

What do patients want?

Jenny Baker and Wendy Fulcher
11 March 2010

Who are we?

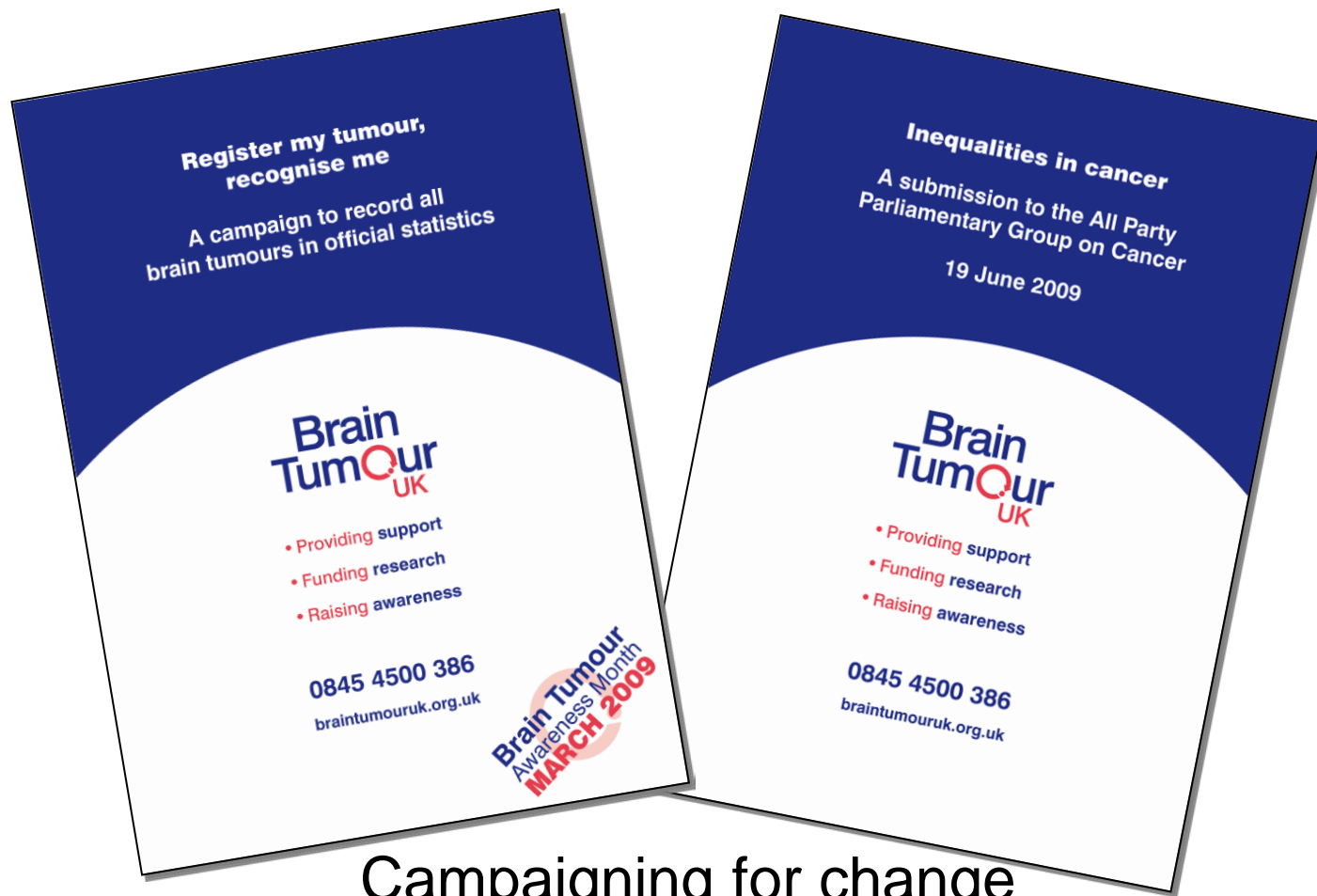
- Registered charity with a national remit
- Founded 1997
- Objective, professional Trustees
- Growing staff and volunteer team
- Presence in a growing spread of UK locations



Three key purposes

- Providing support
- Funding research
- Raising awareness

Raising awareness



Campaigning for change

Providing support and information




SUPPORT
when you need it

If you or someone close to you has been diagnosed with a brain tumour, you are not alone. Brain Tumour UK is here to help you. We provide support when you need it: at relaxed, friendly meetings; with telephone groups and our helpline; and online – both by email and on the internet. We are working to raise awareness of brain tumours and ensure that patients get the best treatments and care. And we're also funding research to beat this disease.

We're here when you need us

Whether you or someone close to you has been diagnosed with a brain tumour, our support and information is accessible and flexible.

Click to reach us



Brain Tumour UK has an extensive and growing **website** full of useful information to benefit patients, carers and their families. If you can't find the answers you're looking for there or need more support, simply send us an **email** and we will get back to you.

If you'd like to make contact with other people in a similar situation to you, check out our busy **social networks** on Facebook, MySpace, Bebo and Twitter.

Sharing with others

Brain Tumour UK is growing its range of **support groups** across the country. These friendly, relaxed meetings provide regular opportunities to share your experiences with others, make new friends and learn more from health professionals. Your specialist nurse should be able to tell you where your nearest support group is or simply give us a call to find out.

Not everyone is able to reach a support group, so we also offer **Phone Pals**. These free, supportive chat groups are run by an experienced facilitator and you can access them with any 'phone, anywhere. Call us if you'd like to find out more about joining Phone Pals.



Brain Tumour UK also runs regular conferences (above) to bring together patients, carers and health professionals. These hugely popular events get booked up quickly, so keep an eye on our website to find out when the next event is taking place.

On the 'phone

Call our **Helpline*** from 10am-1pm or 2pm-5pm, Monday to Friday. At other times, simply leave a message and we'll get back to you.

We're here to provide confidential support. Our sensitive service meets the high standards set by the Telephone Helplines Association, of which we are a full member.




Supporting us

Our vital work is funded by kind donations from fundraisers. If you would like to support our work, contact us for a donation form or download one easily using our website. You can also call our community fundraiser on 0845 4500 386 for advice on how to give your fundraising a boost. Thank you.

*Calls to our 0845 number are charged at the local rate. Charges from landline and mobile phone providers vary. Please check the rate with your phone service provider.



SUPPORT
when you need it

0845 4500 386
support@braintumouruk.org.uk
www.braintumouruk.org.uk

Tower House, Latimer Park
Chesham, Bucks HP5 1TU
Reg. charity no: 1117538

Leaflets for patients/carers now available in 100 outlets



Supporting and listening to patients

- In 2009 we supported 2,463 - 7 per day
- Incoming enquiries covered the whole spectrum of brain tumour sufferers
- Patient confidentiality is strictly upheld
- Data is captured anonymously for reporting and campaigning



We listen – patients share their experiences and needs

Needs on diagnosis

- Patients can feel shock, anxiety and unsupported
- BTUK often seen as 'second stop shop' and 'listening ear'
- Advice on getting the best possible care as fast as possible
- Need for 'key worker' contact for emotional support and to tackle isolation



Needs on diagnosis

FAQ's include:

- where are the treatment centres of excellence? -
- where can I go for a second opinion?
- where can I enrol on a clinical trial?
- where can I find information about my tumour and my life expectancy?

Needs during therapy

- Significant demand to know more about the pathway and its impacts
- The best-supported part of their journey but often little written information
- Continued need for personal contact and answers to their questions

Ongoing needs

- Patients sent home with no contact, no information, no advice on addressing significant needs
- On the ground services and support can be patchy and irregular'
- Huge emotional fall-out with more awareness of their condition and its likely outcome

We listen to what patients and carers are saying

- *“It feels like we have dropped off the edge of the world”*
- *“We needed rehab but there just aren’t any services round here”*
- *“My husband felt he was just being left to die”*



Family needs

- Support on coping with everyday life
- Assistance with managing finances and getting access to benefits
- Need for rehabilitation despite low life expectancy
- Support for carers, who often cope alone



Why does a registry matter to patients?

‘Knowing the numbers of brain tumour patients diagnosed is critical to planning optimum treatments and care’

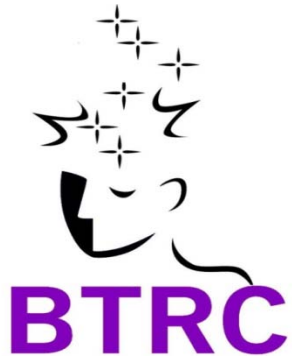
A patient supported by Brain Tumour UK



Why does a registry matter to patients?

Without data we cannot:

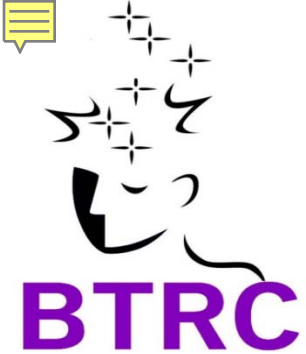
- Inform commissioning and research strategies
- Deliver sufficient services to people's point of need
- Future - proof integrated service delivery for brain tumour patients
- Begin to make a bigger difference
- Transform patients hopes and lives



Wendy Fulcher

Brain Tumour Research Campaign

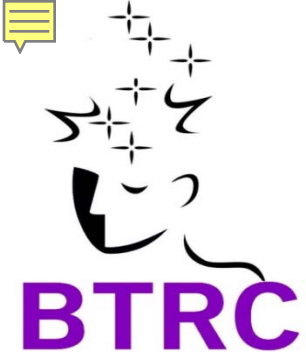




BTRC Story



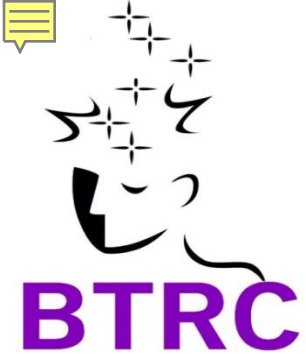
- shocked at lack of funding for brain tumour research
- so working with Neurosciences Division at Imperial College London, we determined to establish a centre of excellence for brain tumour research
 - Step 1 was the establishment of a brain tumour tissue bank
 - Step 2 was the funding of a brain tumour registry at IC



Benefits of Registry



- The benefits of this registry:
 - forms the core of the MDT meetings
 - allows audit of past cases, quality assurance and best practice comparisons
 - forms the basis for scientific research and protocols
 - can provide the structure for further research projects by drilling down further into the hospital records
- it has worked on a local front – how much better if it were extrapolated onto a national basis



Patients Thoughts



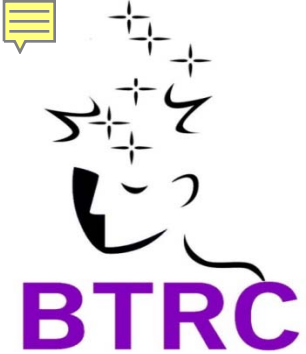
- most frequent question is “why?”
 - you don’t have the answer!
- Their greatest frustration is your answer
 - “we don’t know.....”
- Patients want a cure
 - while you are still trying to understand the causes
- patients are shocked that there is no national database
 - A registry won’t give you all the answers, but it will be all the harder to find them without one

The need for data

- Neuro-oncology needs to catch up
but
- We need robust data to undertake meaningful research

“We can only be sure to improve what we can actually measure”

Lord Darzi, High Quality Care for All, June 2008

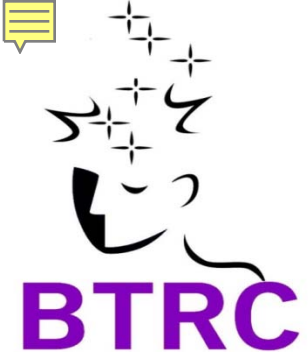


Working together



Need to work together and pool resources

- brain tumour charities recognise this:
 - relaunching an All Party Parliamentary Group on brain tumours
 - influencing the Cancer Reform Strategy's focus on rarer cancers
 - lobbying for greater awareness in both private and public sectors....
- clinicians and scientists need to form a united a national framework too



Please make this happen!