

## Brain tumours and metastases overview

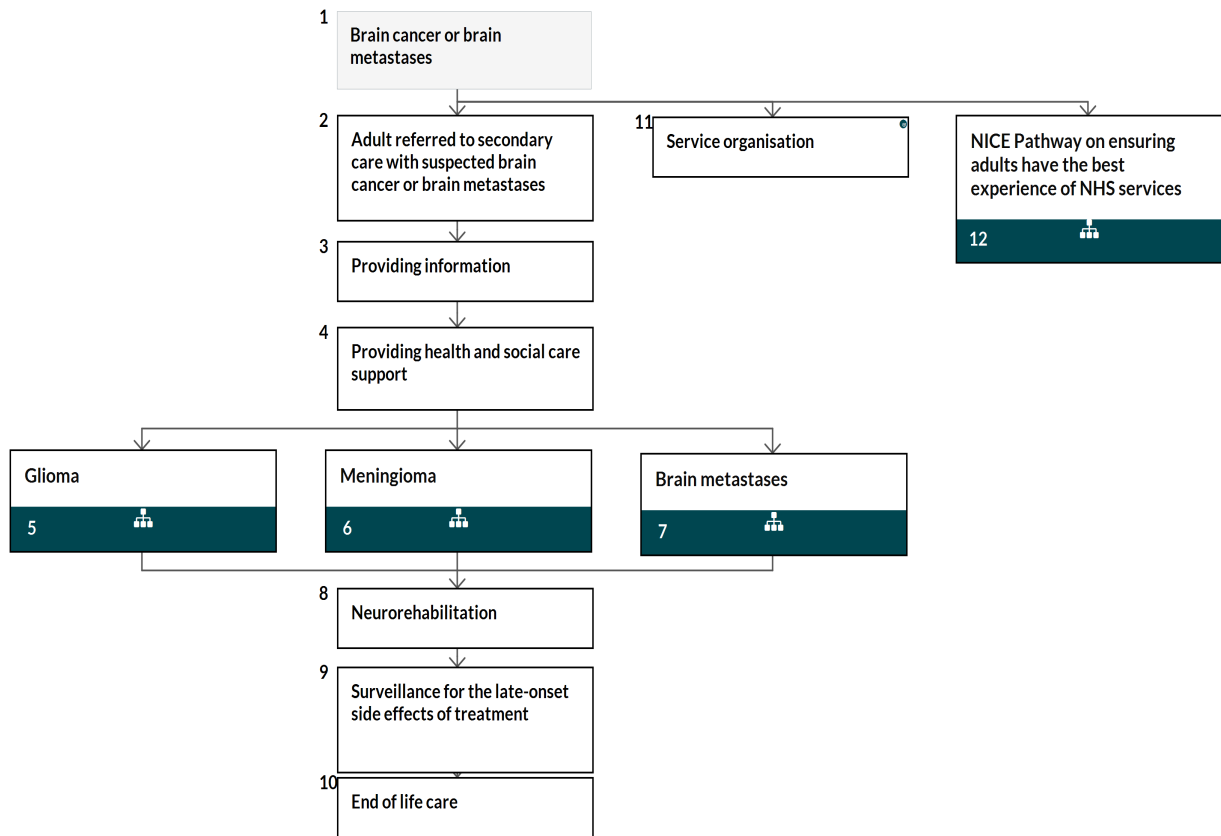
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/brain-tumours-and-metastases>

NICE Pathway last updated: 29 January 2021

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



## 1 Brain cancer or brain metastases

No additional information

## 2 Adult referred to secondary care with suspected brain cancer or brain metastases

See [brain and central nervous system cancers in the NICE Pathway on suspected cancer: recognition and referral](#).

## 3 Providing information

Give information to the person with a brain tumour and their relatives and carers (as appropriate):

- in a realistic and empathetic manner
- in suitable formats (written and spoken, with information available to take away), following the principles outlined in [the NICE Pathway on patient experience in adult NHS services](#). Also see the guidance for the [NHS England Accessible Information Standards](#).
- at appropriate times throughout their care pathway.

Provide and explain clinical results, for example imaging and pathology reports, to the person with a brain tumour and their relatives and carers (as appropriate) as soon as possible.

NICE has written information for the public on [brain tumours and metastases](#).

### Driving

Explain to the person that they have a legal obligation to notify the Driver and Vehicle Licensing Agency if they have a brain tumour, and that this may have implications for their driving.

### Fertility

Discuss the potential preservation of fertility with people with brain tumours where treatment may have an impact on their fertility (see [cryopreservation to preserve fertility in people diagnosed with cancer in the NICE Pathway on fertility](#)).

## Why we made the recommendations

See information on [care needs of people with brain tumours](#) [See page 9].

### 4 Providing health and social care support

Offer supportive care to people with brain tumours and their relatives and carers (as appropriate) throughout their treatment and care pathway

#### Assigning a key worker

Provide a named healthcare professional with responsibility for coordinating health and social care support for people with brain tumours and their relatives and carers, for example, a key worker (often a clinical nurse specialist) as defined in [NICE guidance on improving outcomes for people with brain and other central nervous system tumours](#).

See why we made the recommendations on [care needs of people with brain tumours](#) [See page 9].

#### Eliciting care needs

Be aware that the care needs of people with brain tumours represent a unique challenge, because (in addition to physical disability) the tumour and treatment have affects on:

- behaviour
- cognition
- personality.

Discuss health and social care support needs with the person with a brain tumour and their relatives and carers (as appropriate). Take into account the complex health and social care support needs people with any type of brain tumour and their relatives and carers may have (for example, psychological, cognitive, physical, spiritual, emotional).

Set aside enough time to discuss the impact of the brain tumour on the person and their relatives and carers (as appropriate), and to elicit and discuss their health and social care support needs.

Health and social care professionals involved in the care of people with brain tumours should address additional complex needs during or at the end of treatment and throughout follow-up.

These include:

- changes to cognitive functioning
- fatigue
- loss of personal identity
- loss of independence
- maintaining a sense of hope
- potential for change in personal and sexual relationships
- the challenges of living with uncertainty
- the impact of brain tumour-associated epilepsy on wellbeing (see [the NICE Pathway on epilepsy](#)).

See why we made the recommendations on [care needs of people with brain tumours](#) [See page 9].

## 5 Glioma

[See Brain tumours and metastases / Brain cancer: glioma](#)

## 6 Meningioma

[See Brain tumours and metastases / Brain cancer: meningioma](#)

## 7 Brain metastases

[See Brain tumours and metastases / Brain metastases](#)

## 8 Neurorehabilitation

### Needs assessment and referral

Consider referring the person with a brain tumour for a neurological rehabilitation assessment of physical, cognitive, and emotional function at diagnosis and every stage of follow-up.

## Providing information

Offer people with brain tumours and their relatives and carers (as appropriate) information on accessing neurological rehabilitation, and on what needs it can help address.

Give people with brain tumours and their relatives and carers (as appropriate) information on:

- neurological rehabilitation options in the community, as an outpatient, or an inpatient **and**
- how to get a neurological rehabilitation assessment.

## Why we made the recommendations

See information on [neurorehabilitation](#) [See page 9].

## 9 Surveillance for the late-onset side effects of treatment

### Risk of late effects

Be aware that people with brain tumours can develop side effects of treatment months or years after treatment, which can include:

- cataracts
- cavernoma
- cognitive decline
- epilepsy
- hearing loss
- hypopituitarism
- infertility
- neuropathy (for example, nerve damage causing visual loss, numbness, pain or weakness)
- radionecrosis
- secondary tumours
- SMART (stroke-like migraine attacks after radiotherapy)
- stroke.

See also [pituitary conditions in the NICE Pathway on endocrine, nutritional and metabolic conditions](#) and [the NICE Pathways on stroke](#), [hearing loss](#), [cataracts](#), [neuropathic pain](#) and [fertility](#).

Assess the person's individual risk of developing late effects when they finish treatment. Record these in their written treatment summary and explain them to the person (and their relatives and carers as appropriate).

### **Lifestyle changes**

Encourage people who have had cranial radiotherapy to follow a healthy lifestyle, including exercise, a healthy diet and stopping smoking (if applicable), to decrease their risk of stroke. See [the NICE Pathways on obesity: maintaining a healthy weight and preventing excess weight gain](#), [physical activity](#) and [stop smoking interventions and services](#).

### **Monitoring possible late effects**

For people who are at risk of stroke, consider checking their blood pressure, HbA1c level and cholesterol profile regularly.

Consider ongoing neuropsychology assessment for people at risk of cognitive decline.

If a person has had a radiotherapy dose that might affect pituitary function, consider checking their endocrine function regularly after the end of treatment.

Consider referring people who are at risk of visual impairment, for an ophthalmological assessment.

Consider referring people who are at risk of hearing loss to audiology for a hearing test. (See also [the NICE Pathway on hearing loss](#).)

Consider referring the person to stroke services if an MRI during active monitoring identifies asymptomatic ischaemic stroke. (See also [the NICE Pathway on stroke](#).)

### **Why we made the recommendations**

See information on [surveillance for the late-onset side effects of treatment](#) [See page 10].

## **10 End of life care**

If the person with a brain tumour is likely to be in their last year of their life, refer to [NICE's recommendations on caring for an adult at the end of life](#).

See why we made the recommendations on [care needs of people with brain tumours](#) [See page

9].

See also [the NICE Pathway on opioids for pain relief in palliative care](#).

## 11 Service organisation

In people aged between 16 and 24 years old, refer to the [NICE quality standard on cancer services for children and young people](#).

NICE has published cancer service guidance on:

- [improving outcomes for people with brain and other central nervous system tumours](#)
- [improving outcomes in children and young people with cancer and](#)
- [improving supportive and palliative care for adults with cancer](#).

### Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

1. Multidisciplinary teams for young people
2. Access to clinical trials
3. Electronic prescribing of chemotherapy
4. Psychological and social support
5. Neuro-rehabilitation
6. Follow-up and monitoring of late effects
7. Fertility support

## 12 NICE Pathway on ensuring adults have the best experience of NHS services

[See Patient experience in adult NHS services](#)



## Care needs of people with brain tumours

Based on the evidence and their own experience, the committee determined that people with brain tumours have very specific needs that are often not met. In particular, they highlighted ways in which the care needs of people with brain tumours differ from those of people with other types of cancer, such as the impact on the person's sense of identity and legal requirements related to driving. Losing the ability or legal right to drive can have a profound effect on the patient's independence, employment status and self-esteem. The committee's aim was to improve the support and information offered to people with brain tumours.

The committee described how the care needs of people with brain tumours were often more complex than could be considered in a single guideline. In particular, young people, people wishing to preserve their fertility, and people nearing the end of their life have especially complex needs. In order to address these needs, the committee signposted to existing NICE guidance in the specific area.

### How the recommendations might affect practice

The recommendations should improve care for both people living with brain tumours and their relatives and carers. It is likely that there will be a short-term resource impact in some areas, as supportive care for people with brain tumours is currently variable, with very little support available in some areas.

For more information, see [evidence review D: supporting people living with a brain tumour](#).

## Neurorehabilitation

No evidence was found for this topic. Based on their experience, the committee agreed that neurological rehabilitation is likely to be suitable for many people with brain tumours. Given that neurological rehabilitation is time consuming (especially if the person with a tumour lives a long way from the rehabilitation centre) and sometimes not appropriate, the committee agreed that assessment should be carried out at every stage of diagnosis and follow-up to identify which, if any, forms of rehabilitation are suitable for the person. The aim of the recommendations is to ensure that neurological rehabilitation is considered at every stage of treatment and follow-up.

### How the recommendations might affect practice

There is currently variation in practice in assessing whether people with a brain tumour need

neurological rehabilitation. Some of this reflects the availability of neurological rehabilitation services. The recommendations reinforce current best practice, and will mean a change in practice in some areas, including where assessment is 'ad hoc' rather than systematic.

People with a brain tumour make up a small percentage of people referred for neurological rehabilitation, so only a small increase in demand on resources is expected. There should not be any extra training needs because professionals already have the knowledge and skills to provide the services.

For more information, see [evidence review D: supporting people living with a brain tumour](#).

### **Surveillance for the late-onset side effects of treatment**

No evidence was found for this topic. Some people experience late effects after treatment for a brain tumour. With the possible exception of stroke risk it is unknown if these late effects can be prevented, but the committee agreed that any negative impact can be managed through clinical vigilance and referral into appropriate specialist monitoring pathways. The committee explained that it was important to consider referral for anyone at risk of late effects – not just those at 'high' risk – but that there may be no value in such a referral overall in lower risk groups.

### **How the recommendations might affect practice**

The recommendations should not significantly alter practice, as they reflect common clinical practice.

For more information, see [evidence review D: supporting people living with a brain tumour](#).

## **Glossary**

### **active monitoring**

(regular clinical and radiological review of a person with a brain tumour or brain metastases who are not currently having treatment for their cancer)

## **Sources**

[Brain tumours \(primary\) and brain metastases in adults \(2018 updated 2021\) NICE guideline NG99](#)

## Your responsibility

### Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to

have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### **Medical technologies guidance, diagnostics guidance and interventional procedures guidance**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.