# The *brainstrust* pin board

www.braintumourawareness.org.uk

brainstrust
the Meg Jones **brain cancer charity**

## Background

This year, the *brainstrust* community set out to give Brain Tumour Awareness some real meaning. We wanted to understand, then raise awareness of real patient and carer issues. And then put our heads together and do something about them.

## Method

Since the first day of brain tumour awareness month (1st March 2013), patients and carers from across the UK have been pinning to the online *brainstrust* pin board (accessible at **www.braintumourawareness.org.uk**) issues and challenges they face as a result of a brain tumour diagnosis.

We accumulated just over 2 months' worth of posts – those posted from 1st March until 13th May, and had a good look at them. In that time, we had 67 unique people posting from across the UK, and a total of 146 concerns raised (some people posted more than once, and a number of posts include more than one challenge).

## Results

Four distinct themes emerged, faced by both patients and carers.

1. Feelings of despondency
2. Challenges faced due to brain cancer being unique
3. Feeling unresourced
4. Practical barriers patients and carers are up against

The three charts below identify the significance of these themes to:

a. both brain tumour patients and their carers
b. just patients
c. just carers

Within the four overriding themes are clear sub themes, as identified below with examples of posts submitted.

## 1. Despondency

**Fear:** Fear of what the future holds. Includes fear of recurrence, fear of treatment.

> "Every 6 months facing the same fear that this scan will show that my time has come"
>
> PATIENT

**Sense of loss:** This includes (but not limited to) loss of identity; life as it was; if a carer – person they loved (either died or personality changed so much, no longer person they fell in love with).

> "The tumour has changed my wife's personality so much I no longer see the person I married and love ... I feel so alone and trapped"
>
> CARER

> "Not "recognising" myself when I look in the mirror and wondering where "I" went"
>
> PATIENT

**Hopelessness and powerlessness:** The sense of being unable to do anything but stand by as loved ones struggle with this disease.

> "Watching your best friends [sic] life be snatched away from under feet, and not being able to do a single thing to stop it"
>
> CARER

> "Watching my beautiful wife fight so hard yet slowly deteriorate over the weeks and months. My heart is breaking. Where has our life together gone"
>
> CARER

**Lack of strength:** Psychological strength in themselves.

> "I can't be strong for my family all the time. Sometimes I need a shoulder to cry on"
>
> PATIENT

**Waiting:** Many aspects of the journey are covered here, including waiting for scans, for results, for treatment to start and to work, for recurrence.

> "The worst part of having a brain tumour is waiting for things to happen with your treatment ... the waiting is mental torture"
>
> PATIENT

**Feeling alone/isolated**

> "... I am a mother, a daughter, a sister, an employee. I am surrounded by many, yet so alone ... I'm lost"

## 2. Brain cancer is unique

**Lack of understanding from others:** Examples include others not understanding that 'benign' does not mean harmless; friends and family assume patient is 'cured' after treatment; will return to 'normal' after treatment; others don't realise it is cancer.

> "When you say "At least it's just a tumour" don't be surprised when I reply "IT'S GOING TO B****Y KILL HER!"
>
> CARER

**Dealing with side effects:** This includes personality changes; epilepsy; tiredness; becoming disabled; brain "not working" the same anymore; hair loss, and more.

> "Knowing that my brain just doesn't work the same anymore since surgery"
>
> PATIENT

**A brain tumour is a disability:**

> "Looking for support from the government to recognise that a brain tumour is a disability and not just a condition"
>
> CARER

## 3. Unresourced

**Not enough help:** This refers to having to fight for help navigating the brain tumour pathway.

> "No follow up after release from hospital. I had to contact a brain tumour charity to ask what happens next as hospital & GP didn't offer any help/support"
>
> CARER

**Not enough information:** A large number of these refer to lack of information from hospital and perceived lack of information from consultant, such as not being given options, or finding things out on notes instead of being told, for example:

> "Reading the word 'palliative' on your son's notes"
>
> CARER

> "Nobody from the hospital gives you any information about brain tumours when you are diagnosed. You are just left to try and find it all out for yourself and struggle through"
>
> CARER

## 4. Practical barriers

This encompasses external help that is not forthcoming and makes life harder than it should be. Examples include:

**Early diagnosis**

> "My wife went to the GP for 2 years complaining of headaches for a CT scan to show there was nothing wrong. Only then was a grapefruit sized tumour found"
>
> CARER

**Finances**

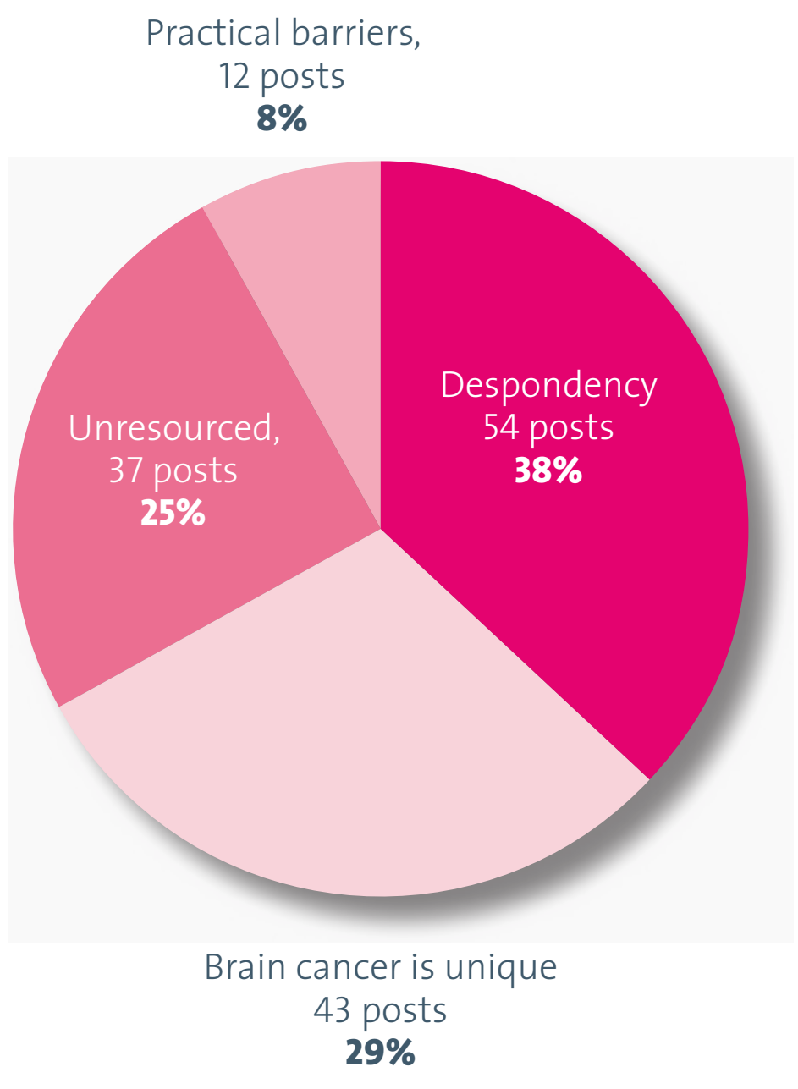
> "my son has a tectal plate glioma and vp shunt fitted have applied for DLA and told not in titled [sic] to anything ..."
>
> CARER

**Driving/DVLA and loss of independence**

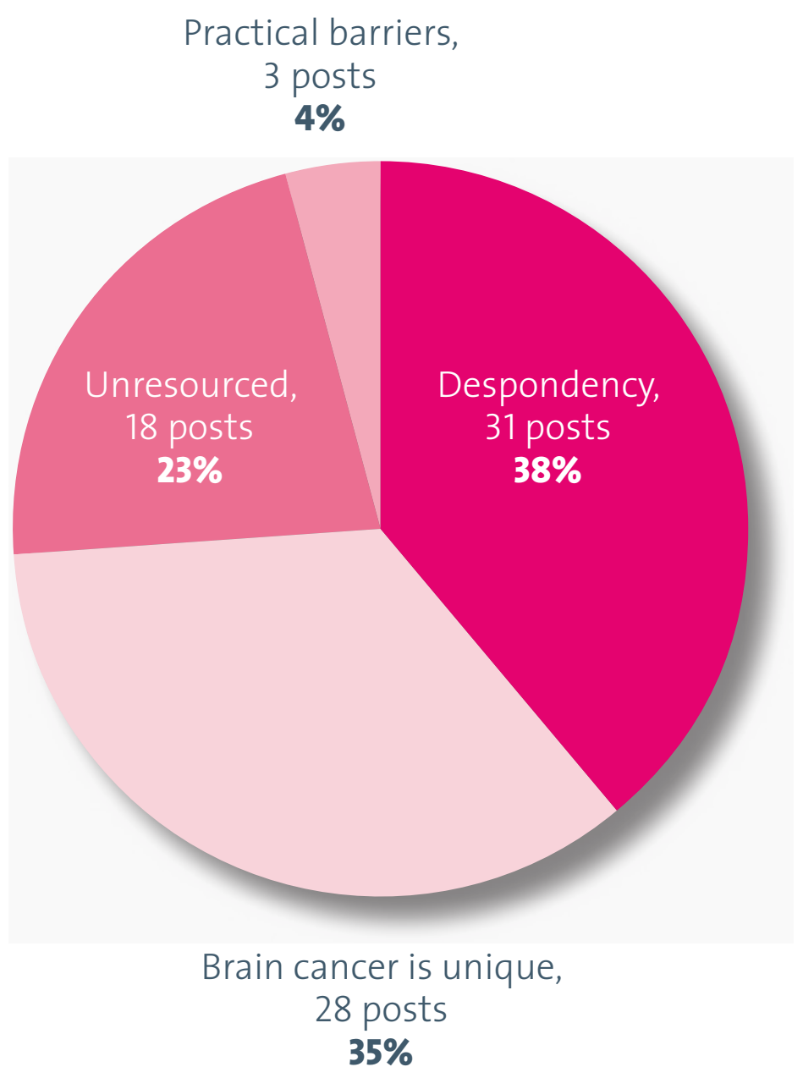
> "The DVLA does not make it easy to get your license back – everything is done by snail mail, no option to do it online and there are not clear guidelines"
>
> CARER

**Raising awareness of the issues that we really face**
Brain Tumour Awareness Month
**March 2013**

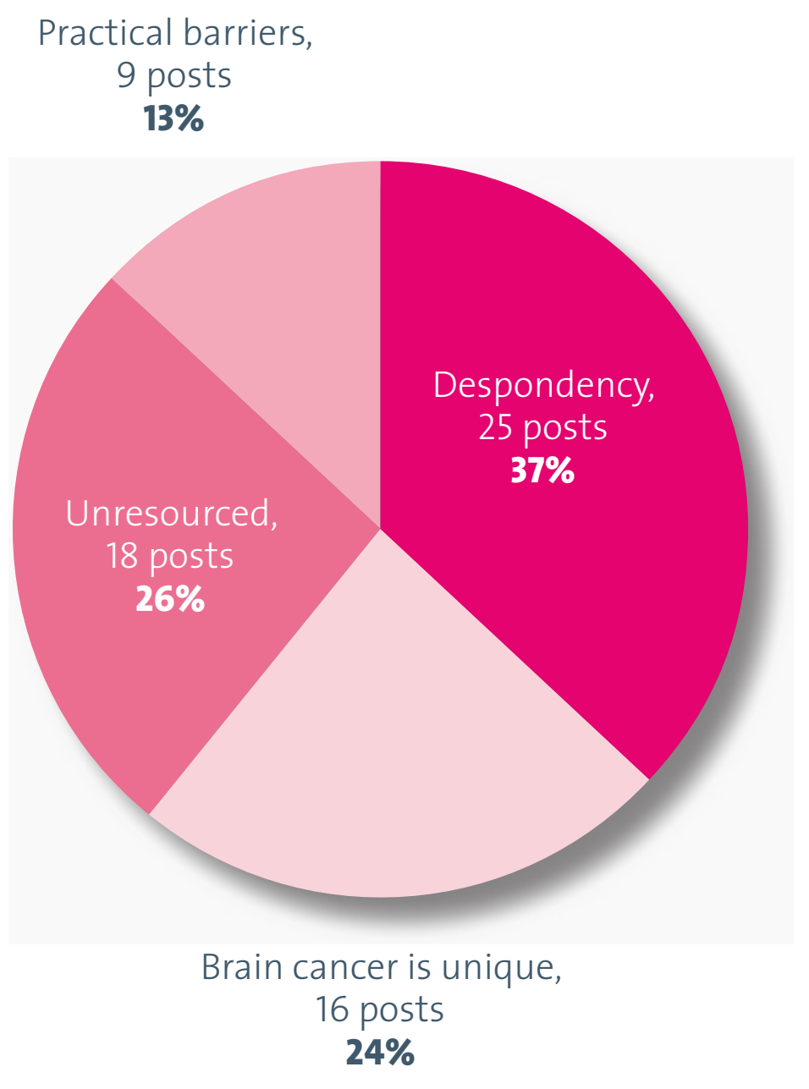
**a. Challenges faced by brain tumour patients and their carers**



**b. Challenges faced by patients**



**c. Challenges faced by carers**



## Conclusions

The differences between the challenges faced by patients and those faced by carers is of particular interest. Although feelings of despondency reigns highest for patients and carers, carers are more impacted than patients by feeling unresourced and by practical barriers. One explanation is that this is how carers feel most able to help their loved one, and so it is a higher priority to them than it is to patients. It could also be indicative of the natural role a carer falls into – of seeking control by helping practically.

The uniqueness of brain cancer was a bigger concern for patients than for carers. Lack of understanding from others is a sub heading within this, which impacts hugely on patients.