

# National Cancer Survivorship Initiative.

Active and Advanced Disease.

## Getting Back into the System

**This report** examines the need for mechanisms for patients to return to rapidly back into the system (secondary care), if they have a suspected recurrence, metastases or experience late consequences of treatment.

Identifies and focuses on the needs of breast or colorectal cancer patients.

Identifies the constraints on the system, including the current tariff system, and the complexities of the disease itself and peoples individual care needs.

It is acknowledged that this work cannot be considered in isolation. Needs rapid re-entry pathways reviewed with the proposed changes to follow up and aftercare services and assessment and care planning. Consideration will also be needed with regard to the new innovative models for information/health and well-being clinics and self management.

**Key Findings**, the focus group identified that little patient information is available both generic and tumour specific on signs and symptoms of recurrence or metastatic disease. For instance some patients are not aware that having had a primary diagnosis that a recurrence, can develop at some point.

There is additionally a gap in the availability of generic information to tumour specific information on signs and symptoms. Patients have identified a need for having simple generic information on the differences between a primary tumour, a recurrence and metastases. Information giving by GPs on signs and symptoms for suspected recurrence/metastases is limited.

Metastatic cancer is not generally discussed at MDT as these are for diagnosis and primary treatment and 50% of breast care nurses do not feel they have the time or skills to dedicate to patients with metastatic disease.

**Recommendations.** To review referral pathways and develop Peer Review Measures to return patients to the system rapidly.

Networks to set up a mechanism for capturing incidence data on recurrence/metastases per tumour site from their provider organisations.

All networks to develop policies for referral pathways back into the system for suspected recurrence/metastases.

Tumour specific top 10 tips for GPs on signs and symptoms to look for suspected recurrence/metastasis.

The development of e-learning modules for GPs and other clinicians for recognition of recurrence/metastases.

The development of national patient information relevant to recurrence, metastases and late consequences of treatment.

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## **Living Well**

**This report**, examines the Living Well approach to developing a service which can help people with active and advanced cancer to improve their health, wellbeing and quality-of-life. Complementing current cancer services offered by the NHS. A model of strategic partnership between health care providers, local authorities/social services, and the voluntary sector can be seen as a strong model of developing Living Well Services which are coherent and sustainable.

The report identifies that Living Well services need to develop an individualised care approach, enable decision making and supported self management.

As incidence and length of cancer survivorship increases then it follows that the quality-of-life (with and beyond cancer) should be as good as possible for every cancer patient.

### **Key findings.**

The report identifies that people needed Living Well support at different times in the care pathway.

There is evidence that exercise has a benefit in preventing recurrence for breast and colorectal cancers and improving quality-of-life (psychological wellbeing in particular). There is extensive research to support the use of exercise programmes for people with cancer; including those with active and advanced disease in terms of cost effectiveness.

The report identifies many examples of good practice in the UK, outside the UK and in chronic condition management. These include Expert Patient Programmes, Exercise and Activity programmes, support and information such as emotional support and counselling, relaxation classes and art therapy.

### **Recommendations.**

There is an emerging evidence base to show that Living Well services improve the quality-of-life of people with cancer, therefore a person-centred, holistic approach to care should be recommended for these benefits.

More research is still needed into the benefits derived from Living Well services; to investigate the complex results from attending these programmes and centres.

Consider access for people in rural areas, online access to services may be appropriate for those who may not be physically able to attend a centre, however this may not be suitable for all.

Consider the role of the key worker/coordinator to signpost people to services.

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## Transition to End of Life

**This report** reviews at what point in the pathway transitions occur, the frequency of transitions, and what happens in relation to interventions at each transitional stage.

This is a complex and challenging area not least because of the terminology used. Active and Advanced disease does not accurately define the concept of living with cancer or cancer as a chronic disease. More people are living for several years with persistent cancer. This may be after a disease free interval of a number of years following primary treatment.

There is a different interpretation of terms to describe transitions, indicating the need to establish a common language. For those with advanced and metastatic cancer terms that are used include “terminal”, “palliative”, “supportive” and “end of life”.

The right conversation at the right time can enable a person to make the best use of what time is left. There is a need to identify and support patient wishes and preferences for care.

**Key Findings.** Public perception is very much based on the terminal phase with limited appreciation of people living well with cancer treatment resistant disease and without deteriorating health.

The Literature review, illustrated the paucity of research into transitions to end of life care for patients with an incurable diagnosis.

Better information is needed to enable patients to make informed decisions about their end of life care.

The transition to end of life care is currently not discussed within an Multi disciplinary Team (MDT) meeting as this is focused on accurate diagnosis and primary treatment.

**Recommendations.** Further information related to the transition is required from research and service review/audit.

Options that need further study are earlier engagement with palliative care and the role of a co-ordinator.

Work is needed to explore how the tariff, Payment by Results (PbR) and other commissioning related tools affect end of life practices and improvements in patient and carer experience.

A review of the national information currently available on transition to end of life care, for patients diagnosed with treatment resistant disease.