

ENHANCED SUPPORTIVE CARE

Integrating supportive care in oncology
(Phase I: Treatment with palliative intent)

INTRODUCTION

ESC is a new initiative aimed at addressing more fully the needs of patients on active anti-cancer treatment in the context of a cancer centre.

This proposal has been developed from a local pilot lead by The Christie NHS Foundation Trust.

THE OPPORTUNITY AND UNMET NEED



- Supportive care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis, through anticancer treatment, to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are all integral to Supportive Care.

*(Multinational Association of Supportive Care in Cancer (MASCC) 2015
<http://www.mascc.org/>).*

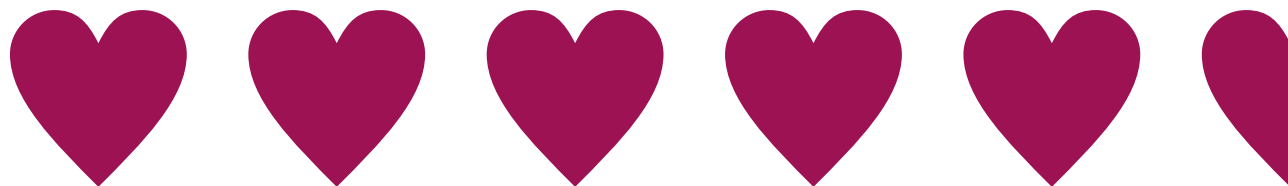
- Palliative Care is currently defined, by the World Health Organisation, as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- Enhanced supportive care has developed through recognition of what specialist palliative care can offer, but also from recognition of the barriers to achieving earlier involvement of palliative care expertise within the cancer treatment continuum. These barriers may be largely due to the perception of palliative care by the public, patients and many health professionals - in particular the association with care at the end of life. The excellent care that is provided for patients who are nearing the end of life, needs to be extended to support them much earlier on in the pathway.
- The landscape of cancer care is changing rapidly. Due to advances in cancer treatment, there are now an increasing number of patients, at different stages of their illness, who are 'living with cancer' (*Living with and Beyond Cancer – Taking Action to Improve Outcome: DH 2010*). They may be actively receiving anti-cancer therapies (sometimes over many years), or be 'off treatment' – either in remission, cured ('beyond cancer'), or living with advancing disease.
- Many of these patients - especially those with advanced progressing cancer - will require the help of healthcare professionals who have expertise in managing a range of problems, whether these are associated with the cancer itself, or as a consequence of cancer treatment.
- There is mounting evidence that good supportive care provided early can improve quality of life in these patients, possibly lengthening their survival and reducing the need for aggressive treatments near the end of their lives. (*Temel et al 2010; Bakitas 2015*).





- Optimising the use of chemotherapy in advanced incurable disease: Patients with advanced disease who progress through several lines of chemotherapy treatment eventually reach a point where there may be little or no benefit. While it is important that such patients have opportunity to access any treatment where there is a reasonable chance of benefit, it is also important that treatment does not become a significant burden during their very last weeks or even days of life. Early integration of supportive/palliative care has also been shown to optimize the timing of final chemotherapy administration (with a longer interval between last dose of chemotherapy and death)(*Greer 2012*).
- Early integration of supportive/palliative care into cancer care may therefore benefit patients with advanced progressing disease, and promote better care in the last days of life. ESC can support teams/patient when making decisions on stopping oncological treatments and help the transition to best supportive care. ESC creates opportunities for earlier conversations and planning care (*Greer 2012*).

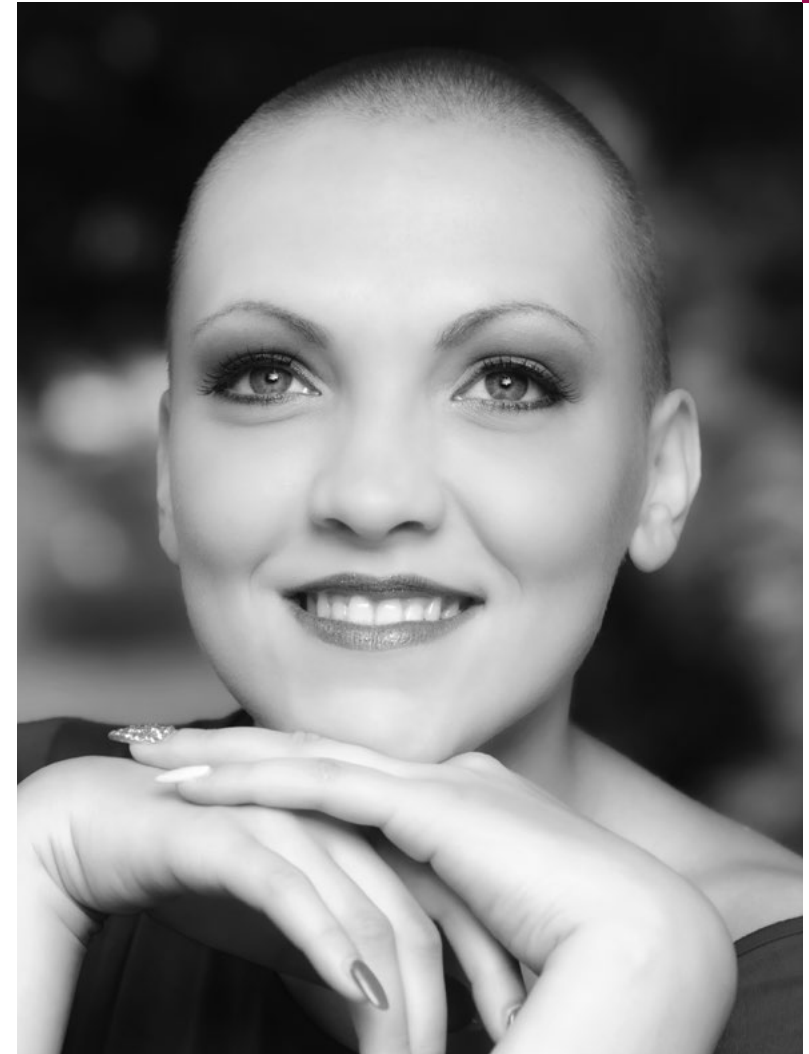


- “Enhanced supportive care”(ESC), developed by The Christie NHS Foundation Trust, has rebranded and re-packaged existing palliative care services that support cancer patients, to better suit the changing landscape of cancer care. The approach and branding to ‘ESC’ has overcome the automatic association with terminal illness / loss of hope. Furthermore, it has demonstrated improvements in patient experience, increased referrals to supportive care services and potential cost efficiencies.

Integration of palliative care services with oncology practice. What’s in a name?
Dalal S et al, MD Anderson cancer centre (poster presentation, MASCC
Copenhagen, 2015).

- ESC can be applied throughout the whole continuum of cancer care. The idea is to introduce ESC in a phased way, starting with those patients who are diagnosed with incurable cancer. Subsequently, ESC should be made available to those patients ‘living with’ curable cancer, or living with cancer as a chronic illness, as well as cancer survivors.

Throughout this document the term supportive care is being used to encompass a range of expertise that includes palliative care alongside pain medicine, interventional radiology, complimentary therapy, psycho-oncology and spiritual care as well as access to physiotherapy, dietetics and occupational therapy.



ENHANCED SUPPORTIVE CARE – THE MODEL

NOTE: This guidance applies to patients who are treated within cancer centres.

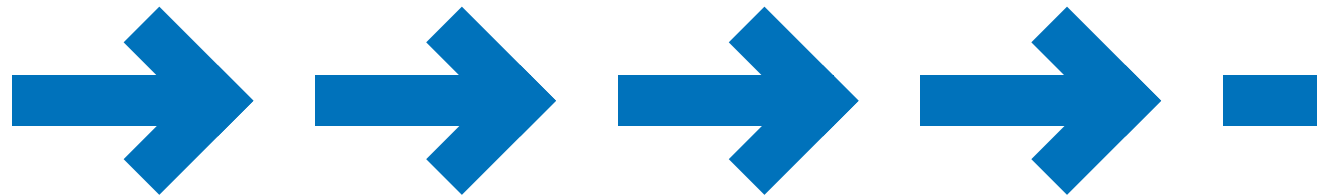
6 PRINCIPLES OF ESC

1. Earlier involvement of supportive care services.
2. Supportive care teams that work together.
3. A more positive approach to supportive care.
4. Cutting edge and evidence-based practice in supportive and palliative care.
5. Technology to improve communication.
6. Best practice in chemotherapy care.



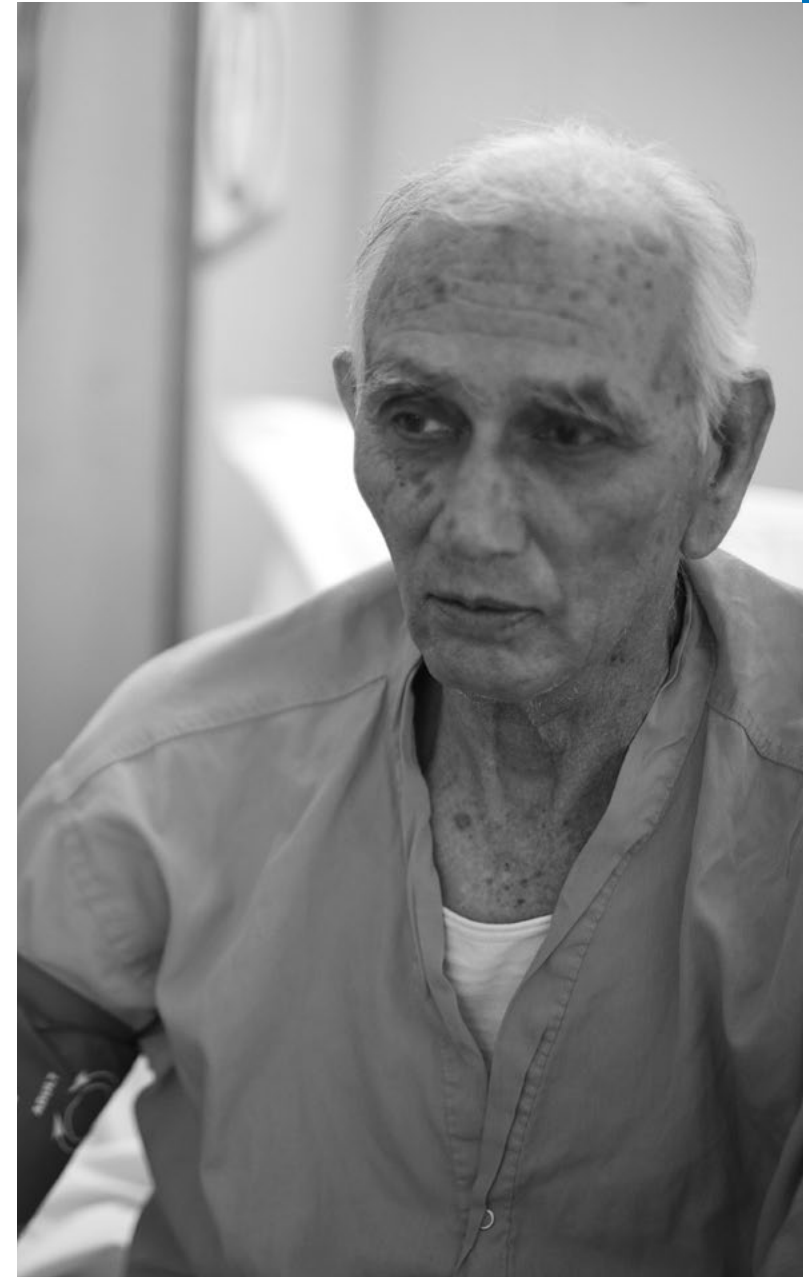
Key practical steps:

1. Appoint a clinical lead for supportive care.
2. Establish a supportive care team within each cancer centre.
3. Ensure offer of referral at the point of incurable disease.
4. Increased joint working in clinics.
5. Systems to ensure availability of prompt phone and face to face advice.
6. A weekly supportive care MDT out-patient clinic.
7. Automatic referral trigger for patients on high doses of Opioids.



1 EARLIER INVOLVEMENT OF SUPPORTIVE CARE SERVICES

Aim: From the point of recognition of incurable disease (whether local or metastatic) all patients should be screened for supportive care needs (NICE 2004). This should include prompt identification and management of physical and psychological symptoms. This has the potential to improve the patient experience and their ability to tolerate anti-cancer treatment.



Practical steps:

Closer working with oncology

Greater integration between oncology and supportive care teams:

- Joint working in targeted clinics and on ward rounds: This interface is most effective within disease groups where there is a high need for supportive care. It is in these groups that the principles of ESC have made the biggest impact.
- Patients are identified proactively rather than reactively, with teams actively seeking out appropriate patients. This reduces professional barriers to referral and makes ESC part of the cancer pathway.
- An identified 'clinical lead' that would bring this group of people together and help shape the organisation, working with supportive care teams, cancer specialists and patient participation groups.
- Joint educational events, case discussions and reflection.

Better access to supportive care

- Providing efficient referral pathways to allow prompt access to supportive care expertise and advice, "making it easy" by having on-call team members for in-patient and out-patient referrals.
- Supportive care teams being 'available' to provide advice to oncology, by phone and face to face.
- Patients having access to an advice line – for issues relating to pain / symptom control / complications of treatment.



Monitoring measures:

Outcome	Tool	Frequency
Reduction in the number of patients who die within 30 days of their last chemotherapy treatment	SACT Database	Monthly report compared with previous 12month figures
Reduction in the number of patients in whom treatment is curtailed after 1 or 2 cycles of a new line of chemotherapy	SACT Database	Monthly figures compared with previous 12month figures
Improved Patient Experience	Questionnaire based on Christie CQUIN	Baseline and 6/12ly intervals
Improved Carer reported experience	Interview based on Christie CQUIN	Baseline and 6/12ly interval
Reduced Hospital admission rate per disease group	Local trust processes	Baseline and annual figure
Reduced Length of hospital stay	Local trust processes	Baseline and annual figures
Increased Evidence patients offered referral to SCT at point of metastatic diagnosis	Audit of monthly deaths per disease group	Baseline and quarterly report

2 SUPPORTIVE CARE TEAMS THAT WORK TOGETHER

Aim: Cancer patients should have access to a comprehensive range of support services, which run alongside their anti-cancer treatments. These supportive care services should work together, ideally under one umbrella, and have recognition in their centres as a core part of the business – being regarded as the “4th pillar of cancer care”.



Practical steps:

Establishing who should be involved in delivering supportive care

Supportive care services in cancer should include a range of expertise from specialist palliative care, pain medicine, interventional radiology, complementary therapy, psycho-oncology and spiritual care, as well as access to physiotherapy, dietetics and occupational therapy.

These teams should consider working within one division, to promote a joined up approach and to maintain a high profile within trusts.

The remit of supportive care

Supportive care teams should recognise the changing landscape of cancer care and be prepared, now in and the future, to deliver care across the whole continuum including,

1. Living with cancer: Supportive care during anti-cancer treatment.
2. Living with cancer: Palliative and end of life care.
3. Living beyond cancer.



Internal processes for supportive care teams

- Hold a weekly MDT to discuss complex patients.
- Define clear channels of communication between supportive care professionals to enable prompt referral and response.
- Joint working on projects – research and audit – to enhance clinical outcomes and care.
- Provision of one-stop supportive care outpatient clinics – with multiple supportive care specialties available within the clinic to help patients (eg palliative care, pain, complementary, OT, physiotherapy).



Monitoring measures:

Outcome	Tool	Frequency
Improved Patient Experience	Questionnaire based on Christie CQUIN	Baseline and 6/12ly intervals
Improved Carer reported experience	Interview based on Christie CQUIN	Baseline and 6/12ly interval
Increased Evidence patients are offered referral to SCT at point of metastatic diagnosis	Audit of monthly deaths per disease group	Baseline and quarterly report

3 A MORE POSITIVE APPROACH TO SUPPORTIVE CARE

Aim: Excellent supportive care should offer patients a positive experience, help them to maintain hope, and even have the potential to extend survival. This approach should be adopted throughout the continuum of cancer care. In particular, for patients in whom further chemotherapy is unlikely to offer any benefit, provision of ongoing high quality supportive care should be seen as a 'real' and robust alternative to continuation of anti-cancer treatment.



Practical steps:

Rebranding and re-packaging of existing palliative care services

- Palliative care teams within cancer centres could consider re-branding as 'the supportive care team' to help overcome existing associations with end of treatment / end of life, and facilitate earlier involvement.

Identifying patients early

- Consideration of referral to supportive care teams should be automatic at the point of diagnosis of incurable disease. There should be early building of rapport and this relationship should continue (with regular review) throughout treatment and beyond.

Maintaining hope and an individualised approach

- Supportive care should be provided in a positive and hopeful way, and be flexible according to patients' individual needs and priorities, which may change with time.
- For some, this will be about maintaining their quality of life, and planning their end of life care. For others, it will be about extending life for as long as possible, and as such they may not wish to discuss or plan their end of life until the time becomes right for them.
- For patients in whom further anti-cancer therapy is felt to be inappropriate, the ongoing provision of 'best supportive care' should be regarded as a real and positive treatment, with the potential to improve or even extend life.
- As part of this, patients need to have confidence and trust that the hospital and community teams involved in their care are communicating effectively.



Monitoring measures:

Outcome	Tool	Frequency
Reduction in the number of patients who die within 30 days of their last chemotherapy treatment	SACT Database	Monthly report compared with previous 12month figures
Reduction in No of patients in whom treatment is curtailed after 1 or 2 cycles of a new line of chemotherapy	SACT Database	Monthly figures compared with previous 12month figures
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Reduced Hospital admission rate per disease group	Local trust processes	Baseline and annual figure
Reduced Length of hospital stay	Local trust processes	Baseline and annual figures
Evidence patients offered referral to SPCT at point of metastatic diagnosis	Audit of monthly deaths per disease group	Baseline and quarterly report

4 CUTTING-EDGE AND EVIDENCE-BASED PRACTICE IN SUPPORTIVE AND PALLIATIVE CARE

Aim: Supportive care teams should commit to ensuring that the care they provide is cutting-edge, with awareness of the latest available pain and symptom control treatments used in different stages of cancer care.



Practical steps:

Right treatment at the right time – excellent pain and symptom control throughout treatment.

- The right treatments for managing pain and symptoms, including management of the side effects of cancer treatments, must be provided promptly.
- Treatments for managing pain and other symptoms must be appropriate to the stage of cancer, and, where possible (during anti-cancer treatment or clinical trials), be made in conjunction with the oncology team.
- Every effort should be made to ensure that the side effects of treatments for pain and symptoms are kept to a minimum – especially regarding the use and doses of opioid medication.
- High dose opioid therapy can be ineffective and be associated with adverse outcomes in chronic cancer pain. Clinicians should consider greater use of non-opioid analgesia, earlier use of interventional analgesia (eg cordotomy / spinal interventions) and where appropriate, non-pharmacological methods (eg complementary therapies) - particularly for patients who are undergoing anti-cancer treatment.
- Specialist pain and symptom control should be undertaken by the relevant supportive care teams who have the expertise and skill to manage difficult problems. Patients who are escalated to high doses of opioids should be promptly referred on to teams that have appropriate pain control expertise.
- Extrapolating the recent evidence in chronic non-cancer pain, the total daily dose of opioids should not be increased above 120mg oral morphine equivalent without either the patient demonstrating improvement in function and pain or first obtaining a consultation from a practitioner qualified in pain management.

Interagency Guideline on Opioid Dosing for Chronic Non-cancer Pain: An educational aid to improve care and safety with opioid therapy 2010 Update Furlan et al 2009



Professional development in specialist teams

- Clear and transparent process of CPD ‘keeping up to date’ – professional development and training for specialist supportive care staff – doctors and clinical nurse specialists (within each team).



Research and Development

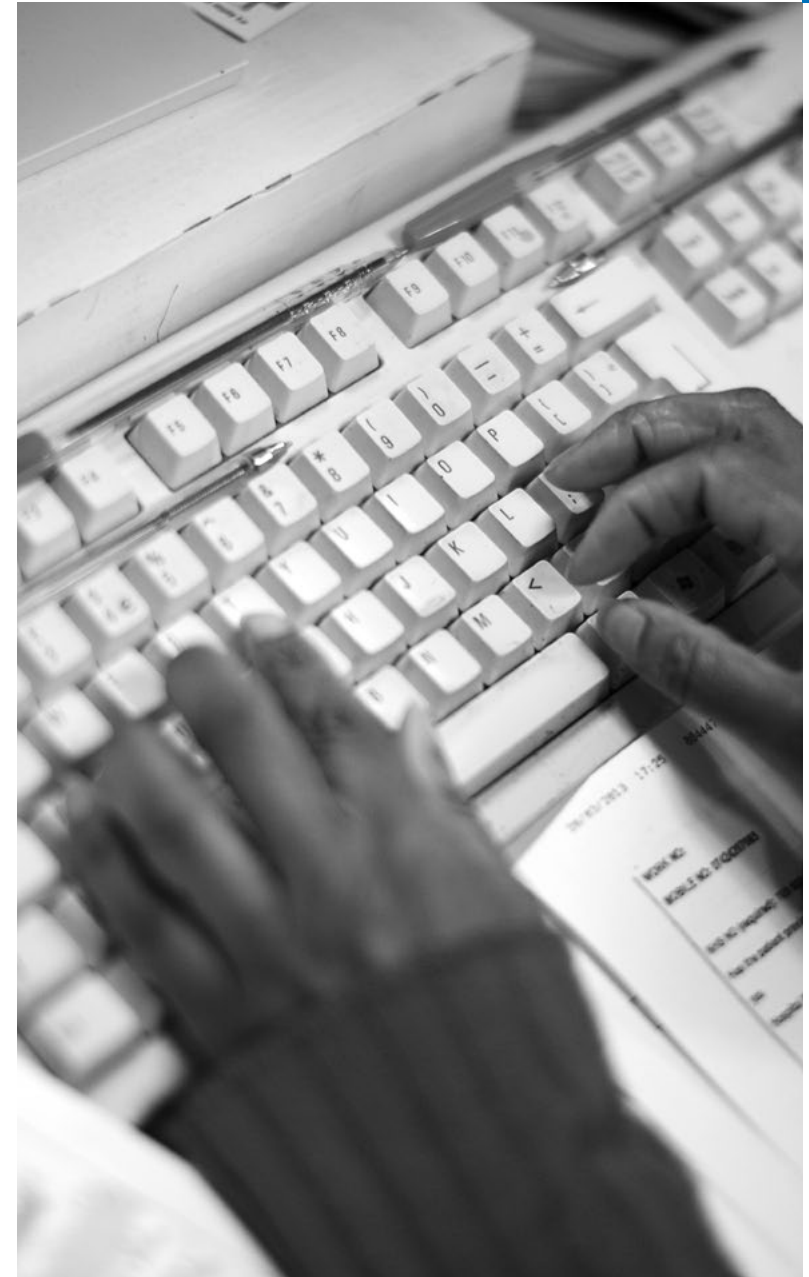
- Good supportive care must be underpinned by research programmes which help to strengthen the evidence base. There should be stronger links between local teams undertaking research and the national NCRI (National Cancer Research Institute) supportive and palliative care CSG (Clinical Studies Group).

Monitoring measures:

Outcome	Tool	Frequency
Improved Patient Experience	Questionnaire based on Christie CQUIN	Baseline and 6/12ly intervals
Improved Carer reported experience	Interview based on Christie CQUIN	Baseline and 6/12ly interval
Reduced Hospital admission rate per disease group	Local trust processes	Baseline and annual figure
Reduced Length of hospital stay	Local trust processes	Baseline and annual figures
Improved Evidence patients offered referral to SPCT at point of metastatic diagnosis	Audit of monthly deaths per disease group	Baseline and quarterly report

5 TECHNOLOGY TO IMPROVE COMMUNICATION

Aim: Incorporating technology to facilitate better communication between the hospital and community services, especially for patients with progressing cancer.



Practical Steps:

Paperless systems

Supportive care teams should become paperless, and have robust IT processes which help to ensure prompt communication.

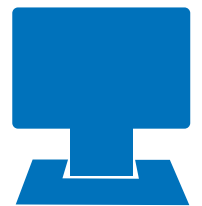
Patient monitoring

Explore the potential use of technology to monitor complex patients at home (eg remote monitoring / electronic patient reporting systems).

Communication between services

Services should consider implementation of the Electronic Palliative Care Control System (EPaCCS). Further information is available in the NHS Improving Quality report on the Economic Evaluation of EPaCCS Early Implementer Sites.

NHSIQ EPaCCS Evaluation Report



Monitoring measures:

Outcome	Tool	Frequency
Documented evidence of communication with GP regarding prognosis (with consent)	Audit of monthly deaths per disease group	Baseline and quarterly report
Improved Patient Experience	Questionnaire based on Christie CQUIN	Baseline and 6/12ly intervals
Improved Carer reported experience	Interview based on Christie CQUIN	Baseline and 6/12ly interval
Reduced Hospital admission rate per disease group	Local trust processes	Baseline and annual figure
Reduced Length of hospital stay	Local trust processes	Baseline and annual figures
Evidence patients offered referral to SPCT at point of metastatic diagnosis	Audit of monthly deaths per disease group	Baseline and quarterly report
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6 BEST PRACTICE IN CHEMOTHERAPY (SACT) CARE

Aim: Cancer patients should be offered appropriate treatment, delivered to a high standard. All chemotherapy treatment regimens and associated supportive care offered should be based on the results of national and international research and audit.





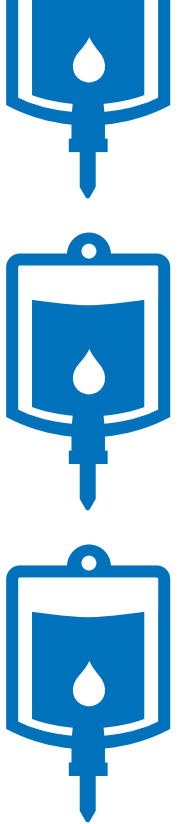
Summary of Key Principles:

1. Informed shared decision making through:
 - a. Discussing the risks and benefit of treatment options
 - b. Clarifying and recording goals of treatment.
2. Re-evaluation of treatment options at regular intervals.
3. Supporting patients to cope with the burden of treatment.
4. Supported patient self care.
5. Not discharging patients when no active treatment is available but proactive onwards referral into supportive care if patient not already engaged.

Practical Steps:

Considering treatment options

The intention of any potential treatment should be discussed and recorded. Clarity regarding the intention of treatment and the expected outcomes (e.g. pain relief, symptom control, tumour size management) may reveal a range of potential options. How much a patient wishes to know about their condition is a personal choice, however each patient should understand their treatment options and the effects of and risks associated with each treatment. Discussions should include consideration of the burden of treatment (i.e. the potential side effects and the likelihood of each occurring) in the context of the benefits of the treatment. Patients at high risk of life threatening treatment related complications should be made explicitly aware of these risks.



Consideration should be given to treatments other than chemotherapy (SACT) (including supportive care) which may have similar intended effects with different relative risks, benefits and treatment burden.

There will be circumstances under which any selected treatment may need to be stopped earlier than expected. These circumstances should be discussed at the earliest opportunity, along with the potential for alternative treatment options and the support available. Wherever possible people who the patient wishes to be involved in their care (e.g. family and friends) should be involved in treatment option discussions.

Before starting Chemotherapy (Consent and Pre-treatment consultation)

If chemotherapy (SACT) is chosen patients should be given adequate time and space to consider whether it is the right choice of treatment for them. In some cases it may be deemed necessary to commence chemotherapy (SACT) very shortly after the choice of treatment is made. In these circumstances every effort should be made to enable the patient to discuss their treatment options with others (such as family or friends) in addition to their oncology and chemotherapy team. Once they have reflected and consulted with other people involved in their treatment the consent and nurse led pre-assessment visit should check the side effects of treatment are understood and check the patient's understanding of the intention of treatment, the relative risks and benefits and the burden of treatment. Consultations should focus on enabling patients to self-manage their treatment and side effects, including when and how to access help. Consent to treatment should be confirmed at each visit.



During treatment

Once chemotherapy (SACT) has commenced there should be appropriately skilled staff available before, during and after treatment to assist patients to manage side effects, identify serious side effects early and assist with adherence.

The actual response to treatment compared to treatment intention should be monitored and recorded. Response to treatment and review of treatment regimen should be discussed with the patient and recorded. Measures of treatment success include:

- Whether the patient is feeling better.
- Measurable clinical benefits including radiological assessment.
- Monitoring tumour markers where appropriate to the tumour site.
- Reassessment of performance status after each chemotherapy (SACT) cycle.
- Assessment of weight loss or gain.
- Reassessment of treatment burden.

All patients at high risk of debilitating or life threatening treatment related complications should be closely monitored at home (e.g. proactive calling) over at least the first 2 treatments of chemotherapy (SACT).

Chemotherapy services should clearly define the role of the chemotherapy nurse (including how they support patients through treatment) and ensure there are clear links to the nurse specialist for the particular tumour site. All patients should be given details of a named key worker, knowledgeable about chemotherapy (SACT) and side effect management, whom they can contact in relation to treatment side effects and management of medicines. This service should be in addition to advice and support which may be available from the acute oncology service.

Appropriately skilled people, including the palliative care team, should be available to help the patient in understanding their response to treatment and review of treatment regimen.

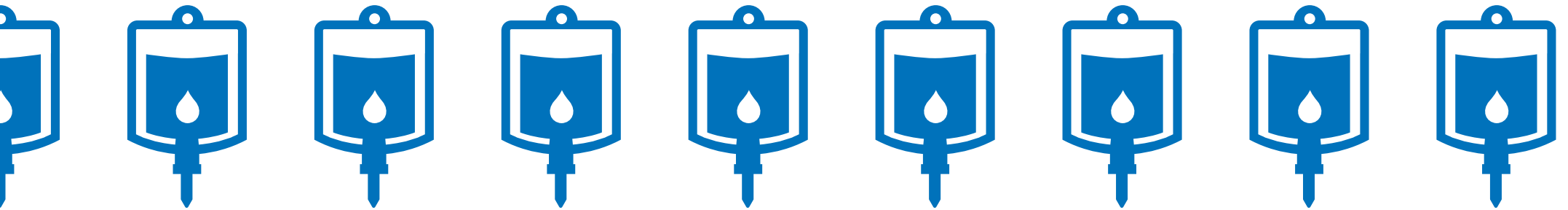


Monitoring measures:

Outcome	Tool	Frequency
Performance Status of all patients is recorded through the SACT Database	SACT Database	Baseline and quarterly intervals
Performance Status is recorded prior to each cycle of chemotherapy	SACT Database	Baseline and quarterly intervals
Patients with poor performance status being treated with palliative intent are reviewed by an MDT	Local Audit	Baseline and Annual Review
Patients have been given the opportunity to discuss their prognosis with their oncologist.	Local Audit	Baseline and 6/12ly interval
There is evidence of communication between the oncology team and the patient's General Practitioner regarding the stage of the cancer	Local Audit	Baseline and 6/12ly interval
Patients have been offered referral to specialist palliative care at the point of diagnosis of	Local Audit	Baseline and 6/12ly interval
Reduction in the number of patients who die within 30 days of their last chemotherapy treatment	SACT Database	Baseline and quarterly intervals

Monitoring measures:

Outcome	Tool	Frequency
Improved Quality of Life in patients with advanced progressing cancer	Recognised Quality of Life Tool	Baseline and Annual Review
Reductions in hospital admissions and length of stay	Local Audit	Baseline and Annual Review
Reduction in cost associated with inappropriate chemotherapy	Local Audit	Baseline and Annual Review
There is documented evidence that patients have been offered the opportunity to be involved in decision making about their individual management plan at each oncology consultation	Local Audit	Baseline and Annual Review



USEFUL RESOURCES

Enhanced Supportive Care Initiative at The Christie NHS Foundation Trust

Further examples of how enhanced supportive care can be implemented are included in the Enhanced Supportive Care Initiative report produced by The Christie NHS Foundation Trust.

Multinational Association of Support Care in Cancer

www.mascc.org

The World Hospice Palliative Care Alliance

www.thewhpc.org



[The World Health Organisation Global Atlas of Palliative Care at the End of Life](#)

National SACT Dataset

www.chemodataset.nhs.uk/home

Additional References

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