International Guideline Harmonization Group
for Late Effects of Childhood Cancer

Potential advantages and disadvantages of meningioma screening options for asymptomatic childhood, adolescent and young adult cancer survivors – A Survivor Information Brochure

The information in this brochure may need to be adapted according to national healthcare guidelines.

Why should I be aware of the risk of developing a meningioma?

- The risk of cancer and benign tumors increases for all people as they get older.
- As a survivor of childhood, adolescent or young adult cancer, you may have a higher risk of developing a new (different) cancer or other benign tumor during adulthood compared to people of similar age in the general population.
- If your brain and spinal cord were exposed to radiation as part of your treatment for a childhood, adolescent or young adult cancer, you have an increased risk of developing a tumor called a meningioma.
- While some people treated with cranial radiation will develop a meningioma, most will not.
- Although a meningioma is most often benign (non-cancerous), it can cause serious symptoms because of its location and growth.
- It is possible to detect a meningioma early by having MRI screening, but screening for meningiomas has benefits and harms.
- This information sheet can be used to help you and your healthcare provider decide if having meningioma screening is the right choice for you.

What type of meningioma screening test is used?

- Magnetic resonance imaging (MRI) is a medical imaging technique that uses powerful magnets and radio waves to generate images of the organs of the body. MRI does not involve X-rays or require exposure to radiation.

What are the potential advantages of having meningioma screening?

- You may feel reassured if you do not have a meningioma at this time. However, a meningioma may still develop in the future.
- You may be more likely to have a meningioma detected at an earlier timepoint when it is more easily treated and before you experience any symptoms.
- Early detection would allow doctors to monitor the size/growth of the meningioma over time, which may help determine if/when treatment is needed.
- You may have a chance for improved survival, fewer side effects, and improved quality of life if the screening finds a small early stage meningioma.

What are the potential disadvantages of having meningioma screening?

- You may experience anxiety and stress about having meningioma screening and what the test results will show.
- You may feel more like a patient rather than a healthy survivor if you decide to have meningioma screening.
- Your scan may show incidental findings of unclear clinical significance, such as treatment-related abnormalities in brain tissue and blood vessels that may lead to unnecessary stress and anxiety.
- You may be diagnosed with a small meningioma that never would have caused problems (overdiagnosis).
- You may experience unnecessary anxiety and distress related to a false positive test. For example, findings on tests which are suspicious for meningioma but further testing shows no meningioma.

- If you have a meningioma or another type of tumor detected by screening, we do not know if you will have better health outcomes compared to having a tumor discovered after it causes symptoms.
- If you have a meningioma without any symptoms, the need to treat is not always clear. This depends on the location, size and growth of the meningioma. This uncertainty may cause some anxiety.
- The diagnosis of an asymptomatic meningioma or other findings may affect your ability to obtain heathcare and/or life insurance.

What are the potential disadvantages associated with MRI?

- An MRI is costly and may not be covered by your health insurance. However, your healthcare provider could write a letter of medical necessity to explain that you are at risk of meningioma after brain radiation and why you may benefit from MRI screening.
- You may feel claustrophobic and have some discomfort when lying in the MRI scanner. Imaging professionals should be able to help with positioning to minimize discomfort.
- You may have deposition of gadolinium (MRI contrast) into the brain when you have an MRI with gadolinium contrast. This gadolinium deposition does not cause symptoms, but it is not yet known whether this causes any long-term health problems.
- If you have poor kidney function, an MRI with gadolinium contrast may place you at risk of kidney damage (a syndrome called nephrogenic systemic fibrosis). Your healthcare provider will be able to discuss with you whether this concern should influence your decision about having a MRI scan.
- You may not be able to have a MRI if you have any medical devices or metal hardware in your body. However, many modern devices are MRI compatible. If this is the case, discuss this with your healthcare provider.

What are the international screening recommendations?

- If you were treated with radiotherapy to your brain or spinal cord it is very important that you are aware of possible symptoms related to a meningioma. You should contact your healthcare provider if you experience any of the following symptoms: progressively worsening, severe, unrelenting headaches, worsening nausea and vomiting, new-onset cognitive (thinking skills), motor, sensory or behavioral changes, balance problems, seizures, or other neurological changes.
- We cannot recommend for or against routine screening with MRI because we do not know if your health outcomes will be better if we detect a meningioma that is not causing symptoms.
- It is important that you make the decision whether or not to screen together with your healthcare providers, oncology and survivorship team, and individual support networks. Careful consideration of the potential advantages and disadvantages is advised.

Thank you for taking the time to read this information sheet. If you have any questions regarding the information included in this brochure or if you require emotional support and advice regarding your thoughts and feelings, please contact your healthcare provider for advice and support.

Publication

Bowers DC, Verbruggen LC, Kremer LCM, Hudson MM, Skinner R, Constine LS, Sabin ND, Bhangoo R, Haupt R, Hawkins MM, Jenkinson H, Khan RB, Klimo P Jr, Pretorius P, Ng A, Reulen RC, Ronckers CM, Sadighi Z, Scheinemann K, Schouten-van Meeteren N, Sugden E, Teepen JC, Ullrich NJ, Walter A, Wallace WH, Oeffinger KC, Armstrong GT, van der Pal HJH, Mulder RL. Surveillance for subsequent neoplasms of the CNS for childhood, adolescent, and young adult cancer survivors: a systematic review and recommendations from the International Late Effects of Childhood Cancer Guideline Harmonization Group. Lancet Oncol. 2021 May;22(5):e196-e206.