



The Brain Tumour Patient Information Portal

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*"With me, it was a case of 'this is what you're having'... no choice, no options...
Actually I want to know what other choices there are"*

*"The attitude seemed to be, well yes, this information is about you
but it's not yours, it's ours"*

Shared decision making

*"How is it so dangerous that you get the information that
is about yourself?"*

Making it easier for patients to access their own information

Why?

- Because this information belongs to the patient
- Because it can help
- Because patients want it

Patient objectives:

- To give me greater involvement in my care
- To help me ask the right questions
- To prepare me for what lies ahead
- To level the playing field
- To help me talk with my carers
- To help my carers talk to me
- To help avoid surprises
- To help others help me
- To explore all the options
- To help me ask the right questions, and get the answers

DH Department of Health

PATIENTS
Stop the silos
Al Mulley, Chair

The power of information:
Putting all of us in control of the health and care information we need

Liberating the NHS:
No decision without
with

Further consultation on proposals for shared decision-making

TheKingsFund

Unlike previous information strategies, this strategy does not reinvent large-scale information systems or set down detailed mechanisms for delivery. Rather, it provides a framework and a route map to lead a transformation in the way information is collected and used. It takes the needs of us as patients, carers, users of care services and citizens as the key driver for change. It provides the infrastructure to support the things that need to be done system-wide but – recognising that information technology is always advancing – it promotes flexibility and local innovation.

This strategy focuses on information in its broadest sense, including the support people need to navigate and understand the information available. This is about ensuring that

Key ambition

- **A change in culture and mindset, so that our health and care professionals, organisations and systems recognise that the information in each of our own care records is fundamentally about us – and so that it becomes routine for us to be able to access our own records online.**

is fundamentally about us – so that it becomes normal for us to access our own records easily;

Information recorded once, at our first contact with professional staff, and shared securely between those providing our care – supported by consistent use of information standards that enable data to flow (interoperability) between systems whilst keeping our confidential information safe and secure;

- Our electronic care records progressively become the source for core information used to improve our care, improve services and to inform research, etc. – reducing bureaucratic data collections and enabling us to measure quality;
- A culture of transparency, where access to high-quality, evidence-based information about services and the quality of care held by Government and health and care services is openly and easily available to us all;
- An information-led culture where all health and care professionals – and local bodies whose policies influence our health, such as local councils – take responsibility for recording, sharing and using information to improve our care.

Outcomes from receiving full and clear information

- Improved knowledge and understanding
- Reduced anxiety
- Increased preparedness for events
- Enhanced sense of control
- Enhanced compliance
- Increased satisfaction with treatment

National Institute for Clinical Excellence (2004). *Improving supportive and palliative care for adults with cancer: the manual*. Available from: <http://www.nice.org.uk/csgsp>

Information unique to the individual

www.braintumourhub.org.uk Registered Charity No 1114634

braintumourhub

Provided by **brainstrust**
the Mag Johns brain cancer charity

Welcome to the **brainstrust** brain tumour hub.

Created for brain tumour patients and carers, the brain tumour hub is an authoritative, easy to navigate database of the brain tumour support resources and UK based brain tumour clinical trials.

We've developed this site for you with the support of brain tumour patients, carers, and leading neuro healthcare professionals. Our aim is to help you turn every stone in your battle against a brain tumour.

Brain Tumour Support | Brain Tumour Clinical Trials | Treatment Information

Enter your postcode to find your nearest brain tumour resource:

postcode Search

View a complete list of brain tumour resources >

Patient Information Portal

Username

Password

Log in

Request an information pack

brain tumour hub news:

March 2012 - 44 updates just completed on the brain tumour hub - new brain tumour support groups, online resources and updated support line details added. Worth checking for new services in your area.

March 2012 - New information uploaded to the brain tumour hub to cover brain tumour support groups, networking and bereavement support in Yorkshire.

Whilst we've made every effort to make this as easy as possible for you to use, if it's still a bit much, then why not give us a call? The brainstrust brain tumour support line is open 24/7. Give us a call on 01963 292405, even if it's just to say 'hi'.

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Support Clinical Trials

Filter list by support type:

Support group | **Support line** | Financial support | Networking | Online information | Bereavement support | Travel insurance

Service	Type	Provider	What it does	Postcode	Distance (miles)
Thome Mason Trust Brain Tumour Support	Support line	Thome Mason Trust	The Thome Mason Trust provide support to suit the needs of individuals who have been affected by a brain tumour or cancer in any way. These include services such as... read more >	SA62 4DL	431
brainstrust 24/7 support line	Support line	brainstrust	With brainstrust's 24/7, 365 days a year support line, patients, carers and families can pick up the phone, or email and know that they will have an immediate... read more >		N/A
Brain Tumour UK Support Line	Support line	Brain Tumour UK	Telephone services offering a one-to-one helpline and shared, group discussions. read more >		N/A
National Brain Tumour Helpline	Support line	Samantha Dickson Brain Tumour Trust	A confidential support and information helpline providing support and a listening ear from people who understand your situation. The line is open during normal office... read more >		N/A
Brain Tumour Action Confidential Support Line	Support line	Brain Tumour Action	Now in its ninth year of service, the Brain Tumour Action Confidential Support Line offers brain tumour support and advice to patients and their family members. The... read more >		N/A
CancerHelp UK	Support line	Cancer Research UK	Questions about cancer? Call a Cancer Research nurse on freephone 9am until 5pm Monday to Friday. read more >		N/A
Maximilian Cancer Support	Support line	Maximilian Cancer	Maximilian provides support for all cancer...		N/A

Brain tumour registry data

- Just the facts!
- Full-text histopathology reports
- Extracts from imaging reports
- Summaries of treatment information
 - Surgery
 - Chemotherapy
 - Radiotherapy

Does not include

- Clinic letters
- Clinical notes
- Information about other health conditions



Quality of life data

Key points

- Being developed in consultation with patients, neuro-oncology specialists, clinical nurse specialists and GPs
- First-time access alongside a health professional, within N3 network
- Full technical and patient / carer support available and clearly signposted
- Similar systems in other areas
- Pilot sites

Ultimately

- Simply another tool for patients and clinicians to use
- Most, if not all, of this information is already available – but patients have to work really hard to get it

“It’s all about empowerment... some people don’t want to know, but some people will want to know and investigate further. You can let people know, it’s your choice...”

...at the moment we haven’t got a choice.”

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