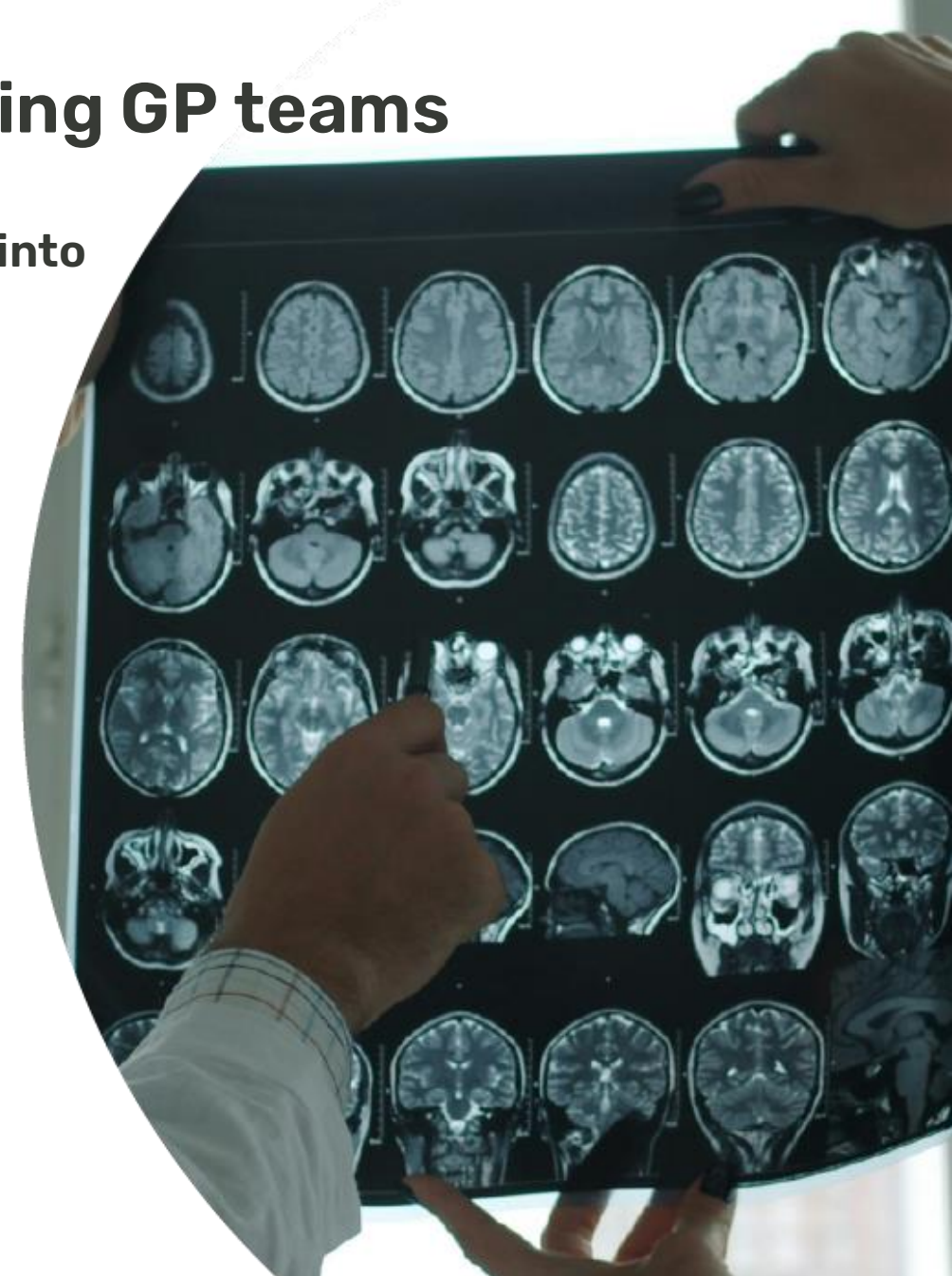
Headsmart GP is an evidence-based toolkit for **digging deeper** into non-specific symptoms to identify possible brain tumours

Built for busy GP teams it covers;

- Four bite sized learning videos
 - **HOW** to dig deeper
 - **WHY** this matters
 - **WHAT** to look for
 - **WHEN** to refer

This toolkit includes;

- Full length video webinar covering all the key our areas and narrated by our Clinical Lead, Dr Victoria McBride
- The webinar slide deck and notes for you to utilise in your GP practice protected learning times
- Links to further resources.



Signs & symptoms to look out for



The importance of **Headache Plus**

GP practice teams see headaches every day – even in 2008 they represented **4%** of appointments



HEADACHE

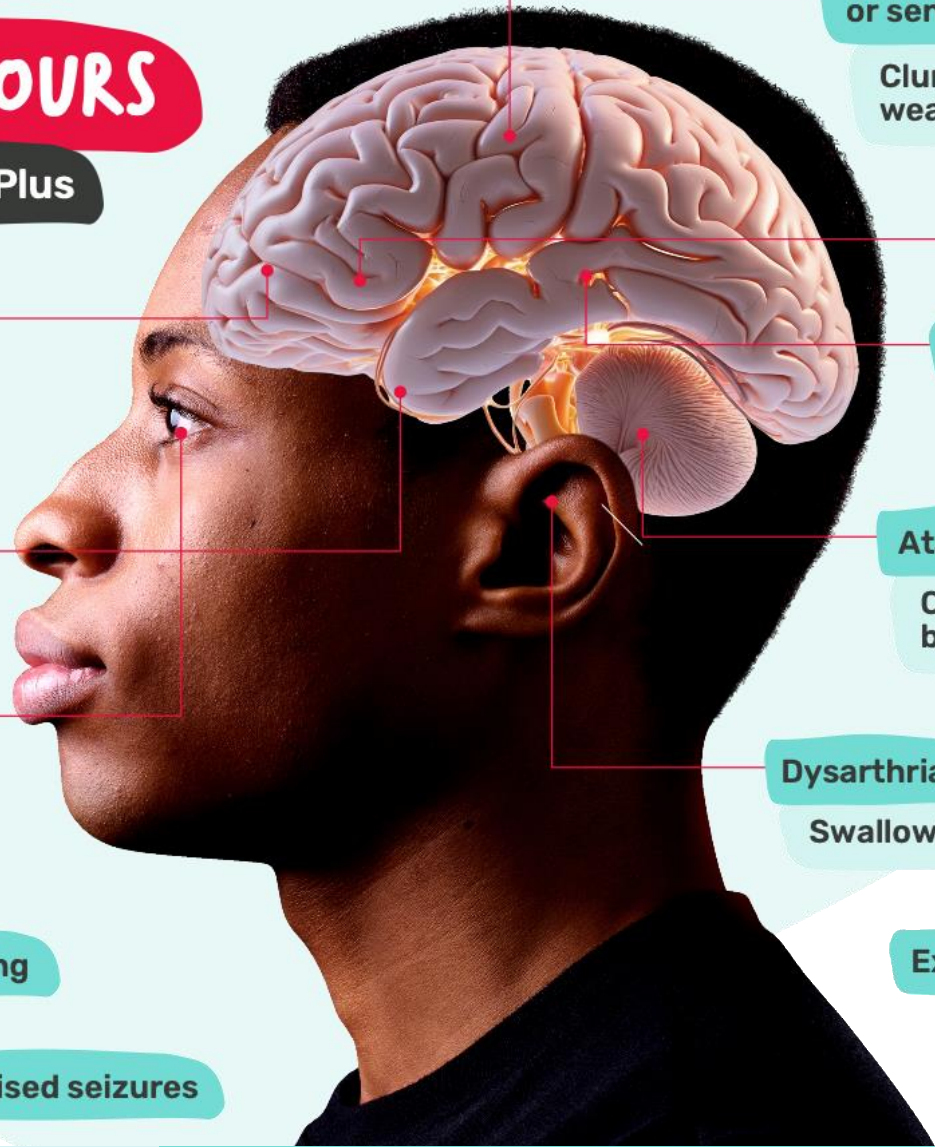
Most are nothing to worry about but, brain tumours rarely present as 'just a headache'

Headache plus another neurologic abnormality or symptom

(NICE, NHS Scotland)

Red Flag Symptom Combinations for POTENTIAL BRAIN TUMOURS

Introducing our 'Symptom Combination Card' Print it, save it, use it whenever you need a refresh



Headache Plus

Personality or behavioural change. Cognitive decline

Can be subtle. Test verbal fluency

Focal seizures and surreal states

Diplopia, abnormal eye movements, squint and visual field defects

Exclude failed lateral gaze of VI nerve palsy and homonymous hemianopia

Nausea/vomiting

Generalised seizures

Evolving focal motor or sensory changes

Clumsiness. Ask about weakness and numbness

Expressive dysphasia

Receptive dysphasia

Ataxia

Coordination or balance issues, tremors

Dysarthria

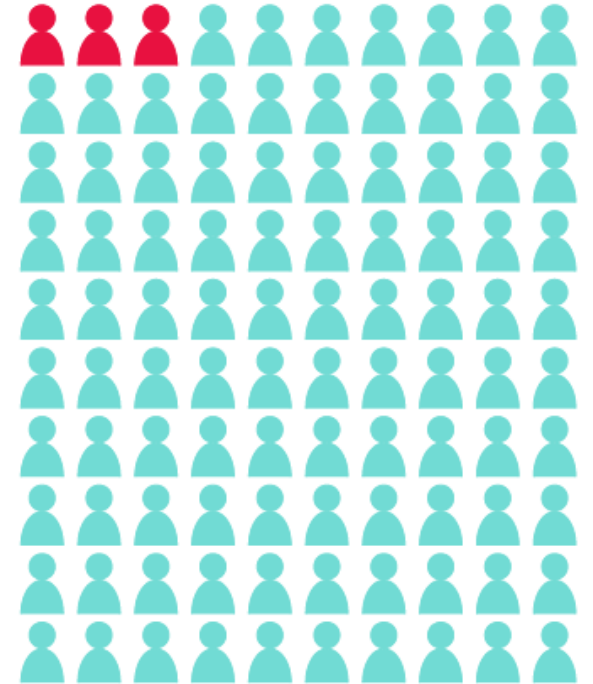
Swallowing difficulty (dysphagia)

Extreme fatigue

Localisations on this diagram are illustrative rather than anatomically accurate.

Positive predictive value

- Positive predictive value (PPV): if 100 people have a symptom pattern and 3 have cancer, that pattern's PPV is 3%.
- Referral threshold: cancer referral guidelines use roughly 3% PPV as the trigger for urgent investigation.
- Headache risk depends on combinations: headache alone has a very low PPV for brain tumour (~0.1%), but headache plus cognitive change (or any new focal deficit like weakness/visual loss/speech issues) increases risk dramatically (>70x), pushing PPV above the referral threshold.
- Look for patterns over time: single mild symptoms can be inconclusive, but constellations of subtle symptoms, especially across repeat visits, should prompt reassessment—many brain tumour patients have 3+ GP consultations before diagnosis.



Late diagnosis tumours are more likely to declare themselves in an **emergency setting**



Raised ICP features
(vomiting, drowsy,
papilloedema)



New-onset seizure



Sudden neurological
collapse

Faster Diagnosis can:



Reduce morbidity



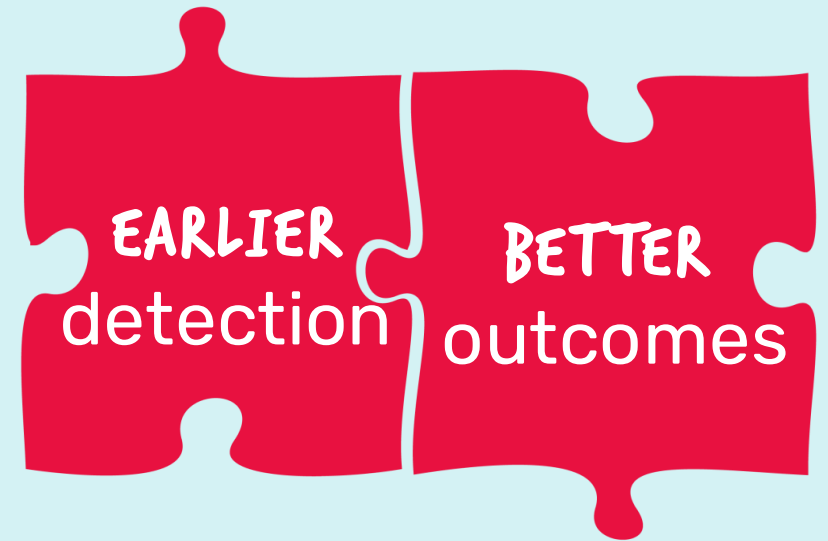
Improve survival odds



Decrease stress & trauma



Give patients a better chance



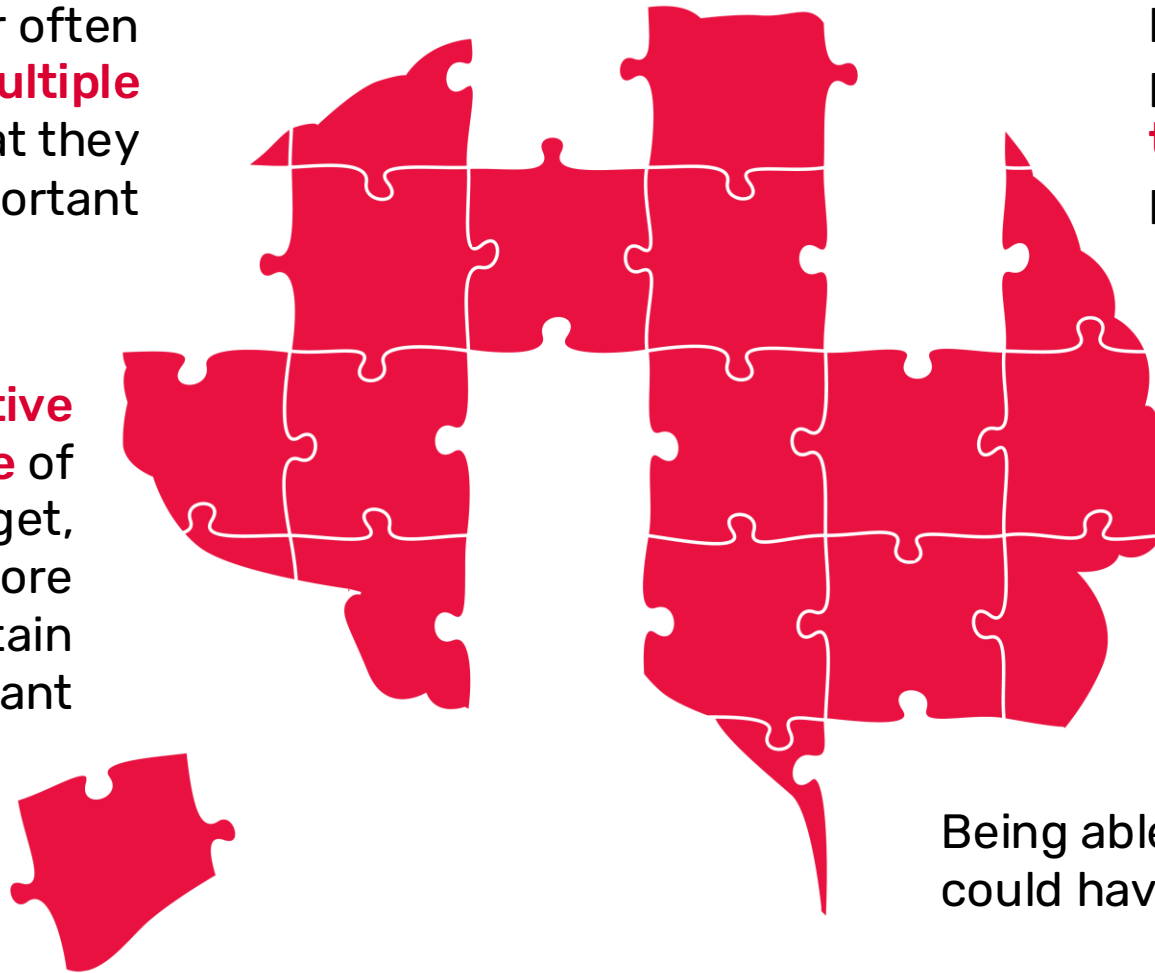
Digging deeper

Safety netting



People diagnosed with a brain tumour often experience **'multiple subtle changes'** that they dismiss as unimportant

Some people are **selective about disclosure** of symptoms as they forget, are reluctant to share more details or are uncertain about what's important



Identifying a suspected brain tumour is like a puzzle - **you need all of the pieces** to put the picture together

Being able to do this effectively could have a **huge impact**

(Scott et al, 2019, Walter et al, 2019)

Digging deeper questions

Do you feel like **yourself**?

Have you made any **unusual mistakes** lately – things that wouldn't normally trip you up?

Has anyone **noticed any changes** in you?

Have you had any trouble **finding words** or **making sense** of things lately?

A PRACTICAL TOOL: Semantic Verbal Fluency Test

The importance of rapport

Putting the patient at ease using personalised care approaches can create the trust needed for a more open discussion

They may feel embarrassed, frightened or not see how it is relevant

Some patients may be reluctant to disclose that their personality or memory has changed

Trusting your gut

There is a lot of evidence for 'something's not right'

Given the potential risk of ignoring non-specific symptoms or symptom combinations, if in doubt, **refer**



Dealing with **Uncertainty & safety-netting**



Why safety netting is **essential**

High quality safety netting:

- Increases the likelihood that patients reattend when symptoms progress
- Reduces delayed diagnosis
- And builds trust between patients and clinicians

When symptoms are dismissed, minimalised or not clearly addressed:

- Patients are **less likely** to come back
- Concerns are **downplayed**
- And opportunities to reassess are **lost**

What good safety netting looks like

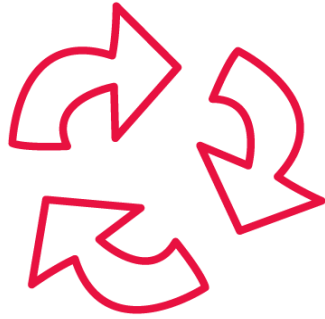
The patient understands:

- **Why** they are receiving the advice
- **What** to look out for
- **When** and **how** to seek further help
- And **what** their role is if things change.

At the same time, the clinician has:

- Communicated diagnostic uncertainty **honestly**
- Explained what they expect to happen **next**
- Provided **tools** to help the patient **recognise escalation**
- And checked that the patient **genuinely understands**.

The three pillars of safety-netting



Process

- Explain what you think is going on
- Acknowledge uncertainty
- Agree responsibility for follow-up
- Walk the patient through what to look for, and when to act



Conversation style

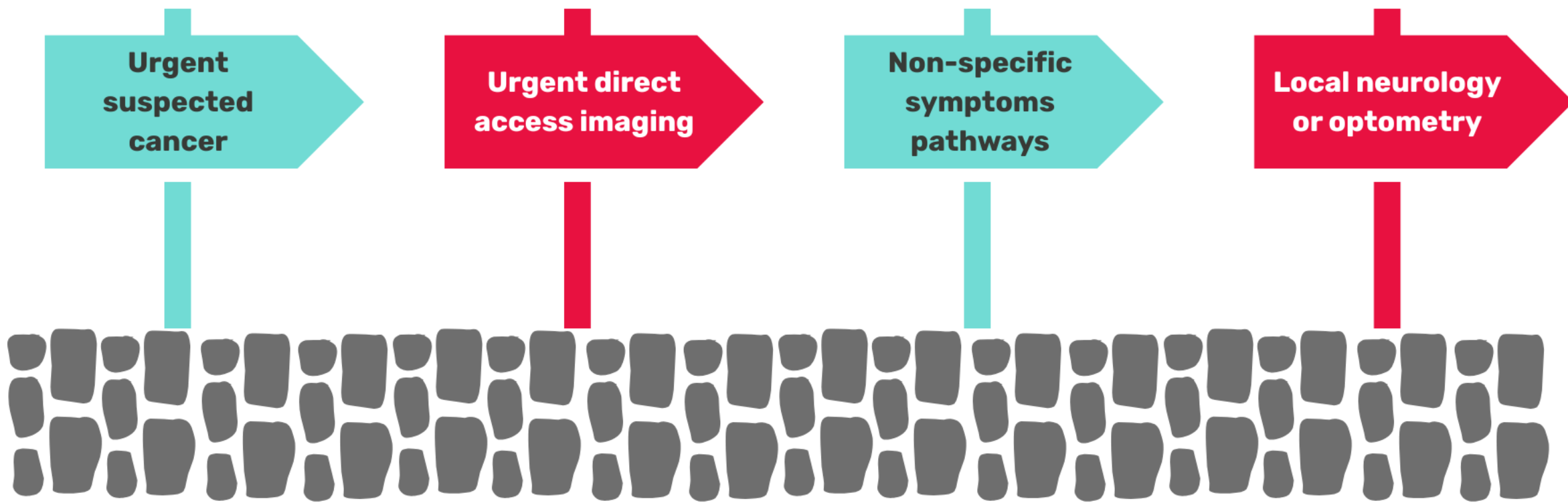
- Use clear, non-jargon language
- Break down information so it's easy to remember
- Personalise explanations
- Actively invite questions



Follow-up and documentation

- Provide written/digital advice where possible
- Reassure patients that returning is appropriate
- Accurately code symptoms and safety netting advice
- Use clinical systems to flag repeat presentations

Referral decisions and local pathways – option 1



Communication and safety netting when English is not the patient's first language



Offer a follow-up appointment



Be explicit about timing



Confirm understanding



Provide written information



Proactive review reduces risks

Real stories

Patient experience



When continuity breaks down

SCOTT

Timeline

- Oct 2020: Intermittent leg paraesthesia and weakness
- Dec to Apr: Re-presentations, advised to monitor, FND diagnosis
- Summer: Headaches, queried migraine
- Oct 2021: Emergency admission with raised intracranial pressure, glioblastoma diagnosed

What went wrong

- Repeated presentations not recognised as a red flag
- Evolving symptoms
- Premature diagnostic closure
- Loss of continuity
- No one joined the dots



When delay leads to avoidable harm

NATASHA

What went wrong

- Repeated presentations without escalation
- Symptoms persisted but the overall picture was not reconsidered

Clinical course

- Two months of headache, nausea and fatigue, treated as migraine
- Repeated consultations with worsening fatigue and functional decline
- Ongoing symptoms despite multiple treatment approaches
- Later development of visual disturbance and difficulty with walking
- Papilloedema identified and brainstem tumour diagnosed



When delay leads to avoidable harm

NATASHA

Impact

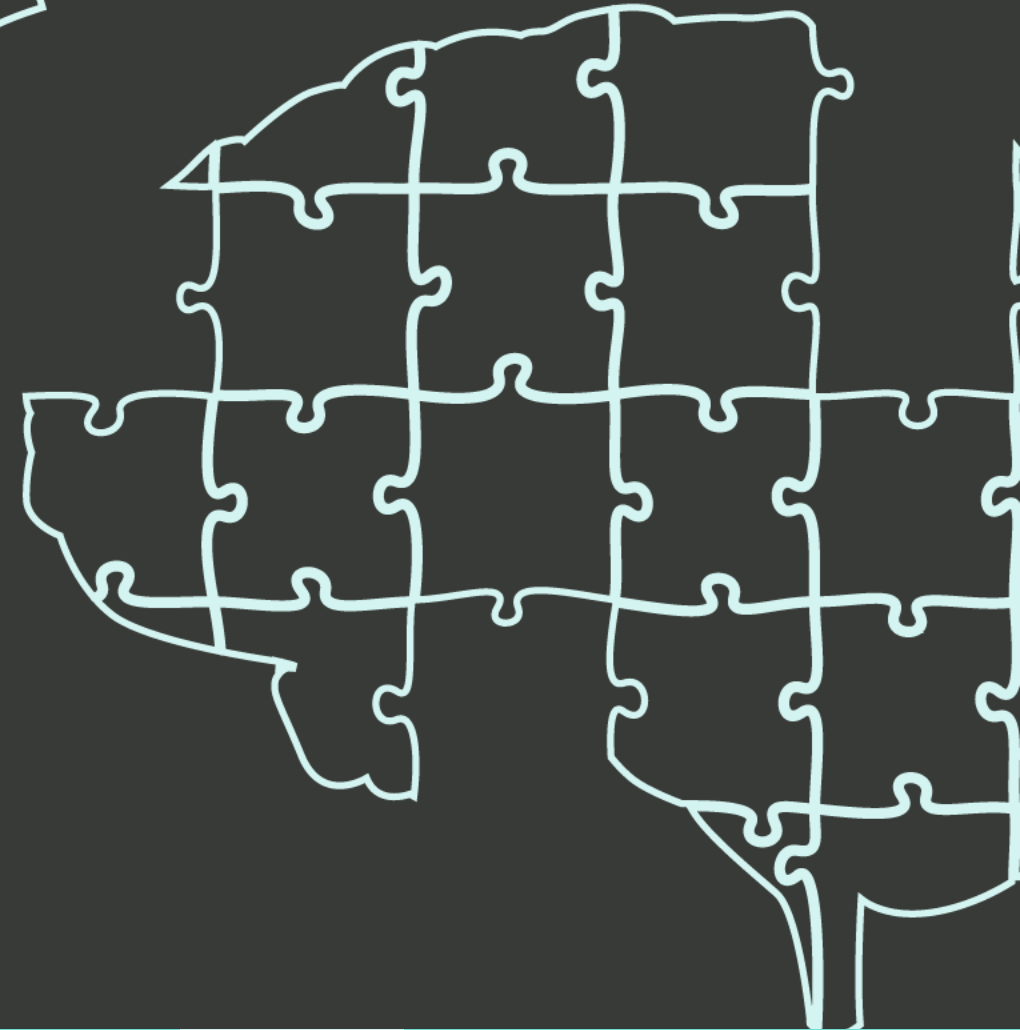
- Raised intracranial pressure requiring emergency surgery
- Permanent visual loss, with less than ten percent vision
- Earlier investigation and imaging may have preserved vision and quality of life over the following years

Key message

- When symptoms persist or evolve, it is important to pause and reconsider
- Earlier diagnosis may not change survival but can reduce harm and preserve quality of life



Overall, what questions would you ask and what examinations would you do to build a bigger picture?



What do these stories **teach** us?



SCOTT



NATASHA

Earlier recognition of patterns, not rare diagnostic brilliance, is where harm can be reduced.

As a GP, you have the power to do that.

Using and **evaluating** our toolkit

- Thank you for completing this important training
- Please visit our toolkit online at www.thebraintumourcharity.org/headsmartgp
- Bookmark it and save/print the resources for future use
- We would appreciate your feedback! Please spare 5 minutes to complete our short evaluation survey
- Right now, many brain tumour puzzles are solved too late - but by taking this training you will help us to speed up diagnoses



THE BRAIN TUMOUR CHARITY

HEADSMART GP



The Headsmart GP toolkit was developed by The Brain Tumour Charity with support from the Royal College of General Practitioners. This toolkit is available as part of a pilot in the West Midlands and Lothian and is endorsed by the West Midlands Cancer Alliance.