Contact information

My Oncologist: _____

My Nurse: _____

My Psychosocial Support: _____

Pharmacy Phone Number: _____

Other: _____

Speaking up for your Rights:

SELF-ADVOCACY WHEN LIVING WITH MBC

When diagnosed with metastatic breast cancer (MBC), you have the right to ask questions, to gather more information on your disease, and to question your healthcare team on treatment decisions. Always remember you are a **partner** in making **shared decisions** about your health, and you have the right to collaborate with your healthcare team in making treatment decisions that incorporates your values and will impact the future of your health.

You have the right to:

- Have full disclosure and understanding of your treatment plan. This includes the recommended order of lines of therapy and why, alternate treatment plans (and why they aren't recommended), prognosis, and referral to any necessary supportive care needs. Supportive care may include but is not limited to financial concerns, pain management support, early palliative care referral, or nutritional needs.

- Seek out a second opinion if you want to hear from another oncologist on the best approach to treat your specific disease. This does not invalidate your appointed oncologist's abilities. It provides additional insight into what course of treatment is best suited for you, increase your knowledge about your illness and help you effectively advocate for yourself. If you would like a second opinion, speak with your appointed oncologist and ask for a referral. An oncologist should not take offence to your request and will recognize that you are educating yourself about your disease and options.

- Change oncologists if you do not believe you are getting the care to which you are entitled. Remember, sometimes patients and their oncologist do not see eye to eye or their personalities don't mesh. That's OK. When you are dealing with a life-limiting illness, you have the right to seek out the medical team that you are comfortable with, can collaborate with, and be an active partner in shared decision making. First, speak with your oncologist and see if the situation can be resolved before changing providers. If this is not possible, speak with your nurse who can then forward your concerns to the appropriate individual to put in a request to change providers.

- Know about clinical trials and how to get access. If you find a trial online, print a copy and share it with your oncologist to ask if the trial is a suitable option for you. Remember clinical trials should be asked about at the beginning of your disease course and not left as an option to consider only when nearing the end of possible treatment options. It may be difficult to gain access to trials later on due to strict exclusion criteria for many trials. Look for Canada-specific trials at: **www.canadiancancertrials.ca** and **www.clinicatrials.gov** for trials in the US.

- Ask for copies of all scans, bloodwork results, and other relevant results. At your appointments, your oncologist will discuss these results with you, but it is important to become an active participant in your care to better understand, and be able to self-advocate for treatment choices. If you do not understand any portion of a result or pathology report, ask your care team to explain them further and take notes.

- Bring someone with you to all of your appointments. It is easy to miss key points when under a great deal of stress and trying to mitigate side effects of your treatment or illness. (Note, if this isn't possible during the pandemic, ask your care team if a friend or family member can join virtually.)

- Inquire about any genetic testing that may be required and the implications it may have on you or your family members. Testing may provide you with clinical trial options that would not be available if genetic testing was not explored. Unfortunately, in some cases, the results of genetic testing may limit your clinical trial options, so it is important to be informed before going ahead with testing.

- Inquire about medications that may be used to treat your illness but are not currently covered by the provincial registry. Your oncologist not may bring them up initially because many drugs are cost-prohibitive.

- Contact a pharmaceutical company to try to gain access to a medication that may have been denied to you based on indication or limited insurance coverage. Sometimes writing a personal letter to state your case to the pharmaceutical manufacturer can put a human approach behind the request as opposed to your oncologist trying to get access based on your disease course and pathology, etc.

Online Resources for Information & Support

www.Rethinkbreastcancer.com/livingwithmbc

https://www.metavivor.org/support/

http://mbcn.org/resources/

https://www.cbcn.ca/en/mbc-newly-diagnosed-guide

http://www.virtualhospice.ca

Notes