DECISION CHECKLIST: CONSIDERING MASTECTOMY WITH OR WITHOUT RECONSTRUCTION

If you're considering a mastectomy for breast cancer prevention or treatment, you probably have lots of questions for your healthcare team. We've compiled several key questions so you can select and build your own mastectomy checklist.

A checklist from FORCE: FacingOurRisk.Org

Notes:

Questions to help you choose between mastectomy or lumpectomy with radiation

- [ ] If I choose lumpectomy and radiation over mastectomy, what is involved? What short-term and long-term side effects should I know about?
- [ ] If I have a mastectomy, what are the short-term and long-term risks? Do you suggest a preventive mastectomy for my opposite breast?
- [ ] Given my genetic status, what is my risk for a new breast cancer diagnosis if I choose mastectomy? What is my risk if I choose lumpectomy and radiation?
- [ ] Will I be more symmetrical if I choose double mastectomy vs. lumpectomy and radiation?
- [ ] If I choose lumpectomy, will it be necessary to rearrange the remaining breast tissue for symmetry? If so, would that procedure be done by a breast surgeon or a plastic surgeon?
- [ ] If I choose mastectomy, will you be able to preserve the nerves that provide sensation? How much sensation am I likely to have and where? How will it differ from the sensation I have in my breasts now? How frequently do you perform this procedure? If I have a lumpectomy and radiation, will I lose any sensation?
- [ ] Am I a candidate for nipple-sparing mastectomy? How many times have you performed this procedure? Will my nipples lose sensation or flatten if I keep them? Is there a higher risk for breast cancer in the remaining nipple tissue?
- [ ] What is my risk for lymphedema after mastectomy or lumpectomy and radiation? Is one procedure more likely than the other to cause lymphedema?
- [ ] What type of short-term and long-term follow-up care or imaging would I need after lumpectomy and radiation? What would I need after double mastectomy with or without reconstruction?
- [ ] If I choose lumpectomy and radiation now, can I have a preventive double mastectomy later? Will my insurance cover it? Will the radiation change my future reconstruction options or outcomes?
- [ ] If I choose mastectomy, will I have my choice of plastic surgeons and reconstruction options?
- [ ] If I choose lumpectomy, how big would my incision be and what would it look like? What would my incision look like if I choose mastectomy?

Notes:

Questions to ask about going flat

- [ ] How big will my incisions be and what will they look like?
- [ ] Will you perform an aesthetic flat closure so that my mastectomy scars are flat against my chest? How many times have you performed this procedure?
- [ ] Am I a candidate for a Goldilocks or SWIM mastectomy? How many of these procedures have you done? How would my chest look after?
- [ ] Am I a candidate for nipple-sparing mastectomy? How many times have you performed this procedure? Will my nipples lose sensation if I keep them? Is there a higher risk for breast cancer in the remaining tissue?
- [ ] Will I need a plastic surgeon if I do not have reconstruction? If so, how will the plastic surgeon complete the surgery?
- [ ] Can my nipples be recreated? If so, when, how and by whom?
- [ ] Can I have 2D or 3D nipple tattooing with or without nipple reconstruction? If so, when, howand by whom?
- [ ] What is my risk for breast cancer after surgery? What should I look for? How will you monitor me?
- [ ] If I don?t have immediate reconstruction, can I have reconstruction in the future?
- [ ] May I see patient before and after photos?

Notes:

Questions to help you choose the type of reconstruction

- [ ] Which reconstruction procedures are you most experienced with? How many times have you performed each of these procedures?
- [ ] What procedure would be best for me? Why? What are the risks? May I see before-and-after photos of your patients who have had these procedures?
- [ ] How would my breasts look after reconstruction? Is it possible to be a [__] cup size?
- [ ] What other reconstruction options should I consider?
- [ ] How many and what kind of follow-up/revision procedures should I expect? Can you describe the procedure(s) and recovery?
- [ ] What is the overall reconstructive timeline from initial surgery to complete recovery?
- [ ] Will chemotherapy or radiation therapy delay or affect my reconstruction?
- [ ] Do I have any health issues?obesity, diabetes, heart disease, etc.? that might delay or impact my reconstruction?
- [ ] If I don?t have immediate reconstruction, can I have reconstruction in the future?
- [ ] How much sensation will I have or regain in my reconstructed breasts? How will they feel to touch? Can you reconnect or repair nerves to improve sensation? To what degree will that improve my sensation? How frequently do you perform this procedure? Will insurance cover the cost?
- [ ] If I don?t have a nipple-sparing mastectomy, how would you reconstruct my nipple(s)? Will my reconstructed nipples have sensation? What are the pros and cons of reconstructing my nipples vs having only tattoos? Who will tattoo my nipples and areolas? May I see photos of 2D and 3D tattoos? How long can I expect the tattoos to last?
- [ ] What cosmetic or other problems might occur? How will you address them?
- [ ] If I am traveling to you for the reconstruction, how will I handle any post-op problems that occur?
- [ ] Will I need a blood transfusion? Should I donate blood before surgery?
- [ ] How will my reconstructed breast change over time?
- [ ] Which breast surgeons do you work with regularly and recommend for my mastectomy?
- [ ] Do you recommend physical therapy before surgery (pre-hab) and/or after surgery (re-hab)? Will you write a prescription for it? Will insurance cover it?
- [ ] What are the differences in short-term and long-term risks and quality-of-life between implants and flap reconstruction?

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Questions about breast implants:

- [ ] Do you recommend saline or silicone implants? Why? Which types do you use? May I see samples?
- [ ] What future MRI or ultrasound screenings are recommended if I have implants?
- [ ] Will I need tissue expanders or am I a candidate for direct-to-implant? How many of these procedures have you performed?
- [ ] Will I have round or teardrop implants? Why? What profile (projection) is best for me? Why?
- [ ] What type of implants do you use?
- [ ] What is the difference in recovery time, discomfort level, outcomes and risks for complications between implants placed above or below the muscle(s)? Do I have a choice in which method is used? Which method do you prefer?
- [ ] How many surgeries will be required?
- [ ] How long can I expect the implants to last? When will they need to be replaced? How will aging and future weight fluctuations affect my reconstructed breast(s)?
- [ ] What problems, including rupture or leaks, might occur? What signs should I look for? How often and how should my implants be screened for rupture?
- [ ] Are short-term and long-term infections after surgery a concern?
- [ ] Who will provide the warranty information for my implants?
- [ ] When will we discuss and sign the FDA required ?Patient Decision Checklist?? Please provide a copy of the signed checklist for my records.
- [ ] What are the signs of and risk for breast implant-related long-term complications, such as breast implant-associated anaplastic large cell lymphoma (BIA-ALCL)?
- [ ] Will I have any long-term restrictions on the types of activities I can do?
- [ ] Do you use an acellular dermal matrix with your reconstruction?
- [ ] May I see before-and-after photos of your patients who have had this procedure?

Notes:

Questions about flap reconstruction:

- [ ] Which flap reconstruction is best for me? How many have you performed?
- [ ] Will you remove part or all of any muscle? Am I a candidate for a muscle-sparing procedure?
- [ ] How will my donor site look afterward? Will I have visible scarring there? Will I lose sensation there?
- [ ] Will I need postoperative physical or occupational therapy to regain strength, flexibility and range of motion at the donor site?
- [ ] How many surgeries will be required?
- [ ] How will aging and future weight fluctuations affect my reconstructed breast(s)?
- [ ] Do I need to make any lifestyle changes to prepare for flap reconstruction?
- [ ] How do risks and long-term quality differ between implants and flap reconstruction?
- [ ] Will I have any long-term restrictions on the types of activities I can do?
- [ ] May I see before-and-after photos of your patients who have had this procedure?

Notes:

Questions to help you choose between reconstruction or going flat

- [ ] Am I a candidate for immediate reconstruction?
- [ ] How do recovery times differ for mastectomy with or without reconstruction?
- [ ] Would the length of my hospital stay differ if I chose mastectomy with reconstruction vs. going flat?
- [ ] Am I a candidate for flap reconstruction? Am I a candidate for implant reconstruction? Do you have a preference? If so, why?
- [ ] If I choose reconstruction, will I have any long-term restrictions that affect the types of activities I can do?
- [ ] What type of short-term and long-term follow-up care or imaging would I need after mastectomy with no reconstruction? What would I need after mastectomy with reconstruction?
- [ ] Are there differences in the types of complications and/or complication rates between going flat vs. reconstruction?
- [ ] If I don?t have immediate reconstruction, can I have reconstruction in the future?
- [ ] May I see before and after photos of each option?
- [ ] How big will my incisions be and what will they look like?

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Questions for your breast surgeon before mastectomy

- [ ] How can I get a copy of my pathology report?
- [ ] What is my risk for breast cancer after surgery? What should I look for? How will you monitor me?
- [ ] Will I be at risk for lymphedema (arm swelling) after surgery? Will I be educated on symptoms, treatment and long-term precautions?
- [ ] Do you recommend physical therapy before surgery (pre-hab) and/or after surgery (re-hab)? Will you write a prescription for it? Will insurance cover it?
- [ ] Will you be able to preserve the nerves that provide sensation? How much sensation am I likely to have and where? How will it differ from the sensation I have in my breasts now?
- [ ] Will I need a special mastectomy bra after surgery? If so, will you provide it? Does my health insurance cover the cost?
- [ ] Am I a candidate for sentinel lymph node biopsy?
- [ ] Am I a candidate for nipple-sparing mastectomy? How many times have you performed this procedure? Will my nipples lose sensation or flatten if I keep them? Is there a higher risk for breast cancer in the remaining tissue?
- [ ] If my nipples are removed, can they be recreated? If so, when, how and by whom?
- [ ] Can I have 2D or 3D nipple tattooing with or without nipple reconstruction? If so, when, how and by whom?
- [ ] How long after surgery can I drive? How long until I can reach above my head? How long before I can lift items over five pounds? How long before I can lift heavier items?
- [ ] Which of my medications should I take or avoid before the surgery? Are there any supplements I should take or avoid?
- [ ] What are the surgical risks? What are the anesthetic risks?
- [ ] What is post-mastectomy pain syndrome? How high is the risk for this complication? What can be done if I develop it?

Questions about insurance coverage

- [ ] Will my insurance cover the cost for mastectomy? Will my insurance cover the cost for reconstruction? What are my estimated out-of-pocket costs?
- [ ] What resources can help cover my out-of-pocket surgery costs?
- [ ] Will my insurance plans cover the cost of at-home care after surgery, including for nurses and physical therapists?

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