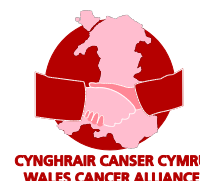


Metastatic Cancer

A Wales Cancer Alliance Policy Paper
Summer 2017



NB: Because of the amount of crossover, it is recommended that this paper is read in conjunction with our policy papers on Palliative and End of Life Care; Meeting Peoples' Needs and Personalised Cancer Treatments and Cancer Research.

Metastatic cancer: overview

Patient feedback suggests that the excellent care they received at primary diagnosis is not replicated following a diagnosis of metastatic cancer. This is compounded by the lack of data available on metastatic cancer. We do not know the number of people who have been diagnosed with the disease or know how it progressively affects their quality of life. This means that the NHS is not able to effectively plan and deliver services that can meet patients' needs.

Background

Metastatic cancer is also known as secondary, advanced or stage 4 cancer. It occurs when cancer cells spread from the original primary tumour to another part of the body. For most tumour sites a metastatic diagnosis means that the cancer cannot be cured; however it can sometimes be controlled and in the case of metastatic breast cancer, some patients can live for many years with ongoing, sequential treatments. The median survival time of a metastatic breast cancer diagnosis is two to three years, although it is recognised¹ that the range is very wide, with some patients having more indolent disease with which they live for many years (sometimes 10-15 years).

Whilst this paper relates to all metastatic cancers there is often confusion regarding what is meant by secondary breast cancer and how this differs from a recurrence of breast cancer. Recurrence of primary breast cancer and secondary breast cancer are often grouped together under the same heading, such as they currently are in the Cancer Outcomes and Services Dataset (COSD) V7.02, despite having clear and distinct differences. These distinctions are important as the needs of patients with local or regional occurrences and secondary breast cancer are quite different.

Cancer Delivery Plan for Wales³

The Cancer Delivery Plan acknowledges that the patient experience among metastatic patients is not as well understood as for other patients and will be considered further to ensure care is equitable⁴. In order to achieve this the Plan places a duty on Local Health Boards to "*Ensure patients with metastatic disease receive care and support appropriate to their needs, through improved collection of information on the care provided and a focus for peer review delivered by the Wales Cancer Network.*"⁵

Calls for action

The Wales Cancer Alliance calls for:

1) Information sharing

People need information when finishing their hospital-based treatment for primary cancer. More needs to be done to ensure that people are aware of the possible signs and symptoms of

¹ Johnston, S. & Swanton, C. (2011) *Handbook of Metastatic Breast Cancer* (second edition), Oxfordshire: Informa Healthcare.

² COSD V8.0 due in April 2018 should include a breakdown of recurrences by region such that primary and metastatic cancers are no longer grouped.

³ Welsh Government (2016) [Cancer Delivery Plan for Wales 2016 – 2020: The highest standard of care for everyone with cancer.](#)

Wales: Welsh Government.

⁴ Ibid p14.

⁵ Ibid p12.

secondary cancer and how to get back into hospital care if they have a symptom or concern. When diagnosed with metastatic cancer, every patient should be made aware of, or referred to, local and national support services.

2) Defined pathways for patients presenting with possible metastatic symptoms

It is important that defined pathways for patients presenting with symptoms that could be either primary or metastatic cancers are in place. In order to avoid delays, it is important that primary cancer patients are given clear information at the end of their treatment, including which possible future signs or symptoms may require further investigation and where to go with any suspicious symptoms. It is important that GPs also have up-to-date training and knowledge of possible symptoms of metastatic disease and that there is clear referral routes for specialist testing. The use of a treatment summary is recommended which includes the opportunity for the specialist team to communicate symptoms that require referral back to them. This should be through direct entry back into the hospital/cancer care team without the need for a GP referral.

3) Data collection for all patients with a metastatic cancer diagnosis

Despite previous pledges in the Cancer Delivery Plan 2012 – 2016, data collection of metastatic cancer patients has not been achieved. Metastatic patients are only recognised in national health datasets in Wales when they have their original primary diagnosis and when they die, not for the time they are living with metastatic disease. Local Health Boards were also mandated by the Cancer Delivery Plan to: *“Plan and deliver co-ordinated services for metastatic cancer patients and measure outcomes”*, yet without accurate incidence data it is impossible to effectively plan services for those living with metastatic cancer. This too is yet to be achieved. This lack of data coupled with poor understanding of the experiences of secondary cancer patients, makes it enormously difficult for healthcare providers to plan for and implement the services that will meet the needs of those with metastatic cancer. The lack of intelligence and understanding also means that we do not have a full picture of the long-term effectiveness of treatments for primary cancer. The fact that no national data is collected for this group in Wales also reflects to this patient group that they are unvalued.

We would welcome the highest standard of care for everyone with cancer in the Cancer Delivery Plan for Wales 2016-2020, where we recommend *“there is a need to ensure patients with metastatic cancer are quickly identified, have data collected and have full access to services and support to meet their specialist needs”*.

The Wales Cancer Alliance is calling for the NHS Wales Informatics Service, the Cancer Implementation Group, the Cancer Network and Local Health Boards to work together to ensure that data should be specifically coded for metastatic patients and must not be ‘grouped’ with recurrence. This should be implemented through the introduction of the single cancer dataset.

4) Access to a clinical nurse specialist at and from the point of metastatic cancer diagnosis

The WCA paper on Meeting People’s Needs covers the importance of access to key workers and Clinical Nurse Specialists for cancer patients generally.

However, for metastatic patients specifically, it should be recognised that these roles take on a particular significance and the provision of specialist nursing for those with metastatic breast cancer has been found to be inadequate.

Accordingly, access to a CNS should be at and from the point of metastatic cancer diagnosis onwards. They should be knowledgeable about the disease in the metastatic form, and about treatment and support needs for people with metastatic cancer. The CNS also has a vital role to play coordinating care, acting as a patient advocate, providing/signposting to ongoing support and information, including local and national support services specifically for metastatic patients and acting as the liaison point between palliative and oncological care. It is essential that emotional wellbeing is regularly assessed through a holistic needs assessment (HNA) particularly at diagnosis and as treatment changes, in what can be a complex long-term illness trajectory encompassing many psychological highs and lows. The CNS will monitor that their patient is receiving appropriate care and services but the actual coordination of this care could potentially be delegated to a support worker to release the CNS to focus on aspects of specialist nursing, appropriate to their skills and care only they can deliver.

5) A multidisciplinary team approach to care

It is important that those living with metastatic disease benefit from a multidisciplinary approach to care. It is recommended the introduction of a dedicated multidisciplinary team for secondary cancer, or at the very least, a specific section in an existing multidisciplinary team meeting for secondary cancer patients to be routinely discussed. We would suggest that a wider team, including representatives from community-based services, be present in these meetings to ensure a holistic discussion of treatment. This team should meet regularly to discuss metastatic cases and ongoing treatments, in order to ensure that each patient receives the optimal care, symptoms and treatment side-effects should be adequately controlled and supportive care (including emotional support) should be offered. This team should include members of the oncology and palliative care teams.

6) Continuity of care between the hospital and community services

Again, much of the paper on Meeting People's Needs applies particularly strongly to patients with metastatic cancers. A diagnosis of metastatic cancer can have a significant impact on someone's employment and capacity for work. In turn, this can substantially affect them financially; potentially causing a great deal of anxiety at a time when an individual will already be experiencing anxiety and stress relating to their diagnosis. Subsequently, the HNA should also include support for accessing financial support and should provide the patient with information about how to access care and support services both within the hospital and the wider community. Patients should be given or signposted to information about their rights, sources of specialist support and advice regarding their employment status.

There is a wish to make integrated care a reality and feedback from patients suggests that by providing patients with access to a named Key Worker who has the time to respond, throughout the care pathway will contribute to meeting their needs.

7) Access to information on support services both nationally and locally which should include the opportunity to meet/talk to others with metastatic cancer

Professional advice is essential, but the opportunity to meet with others who have a personal understanding of life and its pressures following their own metastatic diagnosis offers peer support and mutual empathy. An example of such an opportunity would be the Breast Cancer Care 'Living with Secondary Breast Cancer' programme. Patient feedback suggests that mixing primary and metastatic patients in such groups or on a one to one basis is not helpful, and does not meet the needs of either patient group.

8) Access to appropriate treatments and awareness of the availability of clinical trials before

treatment is started or changed

Clinical trials are a vital way of developing our understanding of the clinical efficacy of new treatments. However, patients highlighted limited knowledge of accessibility to and eligibility for clinical trials and access to clinical trials is variable. Research is required to identify the barriers and to identify:

- Where the care of patients with metastatic cancer is discussed in relation to the multidisciplinary team setting. Research should establish in what forum the care of metastatic cancer patients is discussed, whether this is in multidisciplinary team meetings or other settings. The research should investigate the benefits of different practice on outcomes of care and patient experience.
- The level of need and type of support services required by people with metastatic cancer.
- What information/assistance on 'living well' is required by people living with metastatic cancer and how it can be provided.
- Develop and evaluate different models of specialist care for metastatic cancer patients, in particular the role of a CNS with skills and knowledge in managing metastatic cancer patients.
- The support needs of people living with metastatic cancer and pilot intervention studies best suited to meet these needs.
- The impact on and emotional support needs of families, partners and carers affected by metastatic cancer.
- The support needs of parents with metastatic cancer in particular around talking to their children about their disease, and also the support needs of lone parents.
- National patient experience surveys must continue to ensure they collect the views of those with metastatic cancer.
- What mechanisms could be provided to ensure primary care clinicians, and particularly GPs, have a better awareness of the signs and symptoms of metastatic cancer.
- Understand the treatment journey of a patient with metastatic cancer. This includes the treatment options and sequencing of therapy. Research is needed to guide the decision-making process and in particular to address quality of life issues.