

Personality changes



Personality changes happen most often when the tumour is in the frontal lobes of the brain, but can occur with any brain tumour.



If you'd like to talk to someone about how you're feeling, or would like to find out where you can get further support (including details of support groups), you can contact The Brain Tumour Charity's Information and Support Team:

Phone: 0808 800 0004

(free from landlines and most mobiles)

Email: support@thebraintumourcharity.org

Live chat: thebraintumourcharity.org/live-chat Website: thebraintumourcharity.org/getsupport Closed Facebook groups: bit.ly/FBSupportGroups

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Introduction

Our brains control every aspect of who we are, what we think and how we feel. It makes sense, therefore, that a tumour in the brain could cause some personality changes.

This can be due to the tumour itself, or to the natural reaction to diagnosis and treatment.

This fact sheet aims to outline the possible personality changes associated with brain tumours and to provide practical suggestions for ways of coping with them.



What sort of personality changes might someone with a brain tumour experience?

If you currently have, or previously had, a brain tumour, you may experience changes to your personality.

It's important to realise that not everyone with a brain tumour will experience personality changes that cause problems.

Personality changes due to a brain tumour may include the following:

- Irritability or aggression
- Disinhibition loss of inhibitions or control, behaving in socially or culturally unacceptable ways
- Confusion and forgetfulness
- Apathy lack of interest and motivation
- Depression and blunting or flattening of your emotions
- Anxiety

- Mood swings (known as emotional lability)
 This includes showing exaggerated emotions, such as laughing and crying, in situations when you wouldn't have previously reacted in that way.
- Difficulty planning and organising, which can be frustrating
- Difficulty identifying emotions in yourself and others.

For more information on some of these aspects, see our webpages/fact sheets on *Memory, Depression* and *Thinking difficulties* (cognitive impairment):

thebraintumourcharity.org/memory-difficulties/ thebraintumourcharity.org/depression/ thebraintumourcharity.org/cognitive-difficulties/

How do brain tumours cause personality changes?

There are several reasons why someone with a brain tumour may experience personality changes. These can be interlinked.

Knowing there's a reason for the personality change can feel hugely relieving. It can also be a big help in developing ways to cope.

Location of the tumour

As a brain tumour grows, it puts pressure on the area of the brain it comes into contact with. This can affect the function or part of the body that is controlled by the affected brain area.

For more information, see our *Symptoms* by location in the brain webpage, thebraintumourcharity.org/adult-signs-and-symptoms/



Frontal lobe

The frontal lobes of the brain are responsible for many functions. These include controlling your personality and emotions, and playing a vital role in problem solving and long-term memory. As a result, personality changes are most common in people whose tumour is in their frontal lobes.

Our ability to regulate our behaviour and restrain ourselves is also controlled in the frontal lobes. So if you have a tumour here, you may act in ways that are considered socially inappropriate.

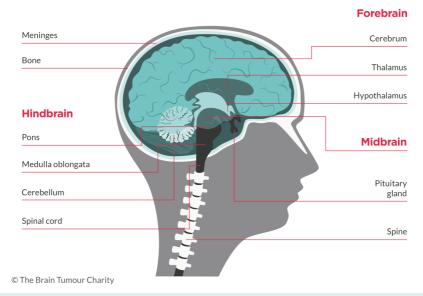
This can be very difficult for those around you to understand. It can also be difficult for you, if you are aware that you are doing it, and it can put a strain on personal relationships.

Pituitary gland

Personality changes can be caused by a tumour in the pituitary gland. The pituitary gland is not technically part of the brain, but it's located very near to the brainstem.

The pituitary gland secretes hormones, so a tumour here can lead to the over or under production of hormones, affecting some emotions and causing changes in your sex drive.

Treatments such as hormone replacement therapy can help to redress this balance, if appropriate.



Main parts of the brain, showing the pituitary gland

For more information, see *The human brain* webpage and fact sheet: thebraintumourcharity.org/the-brain/



Swelling

Treatments for your brain tumour, such as surgery, radiotherapy and chemotherapy, can cause swelling in the brain (known as oedema). As with the tumour itself, this can put pressure on the brain, and lead to personality changes.

Personality changes that resulted directly or indirectly from these treatments usually disappear gradually, as you recover from the treatment.

Steroids can also help to reduce swelling and therefore reduce the personality effects.

However, steroids can also make you feel anxious, irritable and emotional and cause mood swings.

A small number of people may experience what is called steroid-induced psychosis. It's important to know that this usually only happens when given a high dose in hospital, where you/your loved one will be monitored. But if you're worried about your/your loved one's behaviour, talk to your healthcare team.

Please remember that you should never stop taking steroids (nor reduce the amount you're taking) without your specialist advising you to do so.

See our Steroids webpage/fact sheet: thebraintumourcharity.org/treatments/steroids-adults/

Size and grade of tumour

Large tumours can have a greater effect on personality as they affect a greater area. However, a small tumour in a key area of the brain can have a significant impact.

A low grade, slow-growing tumour often allows the brain more time to adapt around it, causing less swelling and so fewer personality change than a high grade, fastgrowing tumour.

Impact of the diagnosis and treatment

The emotional impact of diagnosis, undergoing treatment, and the lifestyle changes that are often necessary when living with a brain tumour, can understandably affect a person's mood, making them more irritable. Personality changes, therefore, can be due to the natural reaction to the diagnosis and treatment.

Treatment and frequent journeys to medical appointments, can also dramatically lower energy levels, so someone who was very active before they had a brain tumour may no longer be.

Confusion and mood swings can also be the result of medication or combination of medications interacting. It's worth speaking to your doctor if you're experiencing such effects as they may be able to alter your medication.

How can I cope with personality changes?

Talking to others

Many people find just talking to others helpful. This can be useful to people with brain tumours and carers alike.

You may wish to share your feelings with close family or friends, or you could seek support from a counsellor.

Your GP may be able to refer you to an NHS counsellor or psychologist (if there's one available in your area), Psychologists can give you strategies and ways of coping with the changes. Alternatively, you could find one who practises privately, but this will have a cost.

See the *Resources* section of this fact sheet to find a counsellor or psychologist in your area.

The Brain Tumour Charity runs closed Facebook groups where you can talk to people in a similar situation [LINK]. We can also point you towards face-to-face groups. See page 2 of this fact sheet for how to contact us.

What's important is that you find support in a way that suits you best and which makes you comfortable.

Monitoring others' reactions

If you're living with a brain tumour and are aware or concerned that you may be acting inappropriately, it can be helpful to pay close attention to others' reactions and responses to you.

This may help to give you an idea of whether the way you're acting is acceptable. If those around you tell you that you're acting inappropriately, try not to take offence - they're most likely trying to be helpful.

You could ask a close family member or friend to give you feedback and guidance on what is appropriate behaviour in situations.

Medication

To help cope with personality change, it's always a good idea to speak to your doctor. They will be able to talk through options available to you, such as medication.

Steroids may be prescribed to reduce any swelling and its effects.

If appropriate, your doctor may prescribe other medications, such as tranquilisers, to help with anxiety or aggression, or anti-depressants if you're experiencing depression.

Neuropsychological assessment

One way to deal with changes in personality is to work out the source of the problem, e.g. are they to do with memory difficulties or thinking speed, concentration or communication difficulties, lack of inhibition, or a combination of such factors.

You can get help to establish the source of the personality changes by asking your GP or consultant to refer you to a neuropsychologist.

Neuropsychologists specialise in the physical effects of brain disease or injury on mental abilities.

In a neuropsychological assessment, the neuropsychologist conducts a series of tests. These look at your memory, thinking speed, attention, concentration, language, motor skills and mood.

They also assess what are called executive functions. These include planning and organising skills.

Information may also be collected from friends and family, as you may be unaware of the changes to your personality.

The results of the tests help the neuropsychologist decide if you need any therapies, and also suggest ways of coping with the changes.

Will I go back to how I was before?

This will depend on several factors, such as the extent of the personality change, what's causing it and whether it responds to the help you get.

Personality changes may be helped by medication or they may fade as the effects of treatment wear off.

If the change in behaviour is caused by physical changes in the brain, for example, as a result of surgery or radiotherapy, the person may not go back to the way they were before.

In some cases, other areas of the brain can develop and take over some of the functions that the damaged area used to control. This is called plasticity of the brain, but may require particular 'training'. You can ask your healthcare team if this is likely/possible in your case.

On the other hand, if a person's tumour continues to grow, personality changes may become more pronounced or other changes in personality may appear.

If the change is due to the emotional impact of living with a brain tumour, psychological support can help.

Some people report they actually feel <u>less</u> stressed by things than they did before their diagnosis.

How can I help a loved one who has personality changes?

It can be very upsetting to see personality changes in someone you love. Some people say, for example, that the person they once knew has changed now that they have a brain tumour.

The best way to help will depend on the nature of the personality change and the nature of your relationship, but having patience and understanding can be very supportive.

Firstly, it's important to be aware that some people are aware of their personality changes, but some people aren't.

Or they may not have full awareness. For example, some people may be aware that they're less patient and have a shorter temper than they did before, but they may not be able to link the cause and the effect.

Others are aware they're behaving inappropriately, but will be unable to stop themselves.

Below are some other strategies that may be helpful:

 To help with planning and organising, break down tasks into small chunks.

For example, rather than asking your loved one to clean the kitchen, break this down into tasks, such as 'please put dirty dishes in dishwasher', 'please clean the floor', etc.

 To help with confusion, it may be useful to minimise distractions.

For example, turn off background noise and avoid busy, noisy or crowded places that could be overwhelming for the person.

 If your loved one is showing signs of aggression, try to create a calm environment or even remove your loved one from stressful situations.

Try to remain calm and tell them what you're doing.

 To help with aggression, pay attention to what triggers the person's agitation and try to resolve the problem before it escalates

For example, there may be something in particular that's bothering the person, such as they may be tired or need to use the bathroom.

• If your loved one is behaving inappropriately, try not to show embarrassment or disgust.

Instead, let them know that their behaviour isn't appropriate, and give them consistent guidance on how to behave.

 To help your loved one with inappropriate behaviour, it may be useful to speak about this with other close friends and family.

If they have an understanding of the reasons behind a person's behaviour, then they'll be able to support the person or ignore some comments.

- Try to avoid comparing the person now with the 'person they were before', which can be upsetting for both of you.
- Try to recognise the change as part of the brain tumour, not the person you love.

This can be very difficult if, for example, the person becomes irritable or snappy and it seems as though they're taking everything out on you.

Take time to look after yourself.

Caring for, or living with, someone whose personality has changed can be wearing - make sure you set time aside for yourself. For example, to do a hobby or something you enjoy. And ask for help if you need time to recharge your batteries.

You may also like to join our Carers closed Facebook group, where you can 'talk' to others in a similar situation and get more tips and advice.

You can find out more and how to join at; thebraintumourcharity.org/facebook-support/

As a carer, you're also entitled to professional emotional support. If you feel like you could do with such help, speak to your GP about receiving counselling for yourself.

For more help and advice, see our Being a carer webpage and fact sheet: thebraintumourcharity.org/being-a-carer/

Resources

Below is a list of resources that you may find helpful in coping with personality change, for anyone affected by a brain tumour.

Books

These books are available on amazon.co.uk:

 Connecting through compassion. Guidance for family and friends of a brain cancer patient.

Aldrich J. and Peterson N.

This book is written by people who have cared for a spouse with brain cancer. It aims to help equip readers with coping strategies.

Checking out: An in-depth look at losing your mind.

Graves C.

This book is a memoir written by someone whose husband developed personality changes as a result of his brain tumour.

Organisations

British Association for Counselling and Psychotherapy (BACP)

Information about finding a therapist is available on the BACP's website:

bacp.co.uk/search/Therapists

British Psychological Society (BPS)

Directory of chartered psychologists is available on the BPS's website:

bps.org.uk/lists/DIR

The Brain Tumour Charity's Facebook Support Groups:

Connect with other people to share experiences, find and give support and feel less isolated. There's a general group, plus groups specifically for parents or carers or young adults:

Closed Facebook groups: bit.ly/FBSupportGroups

One Plus One:

A charity who works to strengthen couple and family relationships.

oneplusone.org.uk

Relate

Relate are a charity who provide support services to people experiencing relationship problems. Their support services include counselling for individuals, couples and families.

relate.org.uk

Child Brain Injury Trust

Child Brain Injury Trust have produced a range of fact sheets to help parents understand and manage personality changes in children as a result of brain injury.

Topics include *Changes in behaviour* and *Behaviour* practical strategies.

childbraininjurytrust.org.uk/how-we-help/parentand-professionals/factsheets/

The Pituitary Foundation

Provides help to people who suffer from disorders of the pituitary gland, including tumours. Publishes various leaflets and provides a list of local support groups in the UK.

pituitary.org.uk

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology. Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you've already been given. Please do continue to talk to your healthcare team if you're worried about any medical issues. If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on 0808 800 0004 or support@thebraintumourcharity.org

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About The Brain Tumour Charity

Going further for a cure

As the UK's leading brain tumour charity, we're here to accelerate a positive change in how people affected by brain tumours are diagnosed, supported and cured.

Brain tumours strike fast. And they can strike anyone, at any age. But what if we could move faster? What if we could stop brain tumours right in their tracks? It's no easy task taking on something this complex, but that's exactly what we're here to achieve. And we won't stop until we have.

We know that if we put our heads together, we're more than up to the challenge. So we're building a movement of people from every walk of life – all coming together to accelerate a cure.

Find out more and get involved: **thebraintumourcharity.org**









Notes		





thebraintumourcharity.org

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