

Creating a structured support pathway for SBC patients

Claire Gaskell and Bethan Daniel

Macmillan Secondary Breast Cancer CNS's

Christie Hospital

BCC Standards of Care

Standards of care for secondary breast cancer patients

Breast Cancer Care's vision is that everyone with a diagnosis of breast cancer receives the best treatment, information and support.

As a person with secondary breast cancer you should:

1. have access to a clinical nurse specialist, at and from the point of your secondary breast cancer diagnosis onwards. They will be knowledgeable about the disease, treatment and support needs of people with secondary breast cancer. This person will act as your 'key worker': co-ordinating your care, acting as your advocate and providing/signposting you to support and information
2. receive a multidisciplinary team approach to your care. All healthcare professionals who contribute to the medical and nursing management of your care should meet regularly to discuss your case, so that you receive the best care for you. Your team should include members of the oncology and palliative care teams
3. experience continuity of care between the hospital and community services. Communication between the hospital-based team and your GP (local doctor) should be as efficient as possible using different methods of communication to ensure your GP is kept informed of your treatment and care. Your GP should be informed and kept up to date about your condition and be able to provide support and care when appropriate
4. be given timely information including a care plan, on all aspects of your treatment and care both verbally and in writing and be clear on the purpose of your treatment, the side effects and potential impact on wellbeing. Your information needs should be assessed on a regular basis and support should be provided alongside all information given
5. have your emotional wellbeing assessed on a regular basis and have access to the appropriate level of psychological support. This should be when you need it, but particularly at diagnosis, when the cancer progresses and at the end of each treatment
6. have access to information on support services both nationally and locally. This should include the opportunity to meet/talk to others with secondary breast cancer. This could be online, on the telephone or face to face
7. have access to expertise in palliative care, symptom control and ongoing management of troublesome symptoms. You should also be provided with information about end of life care when appropriate
8. have access to support and guidance on talking to partners, family, friends and children, about the experience of living with secondary breast cancer and the impact it has on others. Your partner's and family's support and information needs should be assessed separately to your own by a healthcare professional involved in your care. They should be offered/signposted to information/support services specifically for them
9. have access to expert financial and employment advice. This should include information about your eligibility for relevant benefits and your rights at work under disability discrimination legislation
10. have access to appropriate treatments and be made aware of the availability of clinical trials for which you may be eligible before treatment is started or changed.

Changing focus

- Metastatic service
- No recognised, established support pathways for SBC patients
- Macmillan recovery package – for primary patients, but possible to adapt elements of it?
- Importance of time and support from management for service development



BCC Standard 3 – Continuity of care between hospital and community services – requires effective communication between hospital team and GP

BCC Standard 1
Access to CNS at &
from point of diagnosis
onwards

BCC Standard 2
MDT approach

Via regular
HNA

BCC 4
Given
timely
info on
tx &
care

BCC 5
Regular
assessment of
emotional
wellbeing

BCC 6
Access to
support
services
nationally &
locally

BCC 8
Access to
support/
talking to
partners,
family,
friends &
children

BCC 9
Access to
financial &
employment
advice

BCC 7
Access to
palliative care
& symptom
management

BCC 10
Access to
clinical
trials

Joint
working

Multidisciplinary Team Meeting

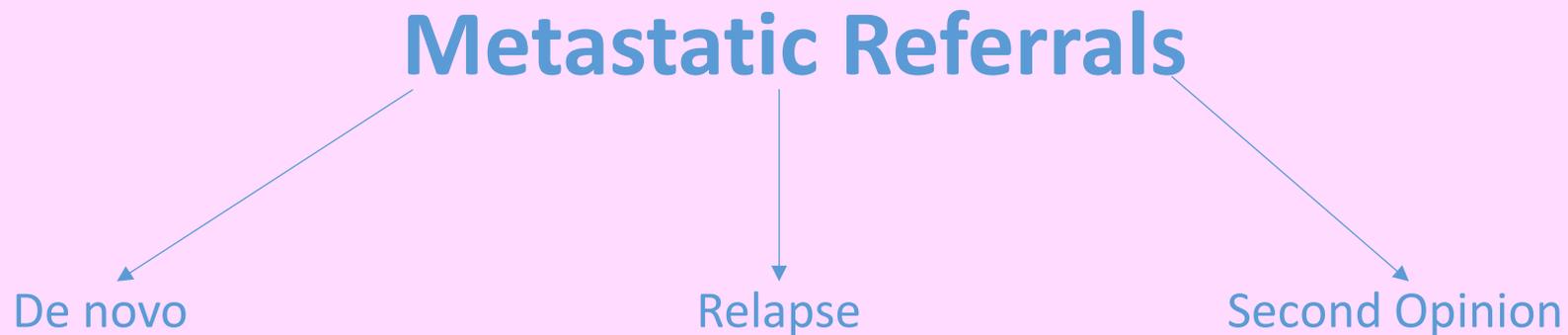
- MDTs are often very busy, discussing large volumes of patients.
- Benign cases
- Surgically/adjuvantly orientated

- Often limited time to discuss patients with metastatic disease unless de novo disease

- Because of this at The Christie a metastatic MDT now exists.

Medical oncology Metastatic MDT

- Weekly meeting
 - Consultant, SPR, Nurse Clinician, BCN, Palliative Care CNS, Breast Research nurses, early phase trials team, Pharmacist (number of HCP representative of a tertiary centre)
- All new referrals are initially discussed



- Enables BCN to identify how many patients and when such patients are coming to clinic that week.
- For patients with very advanced/widespread disease it may be most appropriate to refer straight onto palliative care or adopt joint working approach. MDT helps to plan approach.
- New patients identified
 - BCN introduced in clinic
 - Initial concerns addressed, details provided
 - Appointment letter sent out to patient

Discussion of new patients from previous weeks clinic

- Discuss the treatment plan
- Discuss any issues from the consultation
- Flags any patients BCN may have missed – multiple clinics and sometimes patients are added to clinic last minute without having gone through MDT



This does help but we still can't guarantee all pts discussed (problem we are working towards).



We are also still discussing how best to manage second opinions

Identifying disease progression

- CNS (Breast palliative care lead CNS) looks out for all scans reported in the last week.
- BCN meets with palliative care CNS ahead of the MDT to discuss the patients who have progressed to identify who is to review and support the patient.
- CNS presents those patients with disease progression to the team.
- Preliminary treatment plan is discussed and documented ahead of the patient attending clinic

Advantages

- Helps make clinic more efficient – particularly when such patients are being reviewed by the spr/nurse clinician (aware of the consultants plan)
- Certain referrals can be put in place in advance of clinic e.g. Radiology review.
- Ensure patients have clinic appointment for scan results (not just treatment appointment)
- Sometimes appropriate to defer appointment to collate more information
- Helps to ensure CNS present for breaking bad news/aware to tel pt to offer support post consultation
- Helps BCN plan workload ahead of clinic.

Joint working

Palliative Care/Supportive Care

- Prompt and timely access palliative care
- Palliative care CNS & BCN both present at MDT – promote a closer working relationship
- True understanding of each other's roles – differences and where joint working beneficial
- Regular communication throughout the week – face to face, email, telephone
- Learning from each other – palliative care services in the community
 - ACP
 - Symptom control
 - Caring for patients in the last 12 months of life

- Intense looking after patients with complex physical/emotional symptoms



Good to share each others expertise and share workload



Challenging looking after patients with very advanced disease, joint approach can help

Joint working (2)

❖ Clinical Trials

- Important that patients have an awareness of clinical trials & have the opportunity to access appropriate trials.
- BCN works alongside research nurses and members of the Phase 1 trials team. Both have a presence at weekly MDT
- Phase 1 trials team have also promoted their accessibility more recently
- When patients progress clinical trials should be considered alongside standard treatment options.
- BCN pledge to see at each stage of disease progression & then importantly when patients come off trial. (Important that each patient has met BCN at point of diagnosis to help maintain relationship during treatment pathway)
- When standard treatment options limited – can be important to discuss possible referral to phase 1 team for preliminary discussion.

- Recent meeting with Research nurses to discuss closer working to improve the quality and efficiency of the care we provide.



Highlighted that the majority of research nurses did not feel confident in assessing patients psychological concerns and did not feel confident to refer on for psychological support/community support.



Highlighted many of the assumptions we make and the differences in our roles. Close, joint working approach essential.

Peer support

- Joint working is a key form of peer support
- BCN service has also introduced a more formalised peer support session
- First Wednesday of each month
- Share cases to support our practice & support emotional well being.

Christie vision for structured pathway

- New diagnosis nurse led clinic
 - HNA
 - Stratified follow up
 - Health and Wellbeing days
 - Data Collection

New diagnosis clinic

- Introduced at diagnosis. Initially concentrate on immediate distress/need
- 4-6 weeks post diagnosis, 45 min appt with HNA
- With or without carer/relative
- Appropriate resources given including BCC Resource pack
- Appropriate referrals completed

HNA

- Decision not to use Macmillan HNA
- Measurable tool needed
- HADS and Christie concerns checklist (scored)
- Allows for severity of concern to be measured
- Trackable over time
- Suitable for communicating to consultant/GP

Stratified follow up

- Volume of patients can be a problem over time
- Are some patients more suitable to self manage than others?
- Promote single point of access/contact
- First year important in building trust/confidence – all patient receive telephone follow up initially
- Allows for team working
- Agree each individual's stratified follow up with team

Health and Wellbeing days

- Offered as part of pathway in the first year
- Not in first 6 months
- Invited to attend with partner/relative
- Idea is to educate and increase confidence in self management and living well
- SBC patient focus group attend to mentor and recruit
- Well evaluated but time intensive administratively
- Speakers/workshops/marketplace at lunchtime

H+W schedule

“Living with” Secondary Breast Cancer (SBC) programme

13th October 2016 09:30-15:30

09:30-10:00 **Meet and greet, tea and coffee**

10am-10:05 **Welcome**

10:05-10:15 **What is SBC? A patient’s perspective**

10:15-10:40 **Red flag symptoms, what do I need to know?**

10:40-11:20 **Current treatment and developments in research**

11.20-11.40 **Diet and SBC**

11.40-12.00 **Open microphone question session**

12.00-1.00 **Lunch with information stalls in foyer**

Complementary Therapies available, slots booked at reception

1.00-1.30 **Supportive Care & questions**

1.35-2.20 **Break out session 1**

2.20-2.30 **Tea/coffee**

2.30-3.15 **Break out session 2**

3.15-3.30 **Guided mindfulness/relaxation exercise**

Summing up and close

Breakout sessions 45 mins each. Choose 2 prior to event, each breakout session will be delivered twice.

- Living with uncertainty
- Relationships and communication
- Fatigue Management
- Keeping Active with Secondary Breast Cancer
- Support for carers

Data Collection

- Numbers of referrals
- Numbers on individual caseloads
- Information on complexity
- Informs stratification model and service development
- Measured assessment tools – making a difference
- Educating senior managers re data collection for SBC
- Ensuring accuracy – how do we know what is 100%?
- Contributing to the national conversation around data

BCC Standard 3 – Continuity of care between hospital and community services – requires effective communication between hospital team and GP

BCC Standard 1
Access to CNS at &
from point of diagnosis
onwards

BCC Standard 2
MDT approach

Via regular
HNA

BCC 4
Given
timely
info on
tx &
care

BCC 5
Regular
assessment of
emotional
wellbeing

BCC 6
Access to
support
services
nationally &
locally

BCC 8
Access to
support/
talking to
partners,
family,
friends &
children

BCC 9
Access to
financial &
employment
advice

BCC 7
Access to
palliative care
& symptom
management

BCC 10
Access to
clinical
trials

Joint
working

Communication

- So hard to do well! Time consuming.
- Needs to be 2 way
- What information is important to share?
- Certain time points to focus on?
- Do letters get read? Are phone calls better?
- Capacity issues within different teams

In other words, work in progress, ideas appreciated!

And finally....

- Be careful what you wish for!
 - 504 new referrals in the first year
 - Data = need for business plan and even more time for service development
 - Adding value without adding cost
 - Coping with quantity without cutting quality
 - Educating senior management and commissioners