

## **Potential advantages and disadvantages of breast cancer screening options for female childhood, adolescent and young adult cancer survivors – A Survivor Information Form**

### **Why should I be aware of the risk of breast cancer?**

- The risk of cancer increases for all women as they get older.
- As a survivor of childhood, adolescent or young adult cancer you have a higher risk of developing a new (different) cancer in adulthood compared to people of similar age in the general population.
- Breast cancer is one of the most common new cancers that occur in women treated for a childhood, adolescent or young adult cancer.
- If your breast region was exposed to radiation as part of your treatment (chest radiation), you have an increased risk of developing breast cancer that may present at a younger age than breast cancer in women in the general population.
- If you were treated with high doses of anthracyclines without chest radiation you may have a higher risk of breast cancer as well, especially if you had a diagnosis of leukemia, central nervous system tumor or sarcoma (except for Ewing sarcoma).
- While some women treated with chest radiation and/or anthracyclines will develop breast cancer at a young age, most will not.
- However, among those who develop breast cancer, detecting it early can be life-saving and may reduce the amount of treatment needed.
- It is possible to detect breast cancer early by having breast cancer screening.
- Breast cancer screening has advantages and disadvantages.
- This information sheet can be used to help you and your healthcare provider decide if having breast cancer screening is the right choice for you.

### **What types of breast cancer screening tests are used?**

- Mammography is specialized medical imaging that uses a low-dose x-ray system to see inside the breasts. Mammography is the standard breast cancer screening test in the general population.
- Magnetic resonance imaging (MRI) is a medical imaging technique that uses magnetic waves and a computer to generate detailed images of the breast.

### **What are the potential advantages and disadvantages of having mammography?**

- Mammography has a good track record of detecting breast cancer in the general population.
- Early breast cancer detection has been shown to decrease death from breast cancer in the general population.
- A mammogram is a relatively inexpensive test to perform and should be covered by most national health service programs and insurance plans.
- You may experience pain during the mammogram due to the pressure on your breasts.
- You will be exposed to a small amount of radiation during the mammogram. For example, in a woman treated with moderate to high dose chest radiation for a childhood cancer, the additional radiation exposure that would result from 50 mammograms (annual mammogram from age 25 to 74) is less than 1% of the total amount.
- Mammography may not be as accurate for breast cancer screening in young women with dense breast tissue. Dense breast tissue means that there is less fatty tissue and more dense tissue including milk glands, milk ducts and supportive tissue, which is more common in younger women.

### **What are the potential advantages and disadvantages of having a breast MRI?**

- Breast MRI is more accurate in detecting a hidden breast cancer in young women with dense breast tissue.
- You may experience claustrophobia and some discomfort when lying in the breast MRI scanner. Imaging professionals should be able to help with positioning to minimize discomfort.
- You may not be able to have a breast MRI if you have any medical devices or metal hardware in your body or if you have a MRI contrast allergy. However, many modern devices are MRI compatible.
- You may need to have the breast MRI performed during a specific time in your menstrual cycle. This may be difficult to predict and coordinate especially with lifestyle commitments and requiring time off work.
- 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).
- Breast MRI is costly and may not be covered by your health insurance. However, most insurance companies and national health service programs will cover an annual breast MRI for women in high risk groups such as you.

**What are potential advantages of having both a mammogram and breast MRI for breast cancer screening?**

- You have a better chance of detecting pre-cancerous changes in the breast by a mammogram.
- You have a better chance of detecting hidden breast cancer by a breast MRI if your breast tissue is dense.
- You have a higher chance of detecting a small breast cancer if you have breast cancer screening with a mammogram and breast MRI compared to mammogram or breast MRI alone.

**What are the potential advantages of having breast cancer screening?**

- You may be more likely to have a breast cancer detected at an earlier stage.
- You may need less aggressive treatment if breast cancer is detected at an earlier stage.
- You are more likely to have a good outcome if the screening finds a small early stage breast cancer.
- You may feel reassured that you do not have breast cancer.

**What are the potential disadvantages of having breast cancer screening?**

- You may feel more like a cancer patient rather than a healthy survivor if you decide to have breast cancer screening and you may experience anxiety and stress about having breast cancer screening and what the test results will show.
- You may have additional expenses related to breast cancer screening that are not covered by insurance (in some countries), including travel costs. In addition, you may have to take time off work or use annual leave to attend appointments.
- You may have a false positive test (a test result that indicates that you may have cancer even though you do not). This may lead to additional medical testing including biopsy which can cause unnecessary anxiety and distress.
- You may be diagnosed with a small and slow-growing breast cancer that never would have caused problems if not detected by screening (overdiagnosis).
- You may still have a small breast cancer that is still not detected by screening. In that case you may be falsely reassured that you do not have breast cancer.

**What are the international screening recommendations?**

- If you were treated with chest radiation doses of 10 Gy or higher or upper abdominal radiation exposing breast tissue, especially at a young age, it is very important that you are aware of the risk of breast cancer. You should contact your healthcare provider if you note a change in your breasts.
- If you were treated with chest radiation doses of 10 Gy or higher yearly breast cancer screening with

mammography and MRI is recommended starting at age 25 years or 8 years after radiotherapy, whichever occurs last.

- If you were treated with upper abdominal radiation exposing breast tissue, especially at a young age, annual breast cancer screening with mammography and MRI is reasonable starting at age 25 years or 8 years after radiotherapy, whichever occurs last. It is important that you make the decision whether or not to screen together with your oncology and survivorship team and individual support networks after careful consideration of the potential advantages and disadvantages.
- If you were treated with any type of anthracyclines in the absence of chest radiation, we cannot recommend routine breast cancer screening because there is currently not enough data to determine if you are at increased risk.
- If you were treated with anthracycline doses of  $\geq 250$  mg/m<sup>2</sup> without chest radiation or if you are a survivor of leukemia, CNS tumor or sarcoma (except for Ewing sarcoma) (Li-Fraumeni syndrome-associated childhood cancer types) it is important that you make the decision whether or not to screen together with your oncology and survivorship team and individual support networks after careful consideration of the potential advantages and disadvantages. In addition, if you are a survivor of leukemia, CNS tumor or sarcoma (except for Ewing sarcoma) and treated with high doses of anthracyclines, testing for genetic cancer predisposition syndromes, like Li-Fraumeni syndrome, can be considered. Patients with genetic cancer predisposition syndromes, like Li-Fraumeni syndrome, have an increased breast cancer risk and should be screened routinely.

*Thank you for taking the time to read this information sheet. If you have any questions regarding the information included in this form or if you require emotional support and advice regarding your thoughts and feelings, please contact your treating team, general practitioner, case manager, or nurse specialist if you have one, or another member of your oncology or survivorship team as applicable to you.*

#### **Publication**

Mulder RL, Hudson MM, Bhatia S, Landier W, Levitt G, Constone LS, Wallace WH, van Leeuwen FE, Ronckers CM, Henderson TO, Moskowitz CS, Friedman DN, Ng AK, Jenkinson HC, Demoor-Goldschmidt C, Skinner R, Kremer LCM, Oeffinger KC. Updated Breast Cancer Surveillance Recommendations for Female Survivors of Childhood, Adolescent, and Young Adult Cancer From the International Guideline Harmonization Group. *J Clin Oncol.* 2020 10;38(35):4194-4207.