Breast Cancer Self Directed After Care Protocol and Survivorship Pathway

The thrust behind this pathway redesign is to improve the effectiveness and quality of service delivery for those living with and beyond breast cancer. The current traditional approach to managing patients is based on a medical (illness) model where patients can be followed up for years on completion of treatment. This is unsustainable for two reasons:

- Incidence and prevalence of cancer continues to increase thereby putting pressure on available resources
- The current arrangements are not meeting all the needs of those living with and beyond cancer

This redesigned pathway aims to support patients to get back to living their lives following treatment for breast cancer with remote monitoring replacing routine follow up for identified patients.

Patient Suitability

Self Directed Aftercare (SDA) will be offered to patients who are treated with curative intent. The key consideration for patient inclusion is their ability to self-manage. The aim is to achieve a minimum target of 30% breast cancer patients suitable for self management. Patients undergoing breast reconstruction will be managed outside this pathway by the surgical team until deemed suitable to enter the SDA pathway.

Patient Identification and data capture

- At MDT meeting an initial discussion between the Surgeon, Oncologist and Breast Care Nurse (BCN) should identify potentially suitable patients and the MDM tracker should record this decision within the MDM report.
- BCN or AHP will agree suitability 6-12 weeks post completion of treatment from holistic perspective and where possible record within CaPPs.
- “Thinking Ahead” patient information leaflet should be offered by the BCN/ AHP/ Nurse/ Doctor around the time of MDT / post surgery results appointment

Surgical Appointment (approx day 10 post surgery)

An appointment with the Surgeon and BCN approximately 10 days post surgery will facilitate

- Discussion with the patient regarding SDA suitability
- Provision of “Thinking Ahead” leaflet
- Initiation of mammography request
- Allocation of Patient Administration System (PAS) SDA “discharge code” for surgical episode if patient is suitable and no further surgical appointments required
- Provision of appointment date with BCN
- A copy of the GP appointment letter to be sent to the treating Oncologist.
Remote Surveillance / Review Mammography

- The mammography request detailing the number, month and year for mammograms required should be completed by the Surgeon (or BCN when indicated through local agreement) at the post surgery pathology results clinic. A copy of the GP discharge letter should be sent to the treating oncologist.

- Females will receive annual surveillance mammography for 5 years. After 5 years of scheduled follow-up women over the age of 50 will be discharged to the NHS Breast Screening Programme (NHSBSP). Women under the age of 45 will continue on annual mammographic surveillance until they reach the age of 50, thereafter, they will be discharged to the NHSBSP. Please note: men do not receive mammograms.

- The results of the mammogram should be sent to the patient, GP and copied to the surgeon. If the result is abnormal - the patient must be referred back to the Breast MDM or breast assessment unit.

- Any change to the suitability for SDA following completion of treatment should be communicated to the mammography team by the treating clinician.

- Each Trust’s mammography team should have an agreed mechanism with their MDM to verify all SDA patients have been captured.

- A standard operative procedure for rebooking patients mammograms should be available in each Trust

Holistic Assessment of Patient (6 – 12 weeks post surgery +/- completion of treatment)

- BCN or appropriately trained healthcare professional will assist the patient in completing an assessment of their needs and concerns using an appropriate assessment tool EG: the SPARC tool or a Concerns Checklist and agree suitability for SDA pathway. This should be communicated with the treating Oncologist
  - The patient or carer is encouraged to complete the form and the assessor uses this as a guide to explore their needs and collaboratively develop an appropriate action plan

- Check receipt of the minimum ongoing information required for self directed aftercare.
  - Caring for Yourself Post Breast Cancer Treatment
  - Moving Forward Pack (supplied by Breast Cancer Care)
  - Information on late effects (included within Moving Forward Pack)
  - Rapid access telephone number
  - Signposting - NICaN booklet (Cancer Services for patient, carers, families and friends), and website details – www.survivorship.cancerni.net
  - Information about how to perform breast self examination

- This does not preclude ongoing assessment from any other health and social care professionals across the pathway or a more in-depth holistic assessment at any stage if required

- Signposting and information re survivorship services should be ongoing throughout patients treatment with particular attention paid when patient is approaching the end of treatment
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- If the patient does not attend on 2 occasions – suitability for SDA pathway to be rediscussed with the clinical team

**During the last week of radiotherapy or chemotherapy**

This is a key milestone within the patient pathway in terms of preparing patients for self directed aftercare. The identified therapy radiographer or radiotherapy / chemotherapy nurse will provide an appointment/ opportunity with the patient to begin the process in formulating an aftercare plan if not already completed by BCN. Attention should be paid to raising awareness of health and wellbeing services, referring to a cancer health and well-being event and signposting to relevant services within the community / voluntary / statutory sector.

Check receipt of the minimum ongoing information required for self directed aftercare.

1. Caring for Yourself Post Breast Cancer Treatment
2. Moving Forward Pack (supplied by Breast Cancer Care)
3. Information on late effects (included within Moving Forward Pack)
4. Rapid access telephone number
5. Signposting - NICaN booklet (Cancer Services for patient, carers, families and friends), and website details – [www.survivorship.cancerni.net](http://www.survivorship.cancerni.net)
6. Information about how to perform breast self examination

**Post Treatment Appointments**

1. A consultation with *BCN or therapy staff (radiotherapy /chemotherapy staff)* 6-12 weeks post completion of treatment will facilitate
   - Update of HNA - The CNS / Nurse / AHP will enable the patient to complete an assessment of their needs. Based on this information they will discuss / update their appropriate aftercare plan.
   - Depending on the identified needs of the individual, the BCN / CNS / AHP will ensure the patient has the appropriate information to enable them to self manage, which will include referral to relevant support services eg Cancer Health & Well Being Event or self management programme etc.
   - The healthcare professional (BCN / Radiographer / chemo staff) will ensure the information listed below has all been received.
     a) Caring for Yourself Post Breast Cancer Treatment
     b) Moving Forward Pack (supplied by Breast Cancer Care)
     c) Information on late effects (included within Moving Forward Pack)
     d) Rapid access telephone number
     e) Signposting (NICaN booklet (Cancer Services for patient, carers, families and friends), and website details – [www.survivorship.cancerni.net](http://www.survivorship.cancerni.net)
     f) Information about how to perform breast self examination
     g) Refinement of action plan / aftercare plan and communication of this with the treating clinician

2. Cancer Health and Well-being Event should be offered to all patients on completion of treatment. Its aim is to help patients manage the transition between treatment and
survivorship. It should provide education on signs and symptoms of recurrence and raise awareness of services that can help them with physical, emotional, social and financial needs.

Oncology Review

Medical review approximately **3 - 6 months** post radiotherapy +/- chemotherapy will facilitate

- Confirmation of suitability to remain an SDA pathway
- Issue of Treatment Summary Record (see below for further detail)
- Re-enforcement of rapid access mechanism
- Endorsement of cancer rehabilitation plan and aftercare services
- Allocation of PAS code “discharge code” (if no further appointment required) or “outcome code” if year 2/3 appointment required

Treatment Summary Record / Structured letter template

- The treatment summary / structures letter template will provide patients and GPs with a succinct record of treatment to date, aftercare arrangements and re-access contact numbers

- This is completed at the end of the patient’s final treatment. If surgery only - completed by the Surgeon, if radiotherapy or chemotherapy is the final treatment it will be completed by the Oncologist. Options for completion include a hard copy or electronic record (via CaPPs) and should replace the current dictated discharge letter. A copy will be given to the patient and a copy sent to the GP and other relevant professional where appropriate.

Rapid Access

Each Trust will have a clear pathway for rapid access to the Breast Care Nursing Team (see rapid access telephone guidance). The patient should be given these contact details and know who to contact and when. Calls will be triaged within two working days and referred accordingly as indicated:

1. Face-to-face consultant appointment within two weeks
2. Face-to-face nurse-led clinic (where appropriate)
3. Advise to contact GP
4. Advise to attend emergency department if appropriate
5. Telephone consultation
6. Signposting support to other agencies E.G. Citizens Advice Bureau (CAB)/ AHP/Counselling

This process only applies at the end of treatment. (Chemotherapy telephone helpline guidance is still relevant to patients receiving chemotherapy).

Hormones and Bone Health

An optional Year 2/3 appointment with a member of the breast care team will facilitate the hormone switch and decision regarding requirement for dexa-scanning where local arrangements for dexa-scanning are not in place. This appointment may be carried out by a suitably trained professional and may be an actual or virtual appointment (clinician dependent). Allocation of PAS
code “discharge code” (if no further appointment required) or “outcome code” if year 5 appointment required).

A further optional Year 5 appointment will facilitate the final sign off for a patient as well as adjustments/extension to hormone therapy and requirement for further dxa-scanning if necessary. As with Year 2/3 appointment it may be carried out by a suitably trained professional and may be an actual or virtual appointment (clinician dependent). A PAS SDA “discharge code” will be allocated to the appropriate episode oncology episode.

**Switching pathways**

If a patient re-enters the system with disease recurrence or associated problem and requires a pathway switch e.g. complex, joint care – if the mammograms are no longer required it is the responsibility of the accepting clinician to inform the mammography team.