

FINDING & CLOSING GAPS

IMPROVING BRAIN TUMOUR CARE SURVEYS

DIFFICULT ROUTE TO DIAGNOSIS

28%

GP 3+ times

65%

A&E

“It took **6 years of consistent pestering my GP** to finally be referred for an MRI.”

POOR DIAGNOSIS EXPERIENCE

59%

first told by a non-specialist

38%

don't understand prognosis

“Doctor said ...
You have got a
meningioma, for more
information **Google it.**”

DON'T HAVE GOOD ACCESS TO A
CLINICAL NURSE SPECIALIST

41%

"I've found the **lack of
aftercare** shocking as we
have quite literally been
left to get on with it"

HAVE UNMET NEEDS

74% any

41% emotional

“I have **never been offered** mental or emotional support by ANY medical professional.”

NOT SIGNPOSTED TO BASIC SUPPORT

68% financial

50% emotional

45% charities

“I was **not provided with any information** about free prescriptions or PIP... I lost £1200.”

DON'T HAVE GOOD CARE PLAN

79%

“After surgery **no support**
for ... money work exercise
fatigue speech”

“We only had one virtual consultation, but **in that hour** we had **such a holistic consultation** covering a range of topics, followed up by the CNS referring us to palliative care, physio, occupational health and also for some help with finances.

The conversation about prognosis was hard to hear, but incredibly useful - I felt our local team had really let us down by not being **brave enough to speak about the real issues** and therefore open doors to providing support.”

WORSE IN SOME CENTRES

4% vs 61%

participate in research

“The contrast with the care we received locally **could not have been starker**. I wish we had triggered a referral sooner.”

WORSE FOR LOW GRADE

54% vs 71%

written tumour information

“It felt like I was forcing them to go **out of their way** to see me.”

WORSE FOR WOMEN

52% vs 74%

good CNS access

“GP failed me. Told me it was menopause. **I should have been referred for an MRI much quicker.**”

CLOSING GAPS



THANK YOU

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