UNIVERSIDADE CATÓLICA PORTUGUESA | INSTITUTO DE CIÊNCIAS DA SAÚDE

INTERNSHIP REPORT ON PALLIATIVE CARE AT ST CATHERINE'S HOSPICE

Internship report presented to the Portuguese Catholic University to obtain the degree of Masters in Palliative Care

By
Andreia Marlene da Silva Monteiro
(LISBON, January 2016)

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Under the orientation of the RN, MSc, PhD Manuel Luís Capelas and co-orientation of David Charman RN and manager of the Inpatient Unit at St Catherine's Hospice

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Abstract

This report, performed in the context of the completion of the masters in Palliative Care, presents the activities and learning experiences that I have acquired during the months of training in the different settings of palliative care. This internship was performed at St Catherine's Hospice (Inpatient unit, Day hospice and Community team) and with the National Health Service of East Surrey Hospital Specialist Palliative Care Team. Alongside the institutional involvement, internship activities had other levels of action: the needs of training of the healthcare professionals of the Inpatient Unit of St Catherine's Hospice, with a realization of a training session in Agitation and Restlessness; and the need for updating through the realization of a systematic study on continuous subcutaneous infusion by syringe driver for symptom control at the end of life, a reality with little dissemination and implementation in Portugal, according to my experience.

All activities contributed to personal and professional changes, especially in terms of conceptualization and clarification of the following components: the importance of team work to the efficiency of the Palliative Care network (how the different palliative care settings interact with each other in an efficient manner) for better palliative care; communication as a beginning, a middle and an end; the importance of community care and symptomatic control for improved quality of care. The study case, that allowed me to deepen the reflections about my daily experience during this internship, permitted me to see evidence of how complex it is to provide holistic care to patients, family and carers, as an inseparable unit of intervention.

Resumo

Este relatório, realizado no contexto do terminus do mestrado em Cuidados Paliativos, apresenta as actividades e experiências de aprendizagem adquiridas durante os meses de estágio em diferentes ambientes de prestação de cuidados paliativos. Este estágio realizou-se no Hospicio de St Catarina (unidade de internamento, hospicio de dia e com a equipa da comunidade), e com a equipa de cuidados paliativos do Hospital de East Surrey do Serviço Nacional de Saúde. A par do envolvimento institucional as actividades realizadas tiveram outros niveis de actuação, que vão desde avaliar as necessidades de aprendizagem da equipa de profissionais de saúde da unidade de internamento do Hospicio de St Catarina, com a realização de uma sessão de educação para a saúde; até à necessidade de actualização através da realização de uma revisão sistemática sobre a infusão subcutânea contínua por bomba infusora para o controlo de sintomas no fim de vida, realidade pouco divulgada e implementada em Portugal, de acordo com a minha experiência.

Todas as actividades realizadas contribuiram para mudanças pessoais e profissionais, especialmente no que diz respeito à conceptualização e clarificação dos seguintes componentes: a importância do trabalho de equipa para a eficiência da rede de cuidados paliativos (como os diferentes ambientes de prestacao de cuidados paliativos interagem de forma eficiente); a comunicação como um principio, um meio e um fim; a importância do cuidado na comunidade e do controlo sintomático para melhorar a qualidade dos cuidados paliativos prestados. O estudo de caso permitiu-me aprofundar as reflexões acerca da minha experiência diária durante este estágio, e permitiu-me observar a evidência do quão complexa é a prestação de cuidados holísticos ao utente, família e cuidadores como uma unidade de intervenção inseparável.

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I want to acknowledge the teachers of the Masters in Palliative Care for the support through this educational journey that contributed for my professional development.

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The multidisciplinary team of the Inpatient Unit of St Catherine's Hospice and of the Specialist Palliative Care Team of the National Health Service of East Surrey Hospital, for making me feel welcome and for sharing their knowledge with me.

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To my parents, for their love, care and support in the most critical moments, for helping me go in the right direction and that allowed me the realization of this internship.

To you all, my deep appreciation!

List of abbreviations and symbols

bd - twice a day

CT - Computed tomography

DNA CPR - Do Not Attempt Cardiopulmonary Resuscitation

DxT - Adjuvant Radiotherapy

ESH - East Surrey Hospital

GFR - Glomerular Filtration Rate

GI - Gastro Intestinal

GP - General Practitioner

GSF - Gold Standards Framework

IMCA - Independent Mental Capacity Advocate

MDM - Multidisciplinary Meeting

MDT - Multidisciplinary Team

MND - Motor Neuron Disease

MSCC - Malignant Spinal Cord Compression

MSU - Mid Stream Urine

NHS - National Health Service

NHS ESH - National Health Service of East Service Hospital

NICE - National Institute for Clinical Excellence

NOK - Next of Kin

od - once a day

PFST - Patient and Family Support Team

PICC - Peripherally Inserted Central catheter

PO - oral

POC - Package of care

PR - Rectal

PRN - when needed

qds - four times a day

QOF - Quality and Outcomes Framework

RCT - Randomized Controlled Trials

SC - subcutaneous

SL - Sub-lingual

STM - Short Term Memory

TENS - Transcutaneous Electrical Nerve Stimulation

TNM - Tumour, Nodules and Metastases

UK - United Kingdom

UTI - Urinary Tract Infection

WHO- World Health Organization

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Introduction

This paper work is being done in the context of the masters in Palliative Care started in 2011 at the Catholic University of Portugal in Lisbon, and it's part of the second year of the masters, constituted by 60 ECTS, 15 of witch theoretical and practical, dedicated to the Methodologies of Research and the other 45 to the elaboration of an original dissertation of scientific nature, of a project, or of an internship and its report. Considering the various possibilities I chose the internship and its report. It's in a practical context that we learn to inter-relate the theoretical knowledge with the knowledge that comes with the practical and personal experience (SOUSA, 2002). The curricular internship it's a learning experience in which we improve our technical competencies through error, reformulation and continuous update of the proposed goals, which contributed for some changes to the original project that will be described in this document. The descriptive method is the one used for the elaboration of the report.

The purpose of this paper is to describe how the general and specific goals, for the 300 hour of internship, were achieved and how they helped me improve my learning process and perfect my performance as a palliative care nurse.

The broader internship period was at St Catherine's Hospice, inpatient unit, but shifts where also done at the Day Hospice, with the Community Care Team, and at East Surrey Hospital with the Specialist Palliative Care Team. This allowed me to have a better perspective of how the different settings work as palliative care providers and how they interrelate with each other. Doing this internship enabled me to broaden the knowledge of the palliative care reality in the UK, how acute setting relates and refers to Hospice, how the community teams refer and relate to Hospice inpatient unit and Day Hospice, and how Hospice Inpatient Unit relates and refers to Day Hospice. It also allowed me to observe and experience the dynamics of the different settings in providing palliative care. This internship was a great personal and professional experience and, although nowadays the Palliative care philosophy in Portugal is more disseminated and spread, making direct contact with the weight that Palliative Care as on the daily activities of the English National Health Service was very intense, full of learning experiences and very rewarding.

The report is constituted by the introduction; locals and description of the organizations where the internship took place and period of duration of the internship and hours dedicated to

different activities; goals and strategies/activities done to reach them, with respective analysis and evaluation; and conclusion with discussion of the main implications, positive aspects and limitations of the internship.

2-Locals and description of the organizations and period of duration of the internship

The masters in Palliative Care, as referred in the introduction, was initiated in 2011, meanwhile my professional and personal life changed. I emigrated from Portugal to England and became a registered nurse in an English hospital, but before I went through with this decision I asked professor Manuel Luís Capelas that if I could manage to find an internship in England I could do it as part of the masters and the answer was positive. So when I arrived to the National Health Service East Surrey Hospital and with the masters in my mind I talked with Allison Maitland, the responsible for teaching at the East Surrey Hospital, and Elaine Edwards the manager of the Palliative Care Team. Not being possible to do the internship with the hospital Specialist Palliative Care Team, for various reasons, Elaine Edwards gave me the contact of Penny Jones the Nursing Director at St Catherine's Hospice and in conversation with her it was agreed that I could do the internship there and that the manager of nursing staff of the Inpatient Unit at St Catherine's Hospice, David Charman, would be my co-orientator during the internship. Despite of the impossibility of doing the full internship with hospital Specialized Palliative Care Team, it was possible to do a 4 day placement and Elaine Edwards supervised the shifts of the internship done with the Specialist Palliative Care team of East Surrey Hospital.

2.1. Description of St Catherine's Hospice organization and services offered

St Catherine's Hospice site describes the institution and the services offered by them, which are described as followed.

St Catherine's Hospice is a charity dedicated to providing specialized end of life care and support to local people, their families, carers and friends. They provide quality hospice care, free of charge, to people living in Crawley, Horsham, Mid Sussex and East Surrey. St Catherine's Hospice is more than just a building, it's a philosophy of care, alongside expert medical and nursing care, a person's practical, emotional, social and spiritual concerns need care and attention as well. The Hospice care is based on the belief that each person is more than their illness, and that each individual has a unique physical, emotional, social and spiritual set of needs. St Catherine's Hospice goal is to respond to the needs of each individual, helping people achieve the best possible quality of life. This highly personal, holistic approach to give care implies time, skill and experience from a multidisciplinary team. The care is given to

people in the Hospice, their homes and in nursing homes. St Catherine's hospice specialized professional team also provides training, advice and support to other professionals. Through expert assessments and regular monitoring St Catherine's professional team aims to relieve pain, symptoms and side-effects of illness; to enable people to receive care, treatment and therapies directly, wherever they live, through liaison with other healthcare professionals and by providing 24 hour telephone support; to help people retain their independence, mobility and sense of control by providing practical help, equipment and advice; to help restore self-confidence and well-being by giving patients the opportunity to meet socially, gain support from other in similar circumstances, and benefit from relaxation therapies; to give patients and their loved ones opportunities to discuss their thoughts and feelings which can relieve fears and anxieties; to help people plan for the future so that they can enjoy life as fully as possible; to, where possible, support patient's carers by providing respite care, giving people a much needed break from their caring role; to provide open and honest explanation to questions, enabling people to make informed choices and have greater control throughout the dying process; to support people as their condition deteriorates, helping families, carers and friends to prepare for bereavement; to provide ongoing support to families and carers in bereavement, from simple practical advice through counselling services. (SAUNDERS et al, 1981)

Just over 2.5 million pounds of St Catherine's Hospice funding is provided by the National Health Service and they rely heavily on the support of local people, companies and trusts to raise the rest of their running costs. Each year St Catherine's Hospice needs to raise 5.5 million pounds in voluntary income to ensure that they keep providing the vital services to those who need them.

St Catherine's Hospice Vision is: "We aspire to a time when every individual can approach death informed, supported and free of pain". It's Mission is: "To lead the community in support of all those facing death and bereavement". And its Values are: "We are caring", "We are professional"; "We are passionate"; "We are open"; "We are one team".

St Catherine's Hospice multidisciplinary team provides a holistic and personalised approach to the care of their patients, their families and carers.

The community nurses provide practical, hands-on care for patients in their own homes. The community nurses are the patients primary contact with the Hospice while their at home. They provide the link between the patient and the rest of the hospice team to ensure most appropriate support and care. St Catherine's Community Nurses are experienced nurses specializing in

hospice care. They visit people in their own homes and work alongside General Practitioners (GP), district nurses and other healthcare professionals who are already involved in the patients care. The community nurses are based at the main Hospice building but spend most of their time visiting patients in their homes and meeting other healthcare professionals to ensure the best possible service. Working with the wither team (medical, counselling, welfare and spiritual care, occupational therapy and physiotherapists), the community nurses provide a service covering 7 days a week, that includes specialist advice, assessment and support through home visits; short periods of practical nursing care for patients at home from 8:00-20:00 (this practical care aims to provide Hospice care in the home for short periods of time); access to day services and outpatients, offering the chance to attend Day Hospice, group activities, and receive medical, counselling and welfare support; more opportunities for patients to attend short term support programmes which will help improve their quality of life.

The nursing staff has a large team of experienced palliative nurses and nursing assistants who bring their wealth of experience to caring for people when they are inpatient, attending Day hospice, or at home.

There are three consultants in Palliative Medicine, Dr Catherine Gleeson, Dr Patricia Brayden and Dr Amanda Gregory (one of which is the director of medical services), who are responsible for leading the medical care of inpatients and they offer specialist advice to the community nurses and other professionals. The team of doctors are Specialty Doctors, that include the local GP (the local GP with particular interest in palliative care opted to work part time at the Hospice in order to maintain the skills in end of life), and other qualified doctors who spend time at St Catherine's Hospice to gain experience in palliative medicine. Registrars are fully qualified doctors training to become consultants in palliative medicine. They usually spend 12 months at St Catherine's Hospice. The ward doctors are qualified doctors undertaking a four month placement to gain experience in palliative care.

The Lymphoedema clinic is run by two specialist Lymphoedema nurses, with input from other members of the multidisciplinary team as necessary. The Lymphoedema outpatient clinic provides advice and treatment to people who have swelling as a result of surgery or radiotherapy for cancer. The clinic is a stand-alone outpatient service. GP's, hospital consultants or specialists can refer their patients to the clinic for Lymphoedema treatments. Lymphoedema is a form of swelling due to damage or failure within the lymphatic channels and/or lymph glands. It most commonly affects the limbs but can affect any part of the body.

Lhymphoedema cannot be cured but treatment can be given to control and reduce the swelling. The condition can be managed with compression hosiery (leg wear, garments worn directly on the feet and legs), exercise, skin care and self-massage. More intensive treatment with multi-layer compression bandaging and manual lymphatic drainage may be offered to some patients. The patient will be offered an appointment with one the specialist nurses and on occasions with the Hospice doctor. The treatment options will be discussed with the patient and a plan of care made. Most people are seen as an outpatient at the Hospice but if the patient has difficulty in going to the clinic it is possible to make other arrangements. Hosiery is obtained by the Hospice on a normal National Health Service (NHS) prescription. Alternatively as some hosiery is only available on a made-to-measure or individual basis this will be obtained via clinic. Currently there are no direct charges for hosiery or clinic visits.

The Physiotherapists team provides suitable physiotherapy treatments, tailored to meet patient needs. In palliative care physiotherapy plays an important part in providing relief from pain and other distressing symptoms and can help manage the patient's condition. The physiotherapists can advise and provide treatments that can help the patient relieve pain and discomfort; aid relaxation and mobility; minimize problems with breathlessness and fatigue; help address problems of balance and co-ordination; sustain strength and help maintain movement. Patients attending Day Hospice and inpatients can have treatments during the day. The physiotherapists also run therapeutic groups like the Breathe-Easy Group at the Day Hospice.

The Occupational Therapist and the Therapies Technician work to help keep people mobile, active and independent. The aim is to look at the impact of the illness on the patient's lifestyle and to support in adapting to changes – as and when they happen – and to help continue life as normally as possible. The Occupational Therapists work with the patients, families and carers, both at home and also at the Crawley and Surrey sites. The team includes a therapy technician who works mostly within the Day Hospices. Occupational therapy can help with managing everyday activities like dressing and bathing; anxiety management, fatigue management, loan equipment, relaxation therapy, planning care at home like handrails and portable ramps.

The team of complementary therapists are trained professionals specialised in massage, aromatherapy, reflexology and relaxation (at the moment there is no aromatherapy therapist). St Catherine's Hospice offers complementary therapy treatments to patient's families and carers, alongside with standard medical care, because there may be beneficial effects from them

such as aiding relaxation, reducing stress and help induce feelings of wellbeing. There are a number of fully qualified volunteer therapists who work with the hospice team on a regular basis which offer massage, aromatherapy (not at the present moment), reflexology and relaxation. The goal of the complementary therapies is to aid control symptoms (e.g. relieving muscle tension, soothing dry and brittle skin), to induce a deep sense of relaxation (the systematic, therapeutic use of touch in massage helps relax the soft tissues of the body and can help trigger a release of emotion), to make someone feel special, pampered and cared for.

The Welfare advisor can provide advice and support on a range of financial and practical issues like accessing statutory benefits and mobility aids, disabled parking badges, claiming industrial compensation and arranging financial affairs (benefits, wills, funeral costs and mandatory notifications following death). The welfare advisor offers advice, help and support at any stage of the patients care and is also able to help bereaved families.

The team of counsellors respond to individual need and support patients, families and carers in the most appropriate way (12 individual weekly sessions that the counsellors advice to be taken every week for 12 weeks, or a support supervisor can see the patient either at the Hospice or their home, these sessions are more flexible and can span a number of months, there are also drop-in groups that meet regularly).

The spiritual care provided by the Spiritual Care Team includes religious care, but also covers whatever gives a patient's life meaning- their culture, values and relationships. At times of crisis many issues are raised which may be called "spiritual". Spirituality is a highly subjective and personal concept. For some people, but not all, the quest for spirituality will be expressed in religious terms. The Spiritual Care Team can help the patient discover meaning, direction, purpose and answers, regardless of faith or belief. Through listening and talking the team can help the patient and their loved ones achieve a sense of peace and understanding.

The Hospice has a formal relationship with Kamson's Pharmacy Broadfield, in Crawley, to supply medicine management and clinical pharmacy services to St Catherine's Inpatient Unit and pharmaceutical advice and information to the Community Care Team. (ANNEXE I)

Referrals to St Catherine's Hospice follow the referral Pathway (ANNEXE II). Referrals are discussed by the multidisciplinary team each morning, from Monday to Friday. In order to fully assess the referral the team will sometimes ring the person who does the referral for clarification of the patient, family and carers current problems. The team may also contact the

GP surgery to equality clarify any missing information. If the referral contains the required information and is for support in the community, then the referral is passed onto the Community Care Team that cover the patient's area. It is the responsibility of the local team, either one of the nurses or doctors as appropriate, to make contact with the patient and family within two working days. This contact will generally be made by phone. An appropriate time to meet up with the patient, family and carers will then be arranged. Urgent referrals are prioritized and contact will be made with the patient and family on the same working day. Admissions to St Catherine's Inpatient Unit are directly discussed on a daily basis (Monday to Friday). One of the team members will then make contact with the referrer to offer an admission as appropriate. Urgent admissions to the Inpatient Unit (within 48 hours) will be discussed on contact. (ANNEXE III)

Every aspect of life can be affected when a patient is referred for palliative care, when the patient is told that their illness is no longer responsive to curative treatment. Limited prognosis can bring great anxiety, stress and a sense of loss of control. When referred to St Catherine's Hospice the patients, family and friends can be helped and supported at this difficult time. Palliative Care is based on a simple idea - that the person is more than their illness. Each individual has unique physical, emotional, social and spiritual needs.

St Catherine's Hospice has an Inpatient Unit with two wards and they try to make the environment welcoming and relaxed. St Catherine's Hospice staffs the wards with nurses able to care up to 18 patients, allowing nurses to spend more time with patients and relatives. Each ward has single rooms, four bedded bays (either for ladies or for gentleman) and deep Jacuzzi baths. Most of the rooms open out onto the garden and paved area to allow easy access to the peace and tranquillity of the gardens (there are plugs on the garden that allow beds to go outside). There's also a relatives room where family members, friends and carers can stay overnight. The wards also offer an important training environment for medical and nursing professionals like myself. Over 50 per cent of the patients are discharged after a short stay. Admission to the Inpatient Unit may be suggested by any healthcare professional involved in the patients case (GP's, St Catherine's community nurses or hospital consultants). Patients are admitted for assessment (a period of close observation to clarify palliative care needs and plan necessary care), symptom control (to improve symptoms), respite (a planned admission for an agreed period of time to provide a break for both patient, family and carers, this may be required when the patient has a high level of ongoing palliative care needs and is being cared for at

home with the support from the St Catherine's community nurse and other healthcare professionals), End Of Life Care (provides care and support in the last few days of life).

St Catherine's Hospice cares not only for the person who is ill but also the carer (or carers) who provide their care at home. A carer can be a member of the family or a friend. The support offered (either one-to-one or group basis) consists of medical and nursing teams that are there to listen and answer patients and family questions, complementary therapy (such as massage, reflexology, aromatherapy, reiki and indian head massage), relaxation techniques, spiritual care (this could be religious or whatever makes life meaningful to the carer as an individual), counselling and post-bereavement support, welfare advice (financial and practical).

Carers who need support may also find support at St Catherine's Hospice weekly group **Step by Step**. This group is there to help carers to adjust. Step by Step is a weekly session led by trained nurses and counsellors to give them emotional and practical support. The carers can talk informally to other people in the same situation and hear what helps them; listen to talks from different speakers each week, learn useful skills for daily life; be pampered by the complementary therapists with free reiki and clothed massages to help them relax; enjoy a meditation class at the close sessions, to help them unwind. Step by Step takes place every Friday from 10:00 to 13:00 at St Catherine's Day Hospice in Crawley.

St Catherine's Hospice works in partnership with other health professionals, to help them support and advice patients, family and carers, referred by them for palliative care. Other key healthcare professionals are kept informed by phone, letter or in person via Gold Standards Framework (GSF) or practice-based meetings. The team will work with other healthcare professionals, the patient, family and carers to identify a plan of support which meets their needs.

The Day services are an important part of care offered by St Catherine's Hospice. The services include Day Hospice, group activities, medical or nursing outpatient appointments. Counselling, bereavement support and spiritual care sessions are also available (by prior arrangement). Welfare advice appointments can also be arranged at both sites. Day Hospice is an opportunity to spend time with other people in the same boat, trying new activities and building confidence whilst having an enjoyable day out. The staff are friendly and supportive and have a listening ear. Spending the day at the Day Hospice gives family and carers the chance to have a day off and know that their loved one is being well looked after. St Catherine's Hospice run Day Hospice at two sites (Crawley, West Sussex and in Caterham, Surrey). The

patient will be initially invited to attend for up to three months and then their attendance is reviewed by the patient and the team. In Crawley the Day Hospice is located in its own dedicated part of the main Hospice building. There is a large area for group activities, a conservatory dining area and an art room, all overlook the beautiful gardens. Day Hospice in Crawley runs on Tuesday and Wednesday with clinics and groups on other days. All meals and refreshments are included, with biscuits and tea or coffee in the mornings, and homemade cake in the afternoons. The Day Service centre in Caterham is self-contained in a wing of Dormers, a care home in Foxon Lane, Caterham. There's a day centre to cater patients in the area receiving specialized end of life care. There are also out-patient rooms for complementary therapies, medical and nursing outpatient appointments, counselling and bereavement support. Having these two sites means that the patients have a choice over how and where they access their day care. At both sites the activities range from those to keep minds active, to get exercising, to have a laugh and to try new things. There are outside speakers, day trips, discussions, visiting musicians, quizzes and the staff is always open to suggestions. Day Hospice is available to all of St Catherine's Hospice patients, although it's not necessarily right or suitable for every patient. (HEARN, 2001)

Day services groups exist in addition to Day Hospice. St Catherine's Hospice run several "specialty" groups. These are formed and dissolved according to the needs of the patient population, providing targeted support. If it's identified that a group work might be beneficial to a particular group (such as younger man, women with young children, etc.) there may be considered setting up a group to meet their specific needs. Groups can have a structured approach to how they work (with a programme for each time the group meets) or be very much patient directed (when decisions are made on the day about what will be focus of that day's activity or discussion). Groups may have input from staff and/or be more peer-support groups (the focus can vary according to what the group believes is required on the day). Each group meets regularly but the frequency and duration of the group can vary. For example currently there's a group running whose members consist of women who are living with challenges of integrating their treatment with family and work life. The group makes collective decisions on what they wish to focus on that day and meets fortnightly in term-time only. One of the motivations for this group is that members provide support to each other (peer-support) and they share experiences between themselves so that all may benefit. Within the group some activities may make think, or do things differently or perhaps lead the patient to see a problem in a different light.

St Catherine's Hospice is very proud of the hospitality they offer to their patients in Crawley. All the meals are prepared from scratch, in their own kitchen, using fresh local produce to ensure all nutritional standards are met. A member of the catering team will always be happy to visit the patients in the ward or in the Day Hospice and discuss any questions the patient might have about their dietary requirements. The menu for the week is displayed on a board in the ward corridor and if the patient is not tempted from the menu choice on offer the catering team will try to meet their preference for a particular dish. If family and friends wish to bring in perishable food for the patient, there's a patient fridge and all items need to be labelled with name and date. A nurse will be able to take and collect these items from the fridge for the patient. The Coffee Shop menu has a good choice of items and its open Monday to Friday from 09:00 to 16:00. The supper service is operated by volunteers and there may be occasions when it is not available but there will be information if that is the case. At weekends the Coffee Shop is open from 10:00 to 14:30. They also operate a good selection of vending services for when the counter service is closed and the patient can buy anything from a cup of coffee to a lasagne. If the patient wishes to pre-order a sandwich to eat later, a member of the team will prepare the food and place it in the patient's fridge in the main kitchen and this will be collected by one of the nursing staff and served to the patient.

St Catherine's Hospice holds a Tree of Light remembrance ceremony every year in early December. This is a very important community event which provides people with an opportunity to remember those dear to them.

As an independent hospice St Catherine's Hospice is regulated by the Care Quality Commission. The Care Quality Commission requires to appoint a senior manager which is the Nursing Director. St Catherine's Hospice has a systematic approach to internal regulation which is called Clinical Governance. The Nursing Director is the one responsible for overseeing this, however it concerns all staff at St Catherine's Hospice. This helps ensure a high quality of care, a safe patient environment, continuous improvement (safeguarding high standards of care), that patients remain the main focus and priority.

2.2. Description of the Specialist Palliative Care Team of the National Health Service of East Surrey Hospital and its services

The intranet of the National Health Service of East Surrey Hospital (NHS ESH) includes the characterization and services offered by the Specialist Palliative Care Team which is described as followed.

The Specialist Palliative Care Team of NHS ESH defines Palliative Care as the care given to improve the quality of life of patients living with life-limiting illness. In practice this means seeking to improve control of pain and other symptoms and address psychological, social and spiritual needs. The main activities of the team are pain control; symptom control; psychological, social and spiritual support for patients; support for families and carers; liaison with community-based palliative care teams; end of life care planning; education and training; and research.

The team is constituted by specialist nurses and doctors with specific training and experience in palliative care. Dr Naomi Collins (Monday, Wednesday, Friday) the Macmillan Consultant in Palliative medicine. There are fixed sessions from St Catherine's Hospice consultant on Tuesdays and Thursdays. The Macmillan Lead Nurse for Palliative and End of Life Care Elaine Edwards. The Macmillan Clinical Specialist Nurses Angela Main, Caroline North; Julie Anthony, Lisanne Eagle. And the Macmillan Development Clinical Nurse Specialist Christina Probert.

As of June of 2013, there were 3,942 Macmillan nurse posts across the United Kingdom (UK), both in hospitals and the community. All Macmillan nurses are registered nurses with at least five years of experience, including two years or more in cancer or palliative care. They have completed specialist courses in pain and symptom management, and psychological support. Most of the nurses work in NHS hospitals or the community. A small number work in hospices and private hospitals, but do not charge for their services. As specialists they do not routinely undertake nursing care but are there to assess complex needs, give advice to other healthcare professionals and support people with cancer to understand their treatment options.

The Specialist Palliative Care Team of NHS East Surrey Hospital acts as an advisory service working alongside the multidisciplinary team in the hospital wards. The patient remains under the care of their own specialist consultant for their treatment and the palliative team provides additional help, advice and support when needed. Patients are generally seen on the wards,

although they can be seen in other settings within the hospital. When the patient meets the team one of the Care Specialist Nurse is allocated as the patient's key worker. This person will be the first point of contact with the team for the patient, family and carers as long as the patient stays in hospital. The team does not make home visits, which are usually done by specialist palliative care teams in the community with whom the East Surrey Hospital Specialist Palliative Care Team works closely. All together they constitute the multidisciplinary team that meets weekly on a Friday to plan the best way to support the patient's needs. The information discussed at these meetings can be provided to the patients if they wish. Most of the patients need ongoing support after leaving the hospital. If the patient requires this support the hospital team will make contact with the Community Team for them to make contact with the patient once the patient is home. For the majority of patients in the East Surrey area the Community Team is based at St Catherine's Hospice in Crawley (ANNEXE II). If this is not convenient for the patient the East Surrey Hospital Specialist Palliative Care Team will refer the patient to someone that provides this service in their local area. The GP will be sent a summary of the patient's hospital admission by the ward medical team. For the patients not known to a Community Palliative Care Team an additional summary will be written by the hospital Specialist Palliative Care Team and the patient may require a personal copy if they wish. (HILL, 1998; SKILBECK et al, 1999)

The team offers their services from Monday to Saturday from 09:00 to 17:00. Patients can be referred to the Hospital Specialist Palliative Care Team by telephone, the medical team, patient and their relatives should be aware and in agreement with this referral, when possible. Out of normal working hours advice should be discussed with the medical team on call, preferably at a Registrar level. Specialist Palliative Care Team telephone advice is available via contacting St Catherine's Hospice's, they will contact their on call doctor to contact back. If there is required "out of hours" advice it is recommend that a message is left on the Specialist Palliative Care Team extension to inform the team on their return, leaving the details of patient, ward and a short message on reason for referral. (ANNEXE IV)

2.3. Period of duration of the internship and time dedicated to different activities

The plan was to do two to three shifts weekly, from April until the 300 hours needed were complete, at St Catherine's Hospice. There are 12 hour shifts from 07:00 to 20:00, morning shifts from 07:00 to 15:00 and afternoon shifts from 12:30 to 20:00. I did 12 hour shifts and some flexible shifts in the morning and in the afternoon at the Inpatient Unit. Working full time and doing this internship was quite demanding and there were times I felt quite tired, but co-orientator and team were flexible and allowed me some "flexible" shifts. I did one shift with St Catherine's Hospice Community Care Team, ten shifts with St Catherine's Day Hospice and four shifts (from 9:00-17:00) with the Specialist Palliative Care Team of National Health Service East Surrey Hospital. The manager of the Specialist Palliative Care Team of East Surrey Hospital, Elaine Edwards, supervised me during the shifts I done with the team. (ANNEXE V)

The time that I planned to dedicate to reach each goal defined on the project was specified in a chronogram in annexe (ANNEXE VI). Bibliographic research was done during the entire internship to supplement the gaps of knowledge and to support the activities done on a daily basis in order to achieve the goals I purposed myself to reach. The initial plan was to start the internship in April but this was delayed until all the bureaucracy to start the internship in a proper manner was followed. The start was delayed and that had influence in when the goals where achieved. The placement at East Surrey Hospital was only possible in October due to internal situations related with staffing numbers. The manager Elaine Edwards felt the team, at the time I propose myself to do the placement at East Surrey Hospital, couldn't support me properly, so after a dialogue we decided to postpone it to October. The internship ended in the beginning of November which had influence in when this report was completed (by the beginning of January) and in when it will be presented to the Catholic University of Portugal in Lisbon. The participation on the activities for formation only happened at the end of the internship in November, due to the fact that during the internship I was working full time at East Surrey Hospital and could only manage to do it at this point.

The entire time dedicated to complete this internship was very rewarding, it allowed me to better understand what is Palliative Care and what is the role of a Palliative Care Nurse in different settings, an analysis of the goals and activities to achieve the goals will be presented in the next chapter.

3-Description and analysis of the Goals, acquired Competences/Skills and evaluation

To define a set of goals was important because it was through the correct definition of these that I was able to evaluate if they were reached. The set of goals encouraged and stimulated me to work more and better. To reach them I defined strategies but during the internship the reality, the existing resources and the obstacles that I faced in loco made me adapt and reformulate some of the goals and the strategies.

This internship allowed me the familiarization with Palliative Care in a Hospice, in an acute setting and in the community and how they interact to provide better care and more quality of life to patient, family and carers. It allowed me to understand how the referrals are done and what to consider to prioritize them; to understand the Hospice setting by participating in the daily routines of direct care, multidisciplinary meetings, medical ward rounds, to develop skills of communication and support, to act as part of a multidisciplinary team, to understand the goals of Day Hospice and Community Team and how the Hospice Community Team interacts with community health services to allow patient, family and carers the best possible quality of life.

This internship also enabled me to develop research and training skills by performing a systematic review and a training session.

Considering that the patients with a diagnosis of a life-limiting, progressive illness should be referred from the time of diagnosis the goals/skills and the related activities I set myself to reach/accomplish during this internship are:

1. To understand the goal of the palliative care team of the St Catherine's Hospice:
   Activities
   - Integrate the multidisciplinary palliative care team of the St Catherine's Hospice in the care for the palliative patients, their families and carers;
     1.1. Analysis of the St Catherine's multidisciplinary team and how I Integrated the team

St Catherine's Hospice multidisciplinary team is constituted by consultants, doctors, nursing staff, nursing assistant staff, lymphoedema nurse practitioner, physiotherapist, occupational

therapist, complementary therapies, welfare advisor, counsellors, spiritual care team and pharmacist. The definition of the services provided by each member of the team is defined on the sub chapter 2.1. (description of St Catherine's Hospice organization and services offered). The main point of contact and interaction of the different members of the multidisciplinary team is the Multidisciplinary Meeting (MDM). I participated of the ward MDM's.

The ward is constituted by two inpatient units called Heaselands (one bay with four beds and four private rooms plus a Family room that could also be used to admit patients if necessary) and Beeches (one bay with four beds and with four private rooms, and one room with two beds). The MDM for Beeches Inpatient Unit is on Mondays and Wednesdays, and the MDM for Heaselands Inpatient Unit is on Tuesdays and Thursdays. The meetings are held from 09:00 to 10:00 with the participation of doctors, nurses, nursing assistants, physiotherapist, occupational therapist, counsellor, member of the spiritual team, discharge liaison and pharmacist.

The team was very welcoming and made me feel as a member of staff from the beginning. I participated of all the MDM's held on the days that I was on the ward, for the inpatient unit I was allocated to. I assisted the nurse of the Inpatient Unit where I was allocated to plan the MDM from the nursing point of view. We would list patient's needs, considering handover and morning contact with patients before MDM was held. We were able to assess different needs while giving medication and breakfast like swallowing problems, food and fluid intake (if patient is eating and drinking or not and if there's problems with satisfying these two needs), pain and other symptoms assessment. If patients requested assistance with the elimination needs we could also assess mobility need. If they are independent, assess if they are passing urine or opening bowels. While assisting patient with breakfast (eating and drinking) we could also assess mobility and assistance needs (patient can mobilize independently or needs assistance and what kind of assistance to satisfy this need). This information would be shared during the MDM's with the different members, each member would give their input and plans of action would be made and discussed with patient during medical ward round (done by medical and nursing staff). I was allowed to give my input during these meetings and that made me feel that my input was considered important and as a member of the team.

Patient Advanced Care planning would also be considered during the MDM's (patient's preferred place of care, patient's preferred place of death, and Do Not Attempt Cardiopulmonary Resuscitation - DNA CPR- ANNEXE VII). (ANNEXE VIII)

Patients funding is discussed at the MDM's with discharge liaison and, with the input of all members of the multidisciplinary team (after advance care plan for patients preferred place of care and death is addressed with patient, family and carers), is put in place (ANNEXE IX). If patients preferred place of care and death is at home all the measures, with input of all multidisciplinary team members, will be taken so that patients can be at home and cared for in a manner that would promote the best possible quality of life.

In the MDM's patients deaths would also be discussed, if the advance care planning was fulfilled (preferred place of death) and if not, why not. What were the problems (e.g. not knowing patient's wish because patient came to hospice without and advance care plan in place and not being able to communicate) and what can be done to overcome the problems in the future (e.g. try to define with patient as soon as possible, after referral, advance care planning while patient is able to communicate their wishes). Bereavement is also discussed, family and carers needs and desire for support are assessed and addressed, and plans were made (family and carers remain under the care of St Catherine's Hospice Multidisciplinary team long after patient's death). (ANNEXE X)

The MDM's allowed me to observe how the patient is considered in a holistic view and how the plans to assist patients satisfy different needs where made with every member input, all information shared by all the members was considered important. If the staff had any problems, questions or doubts related with care and plans, those would be addressed to, if not on the MDM, a separate meeting would be held. There was a particular situation in which a young male at the end of life, not able to speak but not in a coma, not able to swallow, very frail, on a subcutaneous continuous infusion by syringe driver for symptom control (secretions, pain and agitation/restlessness), took three weeks to past way, normally the last few days of life are shorter. This raised questions related with subcutaneous fluids, feeding, induced sedation, that where addressed in a particular meeting led by one of the consultants to clarify these questions and to address professionals needs for psychological support.

St Catherine's Hospice cares not only for patient's, family and carers but also for their staff.

During the internship at St Catherine's Hospice I was also able to spend a day with one of St Catherine's Hospice Community Nurse Practitioner. This allowed me to observe how the palliative care team acts in the community from a nursing point of view. How their interact with the other services provided by St Catherine´s Hospice, like the Day Hospice services,

medical, physiotherapy, occupational therapy, counsellor and spiritual support for the patient's in the community; with the NHS community services like the ones provided by GP's, district nurses, and Gold standards Framework; and also how acute settings interrelate with St Catherine's Hospice Community Team and NHS Community Team. The East Surrey Hospital wards can refer patients to the Community Teams both of St Catherine's Hospice and NHS Community Services, and the NHS Community Teams can also refer patients to the Hospice Community Team or other services provided by the Hospice by discussing patient's cases on the Gold Standards Framework meeting. St Catherine's Hospice will support the NHS Community Teams with specialized advice and specialized care. St Catherine's Hospice community nurse will prioritize referrals by assessing the reason for referral that could be pain/symptom control, emotional and psychological support, social/financial advice or support, care support; and the service requested on referral like assessment at home, in hospital, and in community hospital, Day Hospice care, or admission to Hospice. The Gold Standards Framework meeting happens once a month in the community (Surgery) with General Practitioner, nurse practitioner, district nurse, and four nurses, this team covers multiple surgeries. I was able to observe the Gold Standards Framework team meeting, where patients cases where discussed (what support is being given and if they need more support). The way that the Gold Standards Framework works and how the services interact, is defined in more detail in the next point (related with the study case).

I did a visit with the Community Nurse Practitioner to a patient in his house. It was the first assessment by St Catherine's Hospice Community Team, the nurse had read the patients history before the visit. It was a male patient, 80 years old, with diagnosis of colon cancer, pelvic mass and lesion on Lung. Patient's medical history is osteoarthritis, mild depression, hip replacement, recurrent falls, recurrent urinary tract infections, and ileostomy. Preferred place of care is at home, preferred place of death if not able to be supported at home is St Catherine's Hospice. A DNA CPR is in place. Patient lives alone at a ward controlled flat. Known by his low mood, to be hard of hearing and wearing glasses (important for communication). He was referred for symptom control (pain management), because of weight loss, for emotional and psychological and care support. The nurse engaged in conversation (communication skills with active listening and empathic understanding) with patient to try to figure out what the patient knows about is disease, is prognosis, what he wants to know (need for information), support he was having at home, what where is main concerns and review his medication. Patient was aware of his disease and prognosis, sitting on chair, no pain when he's not mobilizing, being

assisted with care by a private provider of care (mobilizing, personal hygiene, meals) and his two daughters, independent with is medication and his ileostomy. He had come to terms with prognosis, felt he had a good life with his wife (that had passed away 10 years ago) and that now that he can't be independent and with his wife gone, he feels that his being a weight for his daughters. Is main concerns where related with care and the impact of his needs of care on his daughters present and future quality of life (the money that he was paying to private carers that could be left to help his daughters when he dyed). The nurse suggested referral for NHS funded Package of Care, with increased visiting times, that would reduce the time that the daughters would have to go to the house to assist him, decreasing the disturbance that that could cause in their daily lives (work, kids and husbands), and he could also save some money that he could use to help his daughters as he wished. Patient was very happy with that. Nurse to do referral for Funded increased Package of Care. Nurse reviewed pain medication with patient, and suggested pre mobilizing painkillers. Patient happy with that suggestion. Nurse to inform GP of medication suggestions. Suggestion for referral to counsellor and spiritual support, for him and his daughters, for psychological support was made. Patient refused that suggestion for him. The nurse asked if he would mind if the nurse contacted the daughters, he agreed with that. Sometimes what the nurse feels that are the needs of the patient are not the ones the patient feels. We need to give the opportunity for the patient to express his needs and allow him to refuse support, after being informed of what he can be assisted with if he wishes (ANNEXE XVII). After visit suggestions where made for next visit, like referral for physiotherapy and occupational therapy assessment, to assess needs and assist patient to be as independent as he possibly can in a safe manner. (BAUGHAN & SMITH, 2013)

It was just a day but the time spent with community nurse practitioner was very fruitful in understanding how St Catherine's Hospice services work in the community setting and with NHS community services.

- Does a study case of a patient since the referral until discharge or death to better understand the plan of action of the palliative care team in a hospice.

1.2.Study case analysis

This study it's integrated on the internship at St Catherine's Hospice for the completion of the masters in Palliative Care. I requested permission to the patient and his Next of Kin (wife) to use his data to realize the study case and informed that this study would be a part of the final

report needed to complete the masters in Palliative Care that will be presented at the Catholic University of Portugal in Lisbon. Patient and Next of Kin (NOK) were also informed that this data will remain anonymous and opportunity to assess the final report when finished was offered to the patient and NOK and that was refused. The patient's name was included on the original permission request, so that I could only access that patient's data from Crosscare (St Catherine's Hospice informatics programme of multidisciplinary registration). The signed authorization is in annexe and the patient's name was omitted to respect patient's privacy (ANNEXE XI). This request was witnessed by Staff Nurse in charge on the 16/07/2015, Andrew Knight. The patient and his NOK gave me permission to use his data on the study case. The authorization request was signed by me and the witness to this request, Andrew Knight.

1.2.1. Characterization of patient and family

N is a Male patient, 64 years old, diagnosis of Lung Adenocarcinoma. N is married, he didn't have any children, is wife is his NOK. N lives with his wife in a house with first floor and stairs to access the first floor.

1.2.2.Clinical situation and evolution

N's past medical history includes Bladder carcinoma in 2011 that was treated locally. A Right Pneumonectomy in 2012. A Post-operative bronchopleural fistula with a drain in situ. Cancer recurrence on the 05/2015 on the Right Anterolateral Chest Wall and Left Upper Lobe Lung. Palliative radiotherapy to the Right Chest Wall was done, N declined chemotherapy. N was recently diagnosed with Parkinson's disease.

On the 27/02/2013 the first assessment visit, for admission to St Catherine's Hospice Community Team, was booked for the 01/03/2013.

On the 06/03/2013 the Multidisciplinary Team (MDT) plan was to review symptoms, support through surgery (Post-operative bronchopleural fistula with drain in situ) and to become more involved if N deteriorates. Professional colleagues will be kept informed of the plan for their patient following MDT meeting and Case review meetings that will happen as appropriate.

On the 15/03/2013 MDT meeting the plan for cancer nurse specialist to review patient in a week was made. Attendance at GSF or palliative care team meetings will ensure effective communication regarding the patient. The first discussion about N at GSF was on the 30/04/2013. There was no evidence of recurrent cancer therefore N was discharged from St

Catherine's Hospice Community Team, recent surgery was apparently curative, drain in situ. For GSF only.

On the 25/07/2013 MDT meeting it was discussed that N had surgery to create a pleural window because the drain that was in situ kept falling out. N is happier with this solution. District Nurse is seeing N to assess surgical wound dressing.

N is admitted with Urinary Tract Infection (UTI) to acute hospital. Worsening confusion at the hospital over recent weeks-months, likely exacerbated by UTI, and recent diagnosis of Parkinson's Disease. Symptomatic pain over right side of chest wall, at site of lung cancer recurrence. N has had a Deep x ray Therapy (DxT- adjuvant radiotherapy) to this site in May 2015, unlikely to be scope for further DxT. Pain improved on increase Zomorph (long release morphine) to 120 mg twice a day (bd). Awaiting Computed Tomography (CT) to head (in view of confusion) and discharge planning from acute hospital was done with fast track funding (ANNEXE XII), increased Package of Care (POC) and night sits. Patient is discharged home from acute hospital with catheter in situ.

On the 06/08/2015 MDT meeting at St Catherine's Hospice it's mentioned that N's case was discussed at GSF with district nurse and G P, and that a plan was made for a joint visit with GP and district nurse for the next week to see if it's possible to figure out N's problems and try to find some solutions/help for N and wife at home. Catheter removed by district nurse the day before the MDT meeting at St Catherine's Hospice took place.

N was admitted to Inpatient Unit at ST Catherine's Hospice for assessment, symptom control of pain, and psychological support. N and his wife are aware of the diagnosis however N doesn't like to focus on it. He has felt anxious since diagnosis and was initially worried about coming in to the Hospice, because he though he wouldn't go back home again.

N is keen to be at home for as long as possible. He does not want to be re-admitted to the acute sector and would prefer St Catherine's Hospice for End of Life Care (ANNEXE VIII). A DNA CPR is in place (ANNEXE VII).

The outcome of the MDT meeting of 16/07/15 at St Catherine's Hospice is that N's wife is concerned about future care plans, she wants to care for him at home, but N is likely to need a lot of care. N mobilising unsteadily, needs a lot of prompting - wheelchair and transfer only. Patient and Family Support Team (PFST) to assess (ANNEXE XIII). PFST offered support to wife. Medical team reviewed options for agitation/delirium and Parkinson's Disease.

Physiotherapist, Occupational therapist and Complementary therapists team (ANNEXE XIV) to assess and teach N relaxation strategies.

On the MDT meeting of 23/09/15 at St Catherine's Hospice the outcome is that N is looking and feeling brighter pleased to know he can go home and the MDT is aiming home for week after this meeting. N is aware of poor Short Term Memory (STM) – he feels that it's frustrating but not so distressed by this.

N's Regular medication is Senna (laxative) 15 mg nocte; Zomorph 100mg bd (long release morphine); Fluoxetine (anti-depressant) od, Aspirin 75 mg od; Tansulasin (prostate) 400 mcg od; Omeprazole (gastric protector) 40 mg od; Folic Acid 5 mg od; Paracetamol (painkiller) 1g qds; sodium docusate (stool softener) 200 mg bd; Pregabalin (neuropatic pain) 75 mg bd; Madopar (Parkinson's disease) 100/25 one tablet at 09:00, 13:00, 15:00, 16:00.

N is not currently on a continuous subcutaneous infusion and injectable medications were not required at the time of discharge.

N's when needed medication (PRN) is Sevedrol 30 mg as required for pain and shortness of breath. Maximum dose 180 mg/24 hours, minimum interval 1 hour. Lorazepam 0.5 Sub-lingual (SL) for shortness of breath/anxiety. Maximum dose 2 mg/24 hours, minimum interval 1 hour.

1.2.3. Patients current issues

Summary of N's current issues: Pain, N has continued to experience pain in the right axillary region despite palliative radiotherapy. He describes it as an ache which was fairly constant however has improved with the adjustments made to his medication (Zomorph was decreased to 100mg bd and Paracetamol 1g is now on the regular side qds) since admission to St Catherine's Hospice.

Other symptoms: N does not feel shortness of breath at rest but can became breathlessness on exertion. He does not complain of nausea or vomiting and has a reasonable oral intake. He was constipated on admission however his bowels are now moving regularly.

N's short term memory is poor and he presented periods of mild confusion during admission.

Psychological issues: N initially felt quite overwhelmed at being in the hospice, with 24 hour care supervision, however he did settled in and feels he benefitted from his stay at the Hospice. N is a patient with high risk of falls, sensor on (bleeps when patient mobilizes), unsteady on

his feet, short term memory affected, trying to stand up by himself to go to toilet even right after he passed urine (urinary frequency).

Social issues: due to his Parkinson's disease N's mobility can be variable however he's able to manage short distances with his zimmer frame.

1.2.4. Plans, interventions and evaluation

N met the St Catherine's Hospice referral guidelines and was referred for Community Team through the patient referral pathway (ANNEXE II).

Ongoing input from MDT will be discussed with patient and NOK on a regular basis according to need, using the ST Catherine's Hospice Community Care Model. On the St Catherine's Hospice clinical policy for all community care teams, patients will be offered support appropriate to their palliative care needs. In red intervention level the patient needs a high level of input and visits/contact (more than once a week). In the amber intervention level the patient needs weekly contact to monitor symptoms, etc. On the green intervention level the patient only needs a short period of face to face contact (e.g. assessment via telephone only). The patient or carer will be contacted via frequent calls for monitoring and support. Blue intervention level. Patient's file remains open but removed from active caseload. Option of monitoring via GSF only. Each patient will have a current contact. This will generally be a member of the nursing team but it also may be from the medical or PFST. Each team member is responsible for appropriate and timely referral to the other parts of the service and effective communication with other professionals, internal and external to the organisation. The intervention level needed from the Community Team will be reviewed by the MDT on an ongoing basis. When N was first referred to St Catherine's Hospice he was under the green intervention level and passed to the blue intervention level when he was discharged from St Catherine's Community Team and was removed from active case load but the patient's file remained open. N's was being monitored via GFS only.

GSF is a framework to deliver a "gold standard of care" for all people nearing the end- of-life. The aim is to enable patients to live well and die well in the place and in the manner of their choosing. GSF is a practical systemic approach, with tools and tasks to enable generalist healthcare teams deliver high quality care for people nearing the end of their life wherever they are. GFS has been used in Primary Care in the UK since 2000. The GSF for Care Homes

Training Programme started in 2004, GSF Acute Hospitals since 2008, and spread continues to other settings in the UK and worldwide. (WATSON et all, 2011).

On the Gold Standards Framework portal it is referred that since 2004, GSF principles at Awareness or Foundation Level have been mainstreamed into general practice in the UK supported by the NHS End of Life Care Programme through the Quality and Outcomes Framework (QOF), with 95% GP practices now having a palliative care/GSF register and regular meetings to discuss these patients.

On the portal it is also defined that the aims of GSF are to improve quality of care, to decrease hospitalization and costs, to improve teamwork, cross-boundary collaboration and communication. The National GSF centre is the National training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide quality care for people nearing the end of life. GSF improves the quality, coordination and organization of care leading to better patient outcomes in line with their needs and preferences and greater cost efficiency through reducing hospitalization. Supportive and palliative care towards the end-of-life will be increasingly needed in future with predicted demographic changes- the aging population is living longer with serious illness, with fewer people available to care for them. Overall, most palliative care is provided by generalists, and demand outstrips supply of specialist support. Optimising primary and specialist services to enable full and complementary provision will maximise benefits for patients. About 90% of the final year of life is spent at home, so good home care is important no matter where the final place of death is. The majority would prefer to die at home, with Hospice as a second choice, but only about a quarter die there, yet over half die in hospitals, despite a small minority choosing this. For many the place of death is by default rather than by choice, due to lack of planning or service provision, problems with symptom control or carer support. Hospital death is more likely for the poor, elderly and women, those with long illness. There is a general drive to reduce hospital usage and increase community care in the UK - there is an over use of hospital beds compared with other countries. Discussion about preference for place of care makes it more likely to be attained e.g. in an Advance Care Plan. By maximising what we already have like the GSF and by increasing community care and provision like nursing, social care, more patients could be supported to die at home if they choose. NICE (National Institute for Clinical Excellence) Guidance on improving Supportive and Palliative Care for adults with cancer states that primary care mechanisms should ensure that the needs of patients are identified, accessed and communicated by using for instance the GSF. (WATSON et all, 2011)

After surgery N was discharged home from acute hospital with bronchopleural fistula and drain in situ. The plan is to restart GFS associated with district nurse visits.

The Department of Health in 2013 published a document that redefines the District Nursing Service Model, this information can be accessed at the Department of Health portal. The model shows "Compassion in Practice" applied to district nursing and aims to promote innovation and disseminate the good practice that exists in many services across the country, to reduce variation and ensure patients and their families everywhere receive high quality services, which improve health and reduce health inequalities.

District nurses are senior nurses in the UK's National Health Service who manage care within the community, leading teams of community nurses and support nurses, as well as visiting house bound patients to provide advice and care such as palliative care, wound management, catheter and continence care and medication support. District nurses are able to prescribe medication to patients, in a similar way to GP doctors, as Community Practitioner Nurse prescriber's under the Nurse Prescribers Formulary for Community Practitioners depending on individual qualifications. They may be trained to assess patient's needs for equipment provision such as mobility and independent living aids, medical equipment such as specialist beds and mattresses, as well as guidance in applying for grants and welfare benefits. Their work involves both follow up care for recently discharged hospital inpatients and longer term care for chronically ill patients who may be referred by many other services, as well as working collaboratively with GP's in preventing unnecessary or avoidable hospital admissions. District nurses assess people to see how to provide nursing care that allows people to remain in their homes, maintain their independence, or have additional support after discharge from hospital. A district nurse will manage a team of nurses that may provide wound care, train carers to administer eye drops if individuals can't do it themselves, support catheter care, and administer complex medication within a patient's home as well as immunisations. As well as treatment, a district nurse can offer advice and support with health concerns and refer to other organisations. District nurses can specialise in different areas such as palliative care. In England and Wales, they are employed by Primary Care Trusts on Behalf of the NHS, whereas in Scotland, they are employed by the health board and may be based at centralised health centres or general practices. District nurses, like all qualified nurses, are regulated by the Nursing and Midwifery Council. District nurses can also be known as community nurse specialist.

Being followed by the district nurse allowed N to remain at home as he wished, supporting patient's choice.

District nurses value the uniqueness of individual patients and understand the complexity of care within home or community settings. The dynamic nature of care in the community calls upon the district nursing service to build on their strong foundations, which include strong values and behaviours, trust, partnerships across GP's and other services, supporting transition of care (working with partners to provide seamless support including discharge planning, transition to residential or hospice care), supporting patients choice (working with patients and carers to encourage active participation in care and decision making), risk management (reducing social isolation through supportive care coordination, supporting the needs of carers and safeguarding vulnerable adults). The service model builds on the strong foundations and, coupled with innovation, this provides opportunities to develop new ways of working which include making every contact count (providing opportunistic public health interventions and supporting the health and wellbeing of carers), maximising efficiency (use of productive community services and innovation to enhance care), integrated working with health and social care (developing strengthened ways of working with partners to maximise resources), delivering complex care (supporting care in community settings e.g. administering chemotherapy at home, reducing avoidable hospital admissions and promotion of early discharge), new technology to enhance care (the use of tele-health and mobile technology to support complex care in the home).

N was discharged home with drain in situ allowing him to be at home but also have the care and supervision he needed to avoid hospital re-admission.

The Community Nursing Development Programme is a contribution to the Government's intention to enable patient-centred care through delivery close to home. The Department of Health and the NHS commissioning Board, with strategic partners, and The Queen's Nursing Institute, have developed the programme with professional organizations, district nurses and their key partners. The new model for district nursing sets out to strengthen the service and provide evidence and good practice to support targeting resources effectively to meet local needs, to enhance delivery closer to home and improve health outcomes. The model captures the importance of technology to promote more effective mobile working and support care delivery and the need for joined up care across professions and agencies.

In Cambridge, a team of district nurses and general practitioners constrictively questioned in order to change how they worked to better support people in achieving their end-of-life care wishes. By working in more integrated ways with multidisciplinary colleagues including working as an integrated health and social care team, they reshaped the care and support provided. Changes in practice included establishing regular Gold Standards Framework meetings at eight weekly intervals, opening up the GSF patient list to include anyone believed to be in the last year of life with any underlying disease, proactively discussing preferred priorities for care with patients and their families, the district nurses writing in the same electronic notes with the general practitioners, routinely providing and updating out of hours services with patient information.

N is re-admitted to acute hospital with UTI. N presents worsening confusion at the hospital that has been evolving over recent weeks-months, likely exacerbated by UTI and recent diagnosis of Parkinson's Disease. N was discharged home from acute hospital with fast track funding, increased POC and night sits, with catheter in situ. (ADAN, 2000)

As referred on the NHS portal the process used to determine if a patient, who may need ongoing care and support from health and social care professionals as a result of disability, accident or illness, is eligible for care funded entirely by NHS it is complex and highly sensitive area because it affects individuals at a very vulnerable stage of their lives. There has been national guidance available since 2007 which sets out a single, National Framework for determining eligibility for NHS continuing healthcare and for NHS funded nursing care. The purpose of the National framework is to provide fair and consistent access to NHS funding across England, regardless of location, so that individuals with similar needs should have an equal likelihood of getting all of their health and nursing care provided free of charge. The National Framework was first introduced on 1 October 2007. It was reviewed in October 2009 and has been updated and revised again to reflect the changes within the NHS from April 2013. NHS continuing healthcare is the name given to a POC which is arranged and funded solely by the NHS for individuals outside of Hospital who have ongoing health care needs (ANNEXE XV).

N's case was discussed at GSF with district nurse and GP. N and his wife are still being supported by district nurse. Plan for joint visit with GP and district nurse for the following week to see if it's possible to figure out N's problems and try to find some solutions/ and help for N and wife at home. Catheter removed by district nurse.

Not only N was supported by the district nurse but his wife, his main carer, also benefited of their support.

After being assessed at home by GP and district nurse plans were made for N to be re-admitted to St Catherine's Hospice.

This time N is admitted to the Inpatient Unit (ANNEXE XVI), with pain escalation and challenging behaviour at home towards his wife. N and wife are aware of his diagnosis however he does not like to focus on it. During his admission his pain medication was readjusted, minor changes were made, and patient refers that pain is controlled.

It became apparent during the admission that N main symptom was that of anxiety. He was concerned about his relationship with his wife, being in the hospice as opposed to his home and his diagnosis of cancer.

When communicating a diagnosis and a prognosis it is important to discuss patient's attitudes and concerns sensitively to unravel confusion and dispel fears. Some patients like to consider writing a formal advance directive or "living will" which, although only legally binding in some circumstances, should give a more clearly defined record of the patient's wishes in order to facilitate more informed decision making (ANNEXE XVII). In reality when for instance patients ask for euthanasia there are often areas of unfinished business, fear, guilty or other issues that need to be explored. After sensitive and open communication most patients feel a sense of relief and their need to press for a deliberate ending of their life diminishes. Ethical issues arise towards the end of life. In this age of great technological advances patients are often anxious, worried, distressed about the possible prolonged process of dying. In health care, most of the times, there's no right or wrong decision, but only a consensus view of a clear aim, considered on the basis of ethical principles. The most widely used ethical principles in health issues in the West are autonomy (patients should be informed and involved in decision making), beneficence (do good), non-maleficence (do no harm), Justice (balancing the needs of individuals with those of society). (WATSON et al, 2011)

There are guidelines that can be followed by health professionals to communicate prognosis and other aspects of end-of-life to adults and their family and carers in advanced stadiums of incurable diseases. All patient's with incurable, advanced and progressive disease should have the opportunity to discuss the prognoses, which includes the time of life they have left, how the disease might evolve, future symptoms, effects on functionality, and questions related with

the end-of-life. The health professional shouldn't assume that the patient doesn't want to discuss these matters just because he doesn't ask about them or because of their cultural context. The opportunity of not discussing it or reschedule the session/conversation should be given to the patient. The health professional should rise these questions with all patients with an incurable, advanced and progressive disease or the prognoses is to 6 to 12 months; when there's an alteration or the perception of alteration in the clinical situation; when there's a decision to be made in relation to treatment; when there are requests or expectations inconsistent with clinical judgement; when a specific treatment is not working or there are complications that limit their efficacy, when the referral to palliative care is done (ANNEXE XVII). (BARBOSA & NETO, 2010)

When preparing for the discussion with the patient the health professional should assure that the patient's clinical circumstances are correct (review patients notes, talk to other professionals that are following the patient's case, updating the details of the stage of the disease and appropriate therapeutically options). Know what had been said to the patient, the health care professional should prepare for a difficult discussion, and if necessary swap impressions with other professionals. Assure a private and quiet room. The health professional should be available and should guaranty enough time for answers, questions and clarification of aspects that aren't clear on the patients mind. Allow the presence of NOK/carer during the discussion if that's what the patient wants. The health professional that conducts the conversation should have the capacity to answer the questions made by patient, NOK or carers, there for, it should be preferentially a senior. The health professional should built trust and show respect using an empathic style, focused on the patient, making sure that the patient is comfortable with the presence of other professionals during the conversation (e.g. nurse), and making sure that the patient is mentally capable of being part of the conversation (i.e., not confused). (BARBOSA & NETO, 2010; BAUGHAN, 2013)

The general strategies that facilitate hope and coping during discussions about prognoses and other aspects about the end-of-life include reassuring patient, NOK/carers informing that the health professional and support team will accompany them through illness trajectory. Emphasis on about what can be done, especially when the treatments fail, should be made. Assure patient, NOK/carers that the therapeutic to control pain and other symptoms is wide. Some symptoms can be hard to manage and we should avoid unrealistic promises (e.g. be without pain all the time). Give importance to the support available (palliative multidisciplinary team, and other structures). When appropriate explore and discuss the goals and realistic expectations, to

facilitate patient and NOK/carers expectations. Identify areas in which the control can be encouraged (decision making, unfulfilled tasks, goodbyes, apologies…). If appropriate discuss ways of coping from daily experience (a day at a time, strategies that allow the maintenance of a relationship - writing letters or remember thoughts, focus in significant relationships). It's important to respect and be sensitive to the patients strategies of coping (i.e. denial can be an important mechanism). Recognise the spectrum of hope - patients can simultaneously hope the cure but also recognise the terminal nature of the disease (be prepared for the worst hoping the best). Respect the patients will to explore treatment or alternative experiences (as long as they're properly informed so that informed choices are made). When discussing the time of life left the health professional should consider ask the patient to talk about they're experience in the last weeks or months, pointing out the changes in their functional state. Explain the factors involved on the prognoses elaboration. Avoid present data in dates, unless it's the last days of life. If a date is given reinforce the idea that it's very hard to predict with exactitude how long someone with that disease can survive. Prefer to give intervals of time. Emphasise the uniqueness of the individual experience. Several approaches can be used to describe the time of life (day's vs week's vs months), the health care professional can also use the probability of the patient being alive when a certain event happens. Find out what is the approach preferred by the patient. When giving statistic data explain their limitations (non-specific for an isolated individual). (DAVY & ELLIS, 2000; BARBOSA & NETO, 2010: MIDDLETON, 2014)

N didn't want to focus on the prognosis and his main cause of anxiety was the possibility of not going back home.

Adaptive anxiety with moderate intensity or proportional to threat has the tendency to alleviate progressively when the threat diminishes or disappears. The transitory anxiety defined as fear or an unpleasant feeling of hopelessness it's an expected and normal consequence of the uncertainty of the illness and the proximity of death (BARBOSA & NETO, 2010; MIDDLETON, 2014).

Anxiety may become desadaptative with disproportional intensity to threat with abnormal increase of frequency, intensity or duration of physical (explained by the increase of the activity of Autonomous Nervous System) and physiological symptoms that are maintained even when the threat is diminished. Comes with the long lasting feeling of loss of control, of increased personal vulnerability and great difficulty to think, plan and make decisions with clarity. The main manifestations of anxiety are concern, fear, terror; humour variation (out of the ordinary);

poor attention and focus spam; the ability to capture and remember information is compromised; ruminations and intrusive thoughts; indecision; restlessness; irritability and instability; persistent muscular tension; inability to relax; insomnia and nightmares; agitation; panic antiques; tremors and palpitations; surprise and poliquiuria; nausea, anorexia, diarrhoea, loss of appetite; thoracic oppression, dyspnoea, hyperventilation. The main events related with anxiety are the initial diagnose; persistence of symptoms; recurrence or progression of disease: changes in treatment or the end of active treatment; terminal stage of the disease; dates related with disease (e.g.one year that the diagnosis was made). (BARBOSA & NETO, 2010; MIDDLETON, 2014)

Even though N is aware of prognoses he doesn't like to talk about it and doesn't want to talk about preferred place of death. On this admission he has not wanted to explore advance care planning (ANNEXE VIII) in great detail and did not want to think about his preferred place of death. However, on a previous admission this was recorded has being St Catherine's Hospice. He has a community DNA CPR (ANNEXE VII) in place.

N has a tendency to constipation which responds well to suppositories. He can became anxious about passing urine at times and passes urine frequently. A Midstream Specimen of Urine (MSU) was negative and a bed ultrasound scan did not show any urinary retention. These findings show that his urinary frequency are more related with STM being affected and anxiety.

He displayed symptoms of agitated depression and paranoia. In view of this, Quetiapina (antipsychotic drug) 50 mg at night time was started and this has had a good effect on his mood and paranoia symptoms. He does still express paranoid thoughts at times but has greater insight into these and can rationalise his thought process.

N is keen to be at home as long as it is possible and has been very anxious about the length of his stay at the hospice.

There are a set of myths that patients associate with hospices has referred on the High Peaks Hospice portal. Like the myth that Hospice means hopelessness, it is "giving up". Choosing hospice doesn't mean a death sentence. What Hospice does mean is a total change on focus. It means that the patient is in control, making choices about what is most important in their life. Hospice philosophy emphasizes the creative and positive outcomes to be realized by defining and achieving personal Goals and by living life as fully as possible. It's not uncommon for people entering hospice care to experience an improved sense of well-being and comfort. This

sometimes happens because pain management and symptom control issues are openly discussed and effectively resolved. Sometimes this sense of well-being is a reflection of the person's sense of control gained from defining their goals and active participation in developing the plane of care. Living with end-stage disease and dying well takes work. Hospice workers handle that job very well and help people in hospice and their families to have some of the most memorable moments of their lives. Another myth is the one that a person to be eligible for hospice, needs to be in the final stages of dying. The truth is that every hospice experience is unique, but one key thing shared by families is that they wish they had known about hospice sooner. Hospice team members also know that having more time to work with a person and family means better quality of life. Because the goal of the hospice is to achieve the highest possible quality of life, some people may actually live longer than expected without the burden of symptoms and aggressive care. People on hospice care and their NOK/carers receive care for an unlimited amount of time, depending on the course of the illness. There is no fixed limit on the amount of time a person may continue to receive hospice services. Another myth is that one where the hospice is the place where people go to die and that the patient has to leave their home. But in reality the hospice isn't really about dying. Hospice is about adding life, quality of life, to someone's final days, weeks or months. Hospice is a program of services available to the person and their loved ones where ever they may be. Most Hospice care takes place where the person already lives (in their own home or a family's member's, a nursing home, or an assisted home facility).

N was reassured that he was at the Hospice temporarily, for symptom control and psychological support, to learn relaxation techniques, and to learn how to cope with changes, related Parkinson's Disease, in mobility, and the aim was to discharge him home once those issues are sorted. N would settle after being reassured but because short term memory was affected, patient needed constant reassurance to help diminished levels of anxiety. PFST and Counsellors Team have regular sessions with N also to help diminish anxiety levels.

N mobility is variable and he requires assistance. He has been reviewed by Physiotherapist and Occupational Therapist during admission and they gave him and his wife advice on equipment and on minimising risk of falls, including advising him to take his Madopar (Parkinson medication) upstairs (first floor) in the morning before attempting to mobilise downstairs (ground floor) and wait for medication to work. N and his wife initially declined any additional services on discharge however following further discussions, and after exploring discharge options with PFST (ANNEXE XIII) and discharge liaison, N and his wife were very clear that

he wanted to remain at home as opposed to Nursing Home. In view of their wish for N to remain at home and considering the care needed by N at the time of discharge they have accepted a Package of Care two times a day. N is going to attend the day hospice on discharge after being explained what the Day Hospice can offer (refer to 2.1. sub chapter – description of St Catherine's Hospice organization and services offered). Wife has started attending Day Hospice (Step by Step support group). When discharged if care at home becomes unmanageable N will need to consider a Care Home or Nursing Home, if patient not suitable for Hospice admission (ANNEXE II)

At St Catherine's Hospice Portal information about the Step By Step Day Hospice Group is available. This meeting happens weekly, every Friday from 10:00 to 13:00. This session is led by trained nurses and counsellors to give emotional and practical support. During this session it is possible to talk informally to other people in the same situation and ear what helps them; to listen to talks from different speakers each week, learn useful skills for daily life; to be pampered by complementary therapists with free reiki and clothed massages that can help relax; to enjoy a meditation class at close session to help unwind. The group provides practical help and advice, offering the opportunity to talk in a safe, open space, with further support such as welfare advice and spiritual care available if needed. During my placement at the Day Hospice I was able to engage in conversation with N's wife and explore how she was coping with N's care at home after discharge. That also allowed me to develop my communication skills.

Doing this study case allowed me to understand how the different members of the MDT interact to promote the best quality care to the patient and family/carers and how after discharge from the Inpatient Unit the patient and family/carers can also be supported so that they can have at they preferred place of care the best possible quality of life. Communication is about more than just exchanging information. It's about understanding the emotion and intentions behind the information. Effective communication is also a two-way street. It's not only how you convey a message so that it is received and understood by someone in exactly the way you intended, it's also how you listen to gain the full meaning of what's being said and to make the other person feel heard and understood. More than just the words you use, effective communication that combines a set of skills including non-verbal communication, engaged listening, managing stress in the moment, the ability to communicate assertively, and the capacity to recognize and understand your own emotions and those of the person you're communicating with. Effective

communication is the glue that helps you deepen your connections to others and improve teamwork, decision making, and problem solving. It enables you to communicate even negative or difficult messages without creating conflict or destroying trust. (NETO & BARBOSA, 2010; BAUGHAN & SMITH, 2013)

Evaluation

*Integrates the Multidisciplinary Palliative Care Team (ANNEXE XVIII)

2. Understand the referral pathway of the patients to the specialist palliative care team of St Catherine's hospice;

   Activities

   - Follows the referral pathway of palliative patients to St Catherine's Hospice.

   2.1. Analysis of the referral pathway

St Catherine's Hospice offers a range of services as described on the 2.1 sub chapter that describes this organization and services offered. I was able to assess St Catherine's Hospice referral pathway (ANNEXE II). During the execution of the study case I was able to understand in more detail how the referral pathway to the Inpatient Unit worked for the particular individual in study. I didn't have the opportunity to make a referral myself to the Inpatient Unit. Referrals can be made from the community or from acute settings and because I started the internship with shifts at St Catherine's Inpatient Unit, the most of the internship I dealt with patients that have been already referred at the point of contact. On the final stage of the placement being at the Day Hospice I was able to do referrals from Inpatient Unit to Day Hospice and vice versa following the referral pathway (ANNEXE XVIII).

Evaluation

*Able to refer patients to the Specialist Palliative Care Team Inpatient Unit from Day Hospice and from Inpatient Unit to Day Hospice;

*Able to prioritize referrals following St Catherine's Hospice policies on referring patients to Inpatient Unit and Day Hospice. (ANNEXE XIX)

3. To facilitate dying with dignity and comfort for patient and provide carers with support;

   Activities

   - Assess symptoms regularly for example pain, breathlessness, agitation, nausea and vomiting, retained secretions and review;

- In the event of symptoms being present, provide appropriate non-pharmacological and pharmacological interventions (medications via subcutaneous syringe pump if symptomatic or no longer tolerating oral medication);
- Maintain excellent basic care, regular mouth care, turning for comfort;
- Monitor bowel and bladder function;
- Encourage and support oral food-hydration as patient is able;
- In conjunction with medical team review appropriateness of on-going observations and nursing interventions;
- Rationalise interventions and medications, focus on comfort and support;
- Ensure dignity and compassion in all care;
- Assess psychological needs of the patient and monitor for any psychological distress;
- Assess spiritual/religious needs with the patient;
- Refer to hospital chaplain or own minister as requested;
- Aim to address other spiritual needs as able;
- Consider patient preferences;
- Try to ascertain patient's preferred place of care and death;
- Consider transfer to hospital if patient desires to spend is final days in hospital (visit East Surrey Hospital Palliative Care team for a period of time, during the internship, to better understand how it interrelates with St Catherine's Hospice);
- Ensure that up to date contact numbers are available for key family members and when they would want to be contacted;
- Explain facilities available to family and carers;
- Consider single room;

3.1. Analysis of the activities done to facilitate dying with dignity and comfort for patient and provide carers with support

At the Inpatient Unit I was able to perform the activities that allow the patient, family and carers dying with dignity and comfort and providing them with support. I engaged on direct daily care that allowed me to develop my communications skills with patient. During direct care, cooperating with nurses and nursing assistants and interacting with patient, I was able to provide physical care that improves patient's comfort and monitor physical needs but also

engage in conversations that allowed me to understand patient's psychological, spiritual and social needs. During direct care I was also able to assess symptoms and provide adequate pharmacological symptom control. Being a registered nurse but not a palliative care nurse at St Catherine's Hospice, doing an internship, I would have to be supervised on giving pharmacological symptom relief, but that allowed me to review my pharmacological knowledge on symptom relief and learn more about pharmacological symptom relief with nurses and medical team, especially during ward rounds and MDT meetings (REGNARD & HOCKLEY, 2004). The ward rounds also allowed me observe effective communication skills, the doctors are well trained on this art, needed to understand patient's needs in a holistic manner (BAUGHAN & SMITH, 2013). In assessing patient needs I was also able to refer to complementary therapies team (music therapy, reiki and massage therapy) and Day Hospice in conversation with nurses that where supervising me directly (ANNEXE XIX). The MDT meetings where also a way to assess patient's needs and plan care, to be discussed with patient on ward rounds, and reassess and confirm their preferences.

Patient may prefer the Hospital as preferred place of death, some patients consider that the hospital as more resources to allow dying with dignity and comfort compared with dying at home when not being able to be admitted to the Hospice's Inpatient Unit (KING et al, 2000). Considering this possibility one the activities consisted in doing some shifts with NHS East Surrey Hospital specialist care team to better understand how acute setting interrelates with Hospice.

As referred on the sub chapter 2.3 (Period of duration of internship and time dedicated to different activities) I did four shifts (09:00 to 17:00) with the Hospital Specialist Palliative Care Team. The team also made me feel welcome and supported me during the placement, sharing their knowledge and answering my questions. The services provided by the team are described on the 2.2 sub chapter (Description of the Specialist Palliative Care Team of National Health Service of East Surrey Hospital and its services). St Catherine's Hospice MDT supports the Hospital team especially during the out of hour's periods with advice.

During the placement with the Hospital Specialist Palliative Care Team I was able to access referral to Hospital Specialist Palliative Care Team (ANNEXE IV), referral from Hospital to Hospice Specialist Palliative Care Team (ANNEXE XX), Fast track tool (for patients with less than three months to live – ANNEXE XXI) and form for Advance Care Planning (ANNEXE XXII). Referrals done at an early stage of the disease (malignant or non-malignant) allow to

discuss at an early phase patient's preferences on care and preferred place of death, and this allows the team to take the needed measures to satisfy patient's wishes and help them die with dignity (ANNEXE XXIII).

I observed the multidisciplinary team meeting (held weekly) where new referrals (referrals within the last week- ANNEXE XXIV), existing patients and new deaths (bereavement follow up), significant events and patient's on the End of Life Care Plan (EoLC) are discussed (ANNEXE XXV). When there's deterioration in patient's condition that suggests that patient has the potential to die in hours/days or is imminently dying multidisciplinary team must assess if there are reversible causes, if there is an advance Care plan or Advance Decision to refuse treatment and if preferred place of care is known. When making referrals the referrer should consider that ideally decisions should not be made out of hours but by the MDT responsible for patients care on the ward (09:00 to 17:00). However, at times, urgent decisions are necessary. Verbal consent is required by the patient, if they have capacity, to start any medications which include the use of drugs such as opioids and benzodiazepines, and also to commence a continuous subcutaneous infusion of medication (commonly known as syringe driver). If the patient lacks capacity a best interest decision should ideally be made by the MDT, involving family or an Independent Mental Capacity Advocate (IMCA), if no family/carer are identified. They should be asked what they feel the patient would want. In an emergency situation treatment can be given based on best interests even if no family/IMCA are present. Oral fluids should always be offered to patients. The use of subcutaneous fluids is unproven and may be detrimental to patients with oedema, heart failure and retained secretions. Leaflets are available on the use of opioids (ANNEXE XXVI) and syringe drivers (ANNEXES XXVII) can be downloaded for patients and families if they wish it (East Surrey Hospital intranet page link on palliative care). Ongoing communication is essential. Changes in condition should be reported as a matter of urgency to family. There always be uncertainty around estimating prognosis as every patient is unique. Although it's possible to inform about what may happen on average to patients with a particular condition, some patients do better some do worse. This should be always mentioned during conversation with family and carers and the understanding of this should be checked.

I observed the Upper Gastro Intestinal (GI) MDT meeting constituted by surgeons, oncologist doctors, oncologist registrar, pathologist, radiologist, Upper GI specialist doctors, colon and rectal nurse, specialist palliative care nurse. Patients past medical history, with input from the

different members of MDT (diagnosis and prognosis), are considered to draw a plan of action. This allowed me to be in touch with to some technical terms. Like the TNM Classification of Malignant Tumours (TNM). The TNM classification is a cancer staging notation system that gives codes to describe the stage of a person's cancer, when this originates with a solid tumour: T describes the size of the original (primary) tumour and whether it has invaded nearby tissue; N describes nearby (regional) lymph nodes that are involved; M describes distant metastasis (spread of cancer from one part of the body to another). The performance status for chemotherapy, which is an attempt to quantify patient's general well-being and activities of daily life. This measure is used to determine whether they can receive chemotherapy, whether dose adjustment is necessary, and as a measure for the required intensity of palliative care. The quantification is from one to four, one and two means that the patient is independent, four means that the patient is bedbound. Normally if the patient can't go to hospital or appointment to get chemotherapy, it means that they are not fit enough for chemotherapy treatment. And the tumour markers. A tumour marker is a substance produced by the tumour or a person's body in response to cancer, they can help the MDT plan and monitor treatment and that different tumour markers for different types of gastrointestinal cancers are used.

I also observed the Lung MDT meeting that is constituted by surgeons, oncologist doctors, oncologist registrar, pathologist, radiologist, specialist lung doctors, specialist lung cancer nurse, specialist palliative care nurse. These work in a similar manner to the Upper GI MDT meeting, where patients past medical history, diagnosis and prognosis were considered for care plan. I also assisted to Specialist lung cancer appointment, and chemotherapy for small cell lung cancer was discussed with patient. The information given to the patient is available at Macmillan cancer support site. A copy of this information was also given to patient.

The patient was informed that he will have his treatment in the chemotherapy day unit or during a short stay in hospital. A chemotherapy nurse will give the chemotherapy. During treatment, the patient will usually see a cancer doctor, a chemotherapy nurse or a specialist nurse. Before or on the day of treatment, a nurse or person trained to take blood (phlebotomist) takes a blood sample from patient. This is to check that it is okay to have chemotherapy. The patient will also see a doctor or nurse before having chemotherapy. They will ask patient about how they have been. If patient's blood results are alright on the day of treatment, the pharmacist will prepare their chemotherapy. Patient's nurse will tell them when their treatment is likely to be ready. The patient's nurse gives them anti-sickness drugs as an injection into a vein or as tablets. The

drugs like the anti-sickness drugs and chemotherapy will be given through one of the following: a short thin tube (cannula) that the nurse puts into a vein in their arm or hand; a fine tube that goes under the skin of their chest and into a vein close by (central line); a fine tube that is put into a vein in their arm and goes up into a vein in their chest (PICC line). The nurse gives the patient carboplatin (a colourless fluid) as a drip (infusion) over 30–60 minutes. After this, they give the patient etoposide (also a colourless fluid) as a drip over an hour. They usually run the drip through a pump, which gives the treatment over a set time.

When the chemotherapy is being given some people might have the following side effects while they are having the chemotherapy: Pain along the vein (if the patient has this they should tell the nurse straight away, the nurse will check the drip site and slow the drip to ease the pain); the drug leaks outside the vein (if this happens when the patient is having etoposide, it can damage the tissue around the vein, this is called extravasation, the patient needs to tell the nurse straight away if they have any stinging, pain, redness or swelling around the vein, extravasation is not common, but if it happens it's important that it's dealt with quickly).

If the patient gets any of the symptoms after they get home, they should contact the doctor or nurse straight away on the number they gave them.

Rarely, carboplatin or etoposide may cause an allergic reaction while it's being given. The nurse will check the patient for this. If they have a reaction, they will treat it quickly. Signs of a reaction can include: a rash; feeling itchy, flushed or short of breath; swelling of the face or lips; feeling dizzy; having abdominal pain, back or chest pain; or feeling unwell. The patient is advised to tell the nurse straight away if they have any of these symptoms.

The patient has chemotherapy as a course of several sessions (or cycles) of treatment over a few months. Carboplatin and etoposide chemotherapy can be given in different ways. The patient's doctor or nurse will be able to give them details of their individual treatment course.

Here is a description of one method of treatment: each cycle of carboplatin and etoposide takes 21 days (three weeks). On the first day, the patient has carboplatin and etoposide. The next day, the patient will have an infusion of etoposide or will be given etoposide capsules. On the third day, they will have an etoposide drip or capsules. They will then have a rest period with no chemotherapy for 18 days. At the end of the 21 days, they will start their second cycle of treatment. This is exactly the same as the first cycle. The patient's doctor or nurse will tell them how many cycles they are likely to have. When taking chemotherapy capsules, before the patient leaves hospital, the nurse or pharmacist will give them chemotherapy capsules to take

at home. The patient should always take the capsules exactly as explained. This is important to make sure they work as well as possible. If the patient has difficulty swallowing the capsules, they should talk to pharmacist. If the patients is sick just after taking the capsules, they should contact the hospital (may need to take another dose). If the patient forgets to take a capsule they should not take a double dose.

Some other things to remember about taking the chemotherapy capsules are: they should be taken whole with water; they should not be open the capsules; if there is a leak, the content should not be touched; the capsules should be kept in the original package at room temperature away from heat and direct sunlight; the patient should keep the capsules safe and out of the reach of children; the patient should return any remaining capsules to the pharmacist if the treatment is stopped.

The nurse or pharmacist will give the patients anti-sickness drugs before he goes home. They may also give them anti-diarrhoea tablets if their needed. The patients should take all their tablets exactly as explained.

The patient may get some of the side effects mentioned but is very unlikely to get all of them. They should always tell their doctor or nurse about the side effects they have. The doctor can prescribe drugs to help control some of these side effects. It is very important to take the drugs exactly as the nurse or pharmacist has explained. This means they will be more effective. The patient's nurse will give them advice about managing their own side effects. After the treatment is over, the side effects will start to improve. The patient should contact the hospital if they feel unwell or need advice at any time of day or night. The nurse will give them the hospital contact numbers that should be saved in their phone or kept somewhere safe. The most common side effects of this treatment are (the rare ones that are unlikely to affect patients are not included) are described below.

Carboplatin and etoposide chemotherapy can reduce the number of white blood cells in the patient's blood. This will make them more likely to get an infection. Their white blood cells start to reduce seven days after treatment and are usually at their lowest 10–14 days after. When the number of white blood cells is low, it's called neutropenia. The patient should contact the hospital straight away on the contact number they were given if: temperature goes over 37.5°C (99.5°F) or over 38°C (100.4°F), depending on the advice given by their chemotherapy team; if they suddenly feel unwell, even with a normal temperature; if they have symptoms of an infection - this can include feeling shaky, a sore throat, a cough, diarrhoea or needing to pass

urine a lot. The number of white blood cells usually increases steadily and returns to normal before patient's next treatment. The patient will have a blood test before having more chemotherapy. If their white blood cells are still low, the doctor may delay treatment for a short time.

This treatment can reduce the number of platelets in patient's blood. Platelets are cells that help the blood to clot. The patient should tell the doctor if they have any bruising or bleeding that they can't explain. This includes nosebleeds, bleeding gums, blood spots or rashes on the skin. Some people may need a drip to give them extra platelets.

Carboplatin and etoposide can also reduce the number of red blood cells in patient's blood. These cells carry oxygen around the body. If the number of red blood cells is low (anaemia), the patient may be tired and breathless. The doctor or nurse should be informed if they feel like this. If the patient is very anaemic, they may need a drip to give the patient extra red blood cells (blood transfusion).

The patient may feel sick in the first few days after chemotherapy. The doctor will prescribe anti-sickness (anti-emetic) drugs to help prevent or control sickness. The drugs should be taken exactly as their nurse or pharmacist explained. If they still feel sick or are vomiting, they should contact the hospital as soon as possible. They can give them advice and change the anti-sickness drug to one that might work better.

Feeling very tired is a common side effect. It's often worse towards the end of treatment and for some weeks after it's finished. The patient should try to pace himself and get as much rest as needed. It helps to balance this with some gentle exercise, such as short walks. If they feel sleepy, they shouldn't drive or operate machinery.

The patients usually loses all their hair on their head, the eyelashes, eyebrows and other body hair may also thin or fall out. This usually starts after their first or second cycle of treatment. It is almost always temporary and their hair will grow back after chemotherapy ends. It is important to cover the head to protect the scalp when they are out in the sun until the hair grows back. The patient's nurse can give them advice about coping with hair loss.

The patient's doctor can prescribe drugs to control diarrhoea. They should inform them if it is severe or if it doesn't get better. The patient should make sure they are drinking at least two litres (three and a half pints) of fluids every day if they have diarrhoea.

Carboplatin and etoposide can affect how the patient's kidneys and liver work. This is usually mild and goes back to normal after treatment. The patient will have blood tests before chemotherapy to check how well their kidneys and liver are working.

Numb and tingling hands or feet are caused by the effect of carboplatin on nerves. It's called peripheral neuropathy. The patient may also find it hard to fasten buttons or do other fiddly tasks. The patient should tell the doctor if they have these symptoms, doctors sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes but in some people they may never go away. The patient should tell the doctor if they are worried about this.

The patient's mouth may become sore and they may get ulcers, this can make them more likely to get a mouth infection. They should clean their teeth and/or dentures morning and night and after meals. Use a soft-bristled or children's toothbrush. The nurse might ask them to rinse their mouth regularly or use mouthwashes. It's important to follow any advice they are given and to drink plenty of fluids. They should tell their nurse or doctor if they have any problems with their mouth. They can prescribe medicines to prevent or treat mouth infections and reduce any soreness.

The patient may get a bitter or metallic taste in their mouth or find that food tastes different. This should go away when the treatment finishes. They should try to use herbs and spices (unless they have a sore mouth or ulcers) or strong-flavoured sauces to give the food more flavour. Sucking boiled sweets can sometimes help to get rid of a bitter or metallic taste. The patient's nurse can give them more advice.

The patient may also lose appetite during treatment. They should try to eat small meals regularly and not worry if they don't eat much for a day or two. If their appetite doesn't improve after a few days, they should their nurse or dietitian know, they can give them advice on getting more calories and protein into patient's diet. They may give them food supplements or meal replacement drinks to try. Their doctor can prescribe some of these and they can buy them from chemists.

Rarely, etoposide can increase the risk of developing a second cancer, usually leukaemia, years later. But the benefits of treatment usually far outweigh this risk. The patient's doctor can talk to them about this.

It's important really important that the patient informs the doctor straight away if they feel unwell or have any severe side effects, even if they're not mentioned above.

It's also important to mention that cancer increases the chance of a blood clot (thrombosis) and chemotherapy can add to this. A clot can cause symptoms such as pain, redness and swelling in a leg, breathlessness and chest pain. Patient should contact their doctor straight away if they have any of these symptoms. A blood clot is serious side effect but the patient's doctor can treat it with drugs that thin the blood. The patient's doctor or nurse can give them more information.

Some medicines can interact with chemotherapy or be harmful when the patient is having chemotherapy. This includes medicines that the patient can buy in a shop or chemist, they should inform their doctor about any medicines they are taking, including over-the-counter drugs, complementary therapies and herbal drugs.

Carboplatin and etoposide may affect fertility (being able to get pregnant or father a child). If the patient is worried about this, they can talk to their doctor or nurse before treatment starts.

The patient's doctor will advise them not to become pregnant or to father a child during treatment. This is because the drugs may harm a developing baby. It's important to use effective contraception during and for a few months after chemotherapy. The patient can talk to their doctor or nurse about this.

If the patient has sex within the first couple of days of having chemotherapy they need to use a condom. This is to protect their partner in case there is any chemotherapy in semen or vaginal fluid.

Chemotherapy can sometimes stop the ovaries working. The patient may not get a period every month and they may eventually stop. In some women, this is temporary, but for others it is permanent and they start the menopause.

Women are advised not to breastfeed during treatment and for a few months after. This is in case there is chemotherapy in their breast milk.

If the patient needs to go into hospital for any reason other than cancer, they should always tell the doctors and nurses that they are having chemotherapy and give them the contact details for their cancer doctor.

The patient should also talk to their cancer doctor or nurse if they think if they need dental treatment. Always tell your dentist you are having chemotherapy.

After a copy with this information is given to the patient on the appointment with the lung cancer nurse, time for the patient make his questions was given and the patient had a written list of questions that where answered.

I also accompanied a different Specialist Palliative Care nurse each day of placement and that allowed me to have different inputs from them (they have different backgrounds), contributing for a wider range of learning experiences. Each nurse has their caseload. I accompanied the Specialist Palliative Care nurses during their visits to the patients at the wards. This made me aware of what a Specialist Palliative Care nurse should consider to prioritize referrals an draw care plan at bed side with patient. Summarizing the nurse should consider the physical, psychological, social, spiritual, information, care needs; preferred place of care and preferred place of death; and plan with the patient strategies to satisfy these needs and wishes for the best possible quality of life while dying.

The specialist nurse should also consider that malignant spinal cord compression (MSCC) is an oncologic emergency. MSCC occurs in 3-5 % of the patients with cancer and 10% of patients with spinal metastases develop spinal cord compression, the frequency being highest in multiple myeloma and cancers of prostate, breast and bronchus. Those looking after such patients should always be vigilant in checking for early signs and symptoms of spinal cord compression. It's important for the health professionals to have a high index of suspicion for possible MSCC because the catastrophic consequences of a delay in diagnosis. Back pain, a sensation of weakness in the legs and often vague sensory symptoms may be early manifestations. For those presenting with profound weakness, a "sensory level" and bladder and anal sphincter disturbance, which are relatively late features, the outcome is poor and the compression is much less likely to be reversible. In 80% of cases it's a result of extradural deposits due to direct extension from the vertebral body into the anterior epidural space. Lesions above L1 (lower end of the spinal cord) may produce upper and motor neurone signs and a sensory level, whereas lesions below L1 may produce lower motor neurone signs and peri-anal numbness (cauda equine syndrome). Where suspicion of MSCC is high, it is quickest to involve the oncological team who have been managing this patient, who will be able to co-ordinate the necessary scan and appropriate treatment rapidly. Some regions have a MSCC coordinator to help the patient through investigations and either oncological or surgical

treatment (NICE cautions against the unnecessary investigations of patients who are too frail or unfit for specialist treatment). The indications for radiotherapy are radiosensitive tumours; multiple levels of compression; unfit for major surgery; or patient's choice. The indications for surgical decompression are; uncertain cause (to obtain histology); radiotherapy has not been effective or symptoms persist or worsen despite radiotherapy; radio-resistant tumour (melanoma, sarcoma); unstable spine; major structural compression; cervical cord lesion; solitary vertebral metastasis. Overall 30% of the patients with spinal cord compression may survive for one year. Function will be retained in 70 % of the patients who were ambulant prior to treatment but it only return in 5% of the patients that where paraplegic at the outset. Return of motor function is better in those with an incomplete block and particularly with partial lesions of the cauda equine. Loss of sphincter function is a bad prognosis sign. In practice, most patients with a established diagnosis are relatively unwell and have multiple metastases, and will be referred for radiotherapy, achieving similar results to those of surgery. Patients with MSCC provide a great challenges to the MDT like mobility management, within limits considered safe for compromised spinal cord; skin care in patient confined to bed; bowel interventions; urinary system management; psychological support. (WATSON et al, 2011)

Hypercalcemia is another oncologic emergency and an indicator of poor prognostic. Hypercalcemia occurs as result of increased osteoclastic activity (which releases calcium from the bone) and decreased excretion of urinary calcium. This is attributed to locally active substances produced by bone metastases or by factors such as ectopic parathyroid hormone related protein or cytokines, and occurs in 10% of the cancer population. The tumours most commonly associated with hypercalcemia includes squamous cell myeloma cell carcinoma of the bronchus, carcinomas of the breast and prostate, multiple myeloma and other squamous cell tumours. Plasma calcium concentration above 2.6 mmol/l defines hypercalcemia. It's often mild and asymptomatic and significant symptoms only develop with levels above 3.0 mmol/l (although some patients may have significant symptoms at lower levels). Levels of 4.0 mmol/l and above will cause death in a few days if left untreated, but 80% of hypercalcaemic patients with cancer survive less than one year. Symptoms include drowsiness, confusion, nausea, vomiting, thirst, polyuria, weakness and constipation. Treatment is only necessary if there are symptoms or there is a high likelihood of symptoms developing and may be unnecessary if the patient is near to death. The management includes fluid replacement (high oral intake if possible), and bisphosphonates (inhibit osteoclast activity and thereby inhibit bone resorption). Bisphosphonates are effective in 70-80% of patients for an average of two to three weeks. The

dose of bisphosphonates may need to be reduced if there is renal impairment. Plasma calcium levels start to fall after 48 hours and fall progressively for the next 6 days. If calcium remains high or rises again shortly following a bisphosphonate infusion it may be useful to try an alternative bisphosphonate. If it is not possible to reduce the calcium levels, attention should be paid to the management of symptoms particularly pain, confusion and constipation. (WATSON et al, 2011)

The Specialist Palliative Care nurse should also consider that patients after chemotherapy and radiotherapy (lowered immune response, typically in the second week after chemotherapy) may become neutropenic and there's a high risk of sepsis. Neutropenia itself may not cause any symptoms. Patients usually find out they have neutropenia from a blood test or when an infection develops. Some people will feel more fatigued. For patients with neutropenia, even a minor infection can quickly become serious. Be vigilant of the following signs of infection (fever, temperature equal or above 38 degrees Celsius); chills or sweating; sore throat, sores in the mouth, or a toothache; abdominal pain; pain near the anus; pain or burning when urinating, or urinary frequency; diarrhoea or sores around the anus; a cough or shortness of breath; any redness, swelling, or pain, particularly around a cut, wound, or where a catheter was placed; unusual vaginal discharges. If chemotherapy causes neutropenia with a fever, the doctor may prescribe white blood cells growth medications. The appropriate oncology unit should be contacted if sepsis in a patient undergoing oncology treatment. These patients should be transferred to the care of the specialised inpatient oncology unit or the acute hospital depending on local protocol, for definitive investigation and management. (WATSON et al, 2011)

That the Specialist Palliative Care nurse should also consider kidney function on choice of opioids. Glomerular filtration rate (GFR) is the best test to measure the level of kidney function and determine the stage of kidney disease. The UK guidelines for chronic kidney disease published in 2005 have replaced the categories of mild, moderate and sever renal impairment with a five stage classification ranging from normal renal function to established renal failure. On the stage 1 the GFR is >90, there's a normal kidney function; on the stage 2 the GFR is 60-89, there's a mildly reduced kidney function; on the stage 3 the GFR is 30-59, there's a moderately reduced kidney function; on the stage 4 the GFR is 15-29, there's a severely reduced kidney function; on the stage 5 the GFR is >15, there's an established renal failure. Renal failure may be due to acute kidney injury which is developed rapidly (days to weeks) and may improve with treatment of the underlying causes, or chronic kidney disease, usually

the result of long term disease states that have caused a progressive loss of renal function over a period of months or years. Palliative care teams are often asked to be involved in the care of patients with different degrees of renal failure. Renal failure can cause an increase in drug side effects by decreasing plasma protein binding ability caused by uraemia; by allowing build-up of active drug metabolites; by changes in hydration affecting the distribution of drugs in the body; by reduction in oral absorption of drugs because of vomiting, diarrhoea and gastrointestinal oedema; and by increasing the permeability of the blood brain barrier (in uraemia) which may exaggerate the unwanted nervous system side effects. When GFR < 10 instead of Morphine for pain control use Oxycodone. (WATSON et al, 2011)

That the specialist palliative care nurse should consider that when there's a suspicion of bowels obstruction pro kinetic anti emetics (metoclopramide and domperidone - increase bowel motility) should not be given as it may cause colic pain. And when patient is on anticonvulsants and not able to take is oral medication this should be replaced by 20 mg of midazolam over 24 hour on continuous subcutaneous infusion by syringe driver. (WATSON et al, 2011)

The placement at NHS ESH with the Specialist Palliative Care Team was very positive and allowed me multiple learning experiences that contributes to assess patients various dimensions and needs and to assist satisfying them, to assure the best possible quality of life in the dying process.

Evaluation

*Able to address patients physical dimension;

*Able to address patients psychological dimension;

*Able to address patients spiritual/religious needs. (ANNEXE XVIII)

4. To ensure good communication with the patient, family and carers regarding the deterioration in their relative's condition;

   Activities

   - Communicate with patient and relatives (Independent Mental Capacity Advocate if no capacity or next of kin);
   - If the patient is unable to communicate their needs, discuss with next of kin;

- Support patient, family and carers and ensure they are aware of the seriousness of the condition, that death is thought likely to be imminent and the focus of care is now on comfort primarily ;
- Document significant conversations in the notes and ensure contact numbers for key family members are recorded;
- Given the opportunity to discuss and document wishes for tissue donation;
- Encourage patients, family and carers to express their emotions;
- Encourage patients, family and carers to ask questions;
- Encourage patients, family and carers to express their emotions;
- Encourage patients, family and carers to ask questions;

4.1. Analysis of the communication skills

Communication is the process that allows people to exchange information about themselves and about what surrounds them. This dynamic and multidirectional exchange of information is done through sensorial and perceptual channels (earing, sight, smell, touch, and heat) that allow to surpass the information transmitted by words. It implies adjustments to a reality changing constantly, with both back and forward steps, and meanings, that implicate patient, family, carers, and palliative care team, that are able to conduct us to an authentic interpersonal relationship (key points to attend with quality every dimension of an ill or suffering person). Effective communication is a basic need in caring for patient, family and carers in palliative care. Communicating effectively in palliative care is, at the same time, important and hard, it's a challenge because it implies the use and development of basic skills needed for the communication between health professional, patient, family and carers. It involves a set of simple things that can be said and done to assure them the opportunity to present their problems, worries and to explain how they feel. Those skills include listening, observing, and take conscience of our own feelings. The technology in this area is time and space and the most important tools are the word and listening. The empathic communication about a clinical situation is an ethical and moral obligation of the palliative care team. Nevertheless there are communication difficulties and barriers when it comes to questions related with the end of life, and those can only be reduced by the training of communication skills (active listening, empathic understanding, feedback, non-verbal communication- by patient and staff). It is essential to communicate considering the patients time, this is according to their needs of information, to what concerns them and to their expectations. Some of the themes that are

common worries for palliative patients are diagnosis and prognosis; natural history of the disease; symptom control; implications of medication; hope and expectations related with treatment; plans for the future; transition for healing treatment to palliative treatment; DNAR CPR; advance care planning and end of life requests. (BARBOSA & NETO, 2010; BAUGHAN & SMITH, 2013)

It was during my placement in the Day Hospice that felt that developed more these skills. The Day Hospice characterization is in the subchapter 2.1. (description of St Catherine's organization and services). Before patients arrival to Day Hospice the patients past medical history and current issues was discussed and one or two patients were assigned to each member of staff. During the time that the patients were at the Day Hospice the staff would try to engage in effective communication trying to assess physical, psychological, social, spiritual, information and care needs; preferred place of care and preferred place of death. We would engage with patient during various activities, like hand massage and art therapy (Art Group that is for patients and happens Thursdays from 13:00 to 15:00). I participated of the Step By Step group (with hand massage therapy - St Catherine's Hospice offers formal training in this area, relaxation sessions and reiki), that happens every Friday mornings; the Movers and Shakers group (run by a St Catherine's Hospice senior physiotherapist), this class uses gentle exercise techniques to help the patients work on their mobility (they also run other exercise groups at the community), that happens every Monday mornings; Breathe Easy group (these sessions help patients self-manage their breathlessness and are run by a Hospice physiotherapist, and includes practising breathing techniques, gentle exercise and relaxation), that happens every Friday afternoons; Managing your fatigue group (these sessions twice monthly by St Catherine's Hospice occupational therapists and includes techniques to help the patients use the energy they have as efficiently as possible), that happens every other Monday afternoons; the Carers Group (that offers support sessions for anyone that is a carer to a St Catherine's Hospice patient, this is a chance to meet others in a similar situation, on complementary therapists to give relaxing treatments) that happens monthly Friday mornings; and the Neuro Support Group (for patients with Motor Neurone Disease, with St Catherine's Hospice physiotherapist and occupational therapist) that happens every fortnight on Tuesdays (10:30-14:30).

Participating in this last group allowed me, not only, develop my communication skills but also contact for the first time with patients with Motor Neurone Disease. The Motor Neuron Disease

(MND) association published in 2014 a document that clarifies what is MND, who does affect, how is diagnosed, what causes MND, what are the symptoms, what help is available, and available treatments, that can be accessed on the MND site.

In the MND the motor neurones (nerves in the brain and spinal cord that control how the muscles work) gradually stop telling the muscles how to move. When the muscles no longer move, they become weak, which can also lead to stiffness and loss of muscle mass (wasting). MND is a life-shortening illness that affects how the patient walks, talk, eats, drinks and breaths. It will be different for each person. The patient may not get all the symptoms and there is no set order in which they will happen, but the disease will progress, which means the symptoms will get worse over time and for some people this can be rapid, for others it is slower. There is currently no cure for MND, but the patient's doctors and other health and social professionals can help the patient manage symptoms and remain independent for as long as possible.

MND is a rare disease that affects adults, although younger adults are diagnosed, in most cases, the patient is likely to be over 40 years old. Most people with MND are aged between 50 and 70. Men are affected almost twice as often as women, but this varies. It depends on the type of MND the patient has, and it evens out if the patient is 70 or older. If the patient's doctor think they have a neurological problem (to do with the brain and nervous system), they will be referred to a neurologist. The patient will be examined and may have a series of tests. These tests can range from blood samples to various nerve tests to check if the symptoms are not being caused by anything else. Normally the patient attends as an outpatient. In some cases the patient may need to spend a short stay in hospital or have further tests at a later date. Following the test results, the patient may receive a diagnosis of MND, but it can take time before the doctors feel sure about the likely cause of the patient's symptoms. MND is difficult to diagnose because it's a rare disease and early symptoms, such as clumsiness, weakness or slightly slurred speech could have other causes. Testing can only prove that the patient doesn't have other condition. There are four main types of MND, each affecting people in different ways. However is difficult to be exact, as they share some of the symptoms: Amyotrophic lateral sclerosis (is the most common form, with weakness and wasting in the limbs, muscle stiffness and cramps, in the early stages the patient may trip or drop things); Progressive bulbar palsy (affects fewer people than Amyotrophic lateral sclerosis and is usually slower to get worse, the patient may notice weakness, diminished reflexes or clumsiness of the hands); and Primary

lateral sclerosis (affects fewer people than Amyotrophic lateral sclerosis and is usually slower to get worse, this causes weakness in the lower limbs, although the patient may also experience clumsiness in the hands or speech problems).

It is not possible to be clear about what causes MND, as each person may be affected by different triggers. MND usually occurs with no apparent family history of the disease. In this cases, a mix of genetic and environmental triggers are thought to be involved, although genes may play a smaller role. The triggers may be different for each individual, so there is no simple way of finding out how the disease starts. In smaller number of cases, there is a family history of MND. This means there is a mistake in the genetic code that has been inherited, although other triggers may still be necessary for the disease actually begin.

MND can cause weakness and increasing loss of movement in the limbs; twitching and rippling sensations under the skin; muscle tightness and cramping (which may cause pain); problems with breathing and extreme tiredness; difficulties with speech, swallowing and saliva. Muscles in the hands, feet or mouth are usually affected first, but not necessarily all at once. Some people may have changes in thinking, reasoning and behaviour, known as cognitive changes, but this is usually mild. Very few will experience severe changes to reasoning. The patient may also have unexpected emotional reactions, where they can cry when happy, or laugh when sad. This is called emotional lability and can feel distressing (health a social team will provide support). It does not happen to everyone with MND.

When needed, support can be given to help the patient remain independent for as long as possible, to manage symptoms, feel more comfortable and assist with mobility, cope with emotional impact of MND, claim financial support, get help with daily activities and personal care, and plan ahead for future care. Support is likely to come from three main sources: health and social care professionals (access expert care, treatments, therapies, counselling and equipment or aids); adult social care services (a variety of aids, equipment and care services may be agreed for the patient, but the patient might need to make financial contribution), and the MND Association (they provide support in a variety of ways, the helpline can provide support, information or a listening ear if the patient needs to talk, can help find external services and introduce the services available, they can also provide certain items of equipment on loan).

Depending on patient's symptoms and progression, discussions with health and social team may likely include Riluzole (currently there is no treatment to cure or halt the disease, but this

drug has shown a modest benefit in slowing down the disease, by few months); other medications (there are a variety of medicines to help with individual symptoms, that in swallowing difficulty can be given in other forms, such as liquids and patches); Physiotherapy (this can't reverse damage to muscles weakened by MND but can help to reduce discomfort, stiffness and improve flexibility); speech communication support (referral and assessment by speech and language therapist when problems first appear) the therapists can help the patient's make the most of the their speech and voice to communicate as clearly as possible (as symptoms progress therapists advice on therapy and communications aids, from simple alphabet boards, to computer programmes and smart phone, it was interesting to see at the Day hospice group that the majority of the members were using tablets to aid them with communication and most of the patients were over 65 years old), they will also advice about managing swallowing problems, saliva and mucus; breathing support (if necessary referral to an respiratory consultant for guidance, this include discussion about whether to use mechanical support for breathing known as ventilation); diet, nutrition and swallowing support (if the patient has problems swallowing they may need advice on nutrition, this allow the patient maintain the food, fluids and medicine intake and swallow safely and comfortably, this will include therapies, supplements, fortified foods, easy to swallow meals or discussing alternative ways to receive food and drink) by referring to dietitian and speech and language therapist for guidance; and complementary therapies (to help relieve symptoms and reduce stress, although there isn't a treatment or a cure for MND, this type of therapy can complement conventional treatments if used in combination) like massage, acupuncture and reflexology.

When someone is been diagnosed with MND there is a lot to think about and this can be overwhelming. First they shouldn't rush into to buying equipment. The patients should have their needs assed by an occupational therapist or speech and language therapist, before buying equipment or aids. Items may not be suitable for everyone and mistakes can be costly. Patient may be able to get some items for free, or on loan to try out, from the NHS or adult social care services. Second the patient should think about how their finances may be affected. The patient should seek advice from a financial adviser and benefits adviser. For example, early retirement payments may affect which benefits you can claim. They may find useful to ask their bank how a trusted carer or partner can help manage their account, in case this becomes difficult for the patient. Third adapting the patient's home can take time, an occupational therapist can help advising about future needs and if the patient is eligible they may seek funding through a Disabled facilities Grant, but this can also be a lengthy process. Fourth it's important to provide

good evidence if the patient is being assessed for care needs or a benefit claim (such as Personal Independence Payment to help live with a disability). The patient should be honest about how their condition affects them to obtain the level of support they need, even if something only feels difficult now and them. If the patient keeps a diary of how their symptoms progress, that can help provide examples of how long the tasks take and the impact of the disease on their routines. It may also help demonstrate the speed at which changes are happening, so that patient's future needs can be considered. The patient should note down any questions, appointments can be tiring and they may forget to ask something important, so patient should prepare a list of questions to take to the appointment and write down the answers or ask the health or social care professional to do this for them if they need to read it later (most mobile phones and computer tablets can record discussions if that is easier).

The patient should seek out palliative care services. Palliative care aims to help the patient and those close to the patient achieve the best possible quality of life, when there is a life-shortening condition. It provides symptom management and wider support to include practical, financial, emotional, spiritual, religious or psychological needs. A relationship with a specialist palliative care professional may help reduce the time spent in hospital, as their knowledge of the patient's case can help other professionals to quickly understand their needs. Not everyone needs palliative care straight away, but the patient should talk to their neurologist or GP about when they can be referred to these services. These may be available at home, in a hospice, hospital or day centre. The patient should find out as much as possible about treatments and discuss treatment options with their health and social care team. The patient should know what is possible, what it could mean for them and the best timing to introduce any treatments. Whether to accept any treatment is the patient's choice but it's important that the decisions made are based on clear information (ANNEXE XVII). The patient should also plan ahead as early as possible. Planning ahead for the later stages of MND can feel intimidating. It means having difficult conversations with those close to them and their health and social care team. However if their speech and communication is affected, or if they experience any changes to thinking and reasoning, they may find it easier to discuss plans earlier rather than later. Planning may include decisions about finance, family and future care. The patient health and social care team can help with these discussions. Many people report that having made their wishes for the future known, helped them feeling calmer and more in control.

One of the patient's, during the neuro support group session, told me that:" I look at what I can do, not what I could do!". This sentence is a good moto not only for patients with MND but for all patients under Palliative Care. We need to see each patient as an individual (holistic view) and for some this sentence won't make much sense, but to me was a "wake up" call, and I'm using it as an encouragement moto that I'm sharing with patients that I feel that will be encourage by it, so that that can look ahead and enjoy with the best possible quality the life they still have to live. It's also one the communication points: focus in what the patient can do to diminish anxiety. (BARBOSA & NETO, 2010; BAUGHAN & SMITH, 2013)

Evaluation

*Able to communicate effectively with patient, family and carers (ANNEXE XVIII).

5. Participation on the activities plan for formation of the Palliative Care Team of the St Catherine's hospice:

Activities

- Do a survey to understand the Palliative Care Team needs for formation;
- Organize a formation/training considering the Palliative Care Team needs for formation (ANNEXE XXVIII)

5.1. Training session

This training session is part of the internship for the completion of the masters in palliative care. On the Internship Project one the goals was to do a survey to understand The Palliative Care Team needs for formation and based on that survey organize a training session. Four themes where suggested by different members of staff (nurses, research nurse, and nursing assistants). The suggested themes where Terminal Agitation, Mouth Care at End of Life, Palliative Care in Portugal, Conflicts in Palliative Care and Medicine. In August of 2015 there was a formal training in Mouth Care at End of Life at St Catherine's Hospice given by the Mouth Care Team of East Surrey Hospital, so that need was fulfilled. Palliative Care in Portugal is in my opinion more of an academic work with a broad range of themes, not very practical for the team in general. Conflicts in Palliative Care and Medicine it is probably more of a management theme. So considering the suggested themes I've chosen the Terminal Agitation because I consider that this theme will be of more interest for the team, because all

members deal with Agitation and Restlessness at the End of Life independently of the role they have in the multidisciplinary team. Laura Meyers the nurse responsible for training and education at St Catherine's Hospice gave me advice on the presentation of the training session. And some of the contents were reduced and removed to adjust to audience, like the medical contents.

A plan for the training session (ANNEXE XXVIII) was made and the session was presented with the use of power point slides (ANNEXE XXIX). Handouts of the slides where given to the participants at the beginning of the presentation.

The summary of the training session bibliography research is presented as follows.

Agitation and restlessness may occur as a pre-terminal event (in final hours or days of life) and 10% of agitated patients may need some sedation. We need to consider the underlying causes which may be treatable: physical discomfort and confusion with restlessness. Physical discomfort is associated with coordinated movements with some voluntary control (e.g. tossing, turning, fumbling, fidgeting). The causes can be uncontrolled pain, full bladder (catheter), faecal impaction (laxatives/enema if appropriate), nausea, pruritus from opioid (consider an antihistamine). Confusion with restlessness is associated with coordinated movements or uncontrolled twitching. The causes can be metabolic failure (liver or renal failure, hypercalcemia, hypoxia), opioid toxicity (look for signs, reduce opioids by 30-50%, consider opioid change), infection (treat as appropriate), cerebral metastases (consider dexamethasone 8-16 mg p.o). Before agitation and restlessness there is a need to consider sedation. (WATSON et al, 2011).

Pain is a complex phenomenon and the experience of pain is unique for each individual. It has been described in many ways:

- "An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (WATSON et al, 2011)".
- "An experience that affects and is affected by both mind and the body. It involves the perception of painful stimulus by the nervous system and the reaction of a person to this (WATSON et al, 2011)".
- "Pain is what the patient says hurts (WATSON et al, 2011)".

Acute pain has a well-defined onset, generally associated with subjective and objective physical signs and with hyperactivity of the autonomic nervous system. It usually responds to analgesic drug therapy and treatment of its underlying cause. Chronic pain persists over weeks or months and may be associated with significant changes in lifestyle, functional ability and personality. Management is challenging as it requires careful assessment, not only of the intensity and nature of pain, but also of the degree of psychological distress. Nociceptive pain is the pain for which there is an identified lesion causing tissue damage, accompanied by stimulation of nociceptors in somatic and visceral structures. Pain may be further classified into: somatic pain (bone, soft tissue); visceral pain (capsular i.e. liver, hollow viscus, cardiac). Neuropathic pain results from and is sustained by nerve damage in either central or peripheral nervous system and is suggested by abnormal sensation or pain in a region of motor, sensory or autonomic dysfunction (Differentiation is pain that arises from damage to the peripheral nervous system; central is pain that arises from injury to the spinal cord or brain; sympathetic is maintained pain, is a relatively uncommon sequel to tissue or sympathetic nerve injury; complex regional pain syndrome is associated autonomic and trophic changes following a soft tissue or nerve injury). Referred pain may be felt in a superficial or deep structure some distance from its anatomical source. The mechanisms of referred pain are not always clearly understood. The Patterns of pain are Background pain (refers to persistent baseline pain which is managed with regular analgesia, often in a slow release format), breakthrough pain (is defined as a transient exacerbation of pain that occurs either spontaneously or in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately background pain), incident pain (is either voluntary or involuntary and has an identifiable precipitant), idiopathic/spontaneous pain (may have no identifiable cause), total pain (includes those aspects of suffering with pain which are not always responsive to pharmacological intervention). (BARBOSA & NETO, 2010; WATSON et al, 2011)

The principles of pain management are: understanding that pain is a subjective experience; comprehensive, individualised and holistic assessment and treatment planning; patient and carer involvement, which should include information about pain and its management (patient should be encouraged to take an active role in their pain management); aetiology should be considered to optimise pain management; treatment should start at the level of the World Health Organization (WHO) analgesic ladder appropriate for the severity of the pain (if pain severity increases and is not controlled on a given step, medication from the next step of the analgesic ladder should be prescribed rather than another analgesic from the same step); oral

analgesia should be the preferred form of delivery where possible, titrated until pain is relieved and given regularly if pain is persistent; morphine is currently considered to be the strong opioid of choice; analgesia for continuous pain should be prescribed on a regular basis and also prescribed as needed for breakthrough pain in appropriate dosages; adjuvant analgesics should be considered where appropriate as per WHO ladder. (REGNARD & HOCKLEY, 2004; WATSON et al, 2011)

When assessing pain it's necessary to consider the physical dimension- related with underlying disease (cancer, abdominal distention from ascites), treatment (surgery, chemotherapy, radiotherapy, drug related neuropathies), associated factors (constipation, pressure sores, bladder spasm, stiff joints, post herpetic neuralgia) , chronic conditions (osteoarthritis, angina); the psychosocial dimension- psychosocial factors may have profound influence on an individual's perception and experience of pain and can affect how the sufferer responds emotionally and behaviourally and there is a large body of scientific evidence to support the role of anxiety and depression, fear, pain-related beliefs and coping styles in the mediation of pain perception in chronic non-malignant pain; the spiritual dimension- people suffering from chronic unremitting pain can experience spiritual distress/pain, it is important to identify spiritual needs in order to offer appropriate support, the spiritual dimension of an individual includes meaning, relatedness, hope and forgiveness- this may or may not include a religious system. (WATSON et al, 2011).

A detailed pain assessment should include: clinical history (site and number of pains, intensity/severity of pains, radiation of pain, timing of pain, quality of pain, aggravating or relieving factors, sensory disturbance, power/functional loss and the effect on activities of daily life, aetiology of pain, analgesic and other drug history, presence of clinically significant psychological disorder, contribution from psychological and spiritual factors, patient understanding and beliefs concerning pain); physical examination; identification of the likely cause of pain and classify the type of pain; arrangement for appropriate diagnostic investigations; arrangement for multidisciplinary professional assessment when practicable; regular review to determine the effectiveness of treatment (the frequency of review depends upon severity of pain and associated with distress) (ASHBY & DOWDING, 2001; WATSON et al, 2011)

Useful Assessment Tools are physical (11 point numerical rating scale - ANEXXE XXX); psychosocial (routine screening for psychosocial distress using a standardised tool such as

Hospital Anxiety and Depression Scale - ANEXXE XXXI); spiritual (HOPE is a simple spiritual assessment tool that can be incorporated into a medical assessment: H- sources of hope, meaning, comfort, strength, peace, love and connection; O- organized religion; P- personal spirituality and practices; E- effects on medical care an end of life care). (WATSON et al, 2011)

The pharmacological management of pain according to the WHO analgesic ladder is:

- STEP 1: mild pain (non-opioids +/- adjuvant)
- STEP 2: pain persisting or increasing- mild to moderate (opioid + non-opioid +/- adjuvant)
- STEP 3: moderate to severe pain (opioid for moderate to severe pain+ non-opioid+/- adjuvant

The adjuvant analgesia: corticosteroids, antidepressants, anti-epileptic drugs, anti-muscarinic drugs, benzodiazepines, bisphosphonates, ketamine (BARBOSA & NETO, 2010; WATSON et al, 2011)

On uncontrolled pain if it is new pain (acute onset chest pain- cardiac cause, pulmonary embolus, etc.; new back pain- rule out spinal cord compression in susceptible patients- give dexamethasone 16 mg if suspected; colic pain- Hyoscine butylbromide 20 mg SC; musculo-skeletal pain- Non Steroid Anti Inflammatory Drugs if tolerated, e.g. Diclofenac PO or PR). Immediate release strong opioids for most pains are indicated if already tried step 1 or 2 analgesics (oromorph 5-10 stat PO; morphine/diamorphine 2.5-5mg stat SC). On breakthrough pain if it is an incident pain of patients on “around the clock” strong opioids consider rapid onset, short duration fentanyl drugs (e.g. Abstral, Effentora, Instanyl); if it is spontaneous breakthrough pain or uncontrolled pain give immediate release analgesia depending on background medication (fentanyl or buprenorphine patches and modified release preparations are not suitable for breakthrough pain). Give a stat dose if not on strong opioids (start with Oromorph 5-10mg PO. Or morphine/diamorphine 2.5-5mg SC), if on strong opioids work out the total 24h dose and divide by 6 to get the equivalent breakthrough dose of the same opioid and route (e.g. modified release morphine 30mg bd = oral morphine 60mg in 24h breakthrough dose = immediate release morphine 10mg). To convert most commonly used opioids like PO morphine to SC diamorphine divide by 3; PO morphine to SC morphine divide by 2; Fentanyl patch 25mcg/hr = diamorphine 30mg SC in 24 hours. Remember breakthrough dose is then

1/6-1/10 of the 24hr dose. After painkillers are given it's necessary to assess response that should be effective within 30 min and if not consider repeat dose (ensure repeat doses available if it is effective), if ineffective ask for advice. (WATSON et al, 2011)

Another underlying cause for agitation and restlessness is nausea and vomiting. It's necessary to select appropriate treatment/antiemetic and treat reversible causes (e.g. infection, constipation, medication, hypercalcaemia). It's also necessary to consider route of administration (parenteral drugs likely to be needed if absorption compromised, give them by Continuous Subcutaneous Infusion in a syringe driver) and also consider non drug measures (management of distress and anxiety with psychological therapy and dietary advice, such as small, frequent and low fat meals). (KINGHORN, 2001; WATSON et al, 2011)

Complementary therapies which include touch therapies (e.g. massage, aromatherapy, reflexology) and psychological interventions (e.g. relaxation, hypnotherapy, meditation) are often used alongside mainstream treatments in managing cancer pain. Cognitive behavioural interventions can help minimise the impact of pain on mood and function in this group. The evidence to support other interventions is week but there may be short term benefits. Creative therapies include art, music, and writing therapies. Evidence for efficacy in reduction of pain is sparse. They may be used to assist in exploration of non-physical pain. (KINGHORN, 2001; TAVARES, 2003)

The NICE guidance on supportive and palliative care refers that Complementary therapies are to be included as one aspect of the *Guidance on Improving Supportive and Palliative Care for Adults with Cancer;* that *Complementary therapies* refers to those therapies which are used alongside conventional health care; that the Therapists are to be trained to the standard required for registration with a professional complementary therapy bodies should be knowledgeable about the general contraindications and precautions for the therapy they practice; that Staff in conventional healthcare who are not therapists will need familiarisation, guidance or training on when, and when not, to refer patients to complementary therapies, how to communicate with patients about complementary therapies, so that it doesn't raise false hopes. (TAVARES, 2003; LLOYD-WILLIAM, 2008)

Evidence base for complementary therapies is a significant consideration for managers and clinicians, as well as commissioners and providers of care. Evidence based care is described as the conscientious, explicit use of the current best evidence in making decisions about the care of individual patients. It requires practitioners to integrate the best external evidence based

practice. Evidence derived from randomised controlled trials or reviews of randomised trials; from prospective studies with a comparison group (non-randomized controlled study or observational studies); from comparison group, calculation of sample size and accurate, standard definition of outcome variables; from cross-sectional studies; and from professional consensus. The best available evidence suggests that massage, aromatherapy and reflexology may be useful to: promote relaxation, alleviate anxiety, reduce depression, reduce pain, reduce nausea, alleviate symptom, alleviate side effects of chemotherapy, improve sleep pattern, reduce stress and tension, reduce psychological distress/provide emotional support, improve well-being and quality of life, live with altered body image. (KINGHORN, 2001; LLOYD-WILLIAMS, 2008; TAVARES, 2003)

Gentle massage can be given to areas of the body no affected by cancer (there is no evidence that massage increases the spread of lymphoma or leukaemia cells and cancer it is not a contraindication to receiving gentle massage). Massage therapists are advised to be cautious over tumour sites because any mechanical force on the tumour may contribute to the pressure already taking place due uncontrolled growth of the cancer and may influence spread. Deep massage of any part of the body is not advisable for those with active cancer, in order to avoid trauma and activation of the immune response. (TAVARES, 2003; LLOYD- WILLIAMS, 2008)

Massage therapists, aromatherapists and reflexologists are trained to assess and screen for conditions in which treatment is contraindicated for any individual (e.g. pyrexial). Therapists with limited experience will need further training from experienced therapists in the use of the therapy in palliative care. In massage and aromatherapy it's necessary to avoid using any pressure directly on the area of cancer, avoid pressure work with patients who are taking anti-coagulation medication or who have low platelet count (some haematologists advise that patients with a platelet count of 50 000 or less are not to be treated with massage or aromatherapy). Be aware of the risks of massaging patients with areas of petechiae (pink bruising is an indicator of very low platelet count). Use gentle stroking or light, holding touch only, unless working in a specialist area and in consultation with the medical team. Avoid limb or foot with suspected or recently diagnosed deep vein thrombosis (check with clinical team, be aware of the signs and symptoms of deep vein thrombosis). Be aware that patients with advanced cancer or severely impaired mobility are more susceptible to low grade undiagnosed and asymptomatic deep vein thrombosis. Use gentle massage only. Avoid areas of bony metastases and use gentle stroking or light holding touch only. Only treat lymphoedematous

limbs or areas if working in conjunction with lymphoedema specialist nurse or physiotherapist. In the absence of specialists, refer to local policy or avoid working the area or limb. Avoid massaging over ascites (fluid retention in the abdomen) and use gentle stroking or light holding touch only. Avoid stoma sites, dressings, catheters and TENS (Transcutaneous Electrical Nerve Stimulation) machines. Be aware that patients have lowered immune function and more susceptible to infection. Be aware that the skin can be sensitive and/or paper thin due to medication and treatment, especially in elderly or cachectic patients. Use gentle touch only. Be aware of possible side effects, such as fatigue, soreness of skin, digestive disturbance. Avoid the entry and exit sites during and for 3-6 weeks following radiotherapy; check with the patient and assess whether the skin is still sensitive, tender and sore. Encourage the patient to seek advice from radiotherapy department regarding the use of gels and creams. Be also aware of possible side effects of chemotherapy on the whole person e.g. extreme fatigue, lowered immune function and increased risk of infection, increased risk of bruising, dryness or peeling skin, digestive disturbance, nausea, altered sensation in extremities, hair loss, altered behaviour or personality, skin sensitive to touch. Be aware that patients could have altered smell preferences. Consider using gentle massage only, as the patient may not be able to cope with even moderately energising or vigorous treatment. Modify pressure and adapt approach and duration of session to take account of the patient's preferences, and also the physical, emotional and energetic condition of the patient (e.g. use gentle stroking or light touch if the patient is very tired, unwell or emotionally label). Be guided by the patient's body language and clinical issues. Consider massaging part of the body only and in shorter sessions.

When using aromatherapy associated with massage be aware of respiratory conditions such as asthma, when used in a room where there are other patients or individuals with respiratory conditions, or different smell preferences or allergies. Use of electric vaporisers in the presence of oxygen. Use burners with caution: follow the health and safety policy of the organization with regards to risk of fire if using aromatherapy burners, for instance patients should not be left on their own at any time when a burner is used and burners should not be left unattended. It may be helpful to the patient and/or their carers for the therapist to teach them basic massage skills, with or without essential oils. Is the systematic use of essentials oils in treatment to improve physical and emotional well-being. The therapeutic effect of aromatherapy results from a combination of the physiological effects of the oils and the relaxation of massage. As the fragrance of the oils also stimulates the sense of smell, which elicits certain emotions, the limbic system of the mid brain, which is concerned with emotional as well as visceral function,

may be involved in the release of hormones which influence mood. The decision to use mix essential oils should only be made by aromathereapists who are registered with an appropriate professional body. Essential oils should only be used and mixed by aromatherapists following an assessment of the patient and screening for contraindications (ANNEXE XXXII). (TAVARES, 2003)

Massage therapists, practitioners of simple massage or carers who have been shown how to massage the patient should use blends made by aromatherapists for individual patient.

With Reflexology it's important to avoid a limb or foot with suspected deep vein thrombosis and avoid varicose veins. Be aware of any tender areas on the foot or hand that relate to new surgical wounds. Only treat lymphoedematous limbs or areas, if working in conjunction with a lymphoedema specialist. In absence of a specialist, refer to local policy or avoid working the area or limb. Avoid areas corresponding to colonic stimulation if there are any symptoms or risk of intestinal obstruction due to causes other than constipation. Adjust pressure for patients with low platelet count, taking note of any existing bruising and skin viability. A patient with platelet count of 50 000 or less are not to be treated with reflexology. Be aware that peripheral sensation may be affected by a person's psychological state, or medication, such as steroids, opioids or chemotherapy. Be aware that peripheral neuropathy may be a symptom of diseases such as multiple sclerosis and certain tumours, although diabetes is the most common cause of peripheral neuropathy. Palpate gently and sensitively over the reflexes relating to tumour site (s). Assess the condition of the reflexes and adapt treatment accordingly so that the feet are not overstimulated in any way, especially in patients with altered peripheral sensation or peripheral neuropathy. Establish a working pressure that is comfortable for the patient at all times, and tailor treatment to avoid strong reactions. Use fragrances free talcum powder or appropriate cream if skin is very dry. (TAVARES, 2003)

Acupuncture it's "A practice in Chinese medicine in which the skin, at various points along the meridians, is punctured with needles to remove energetic blockages and stimulate the flow of qi" (Jonas, 2005 in TAVARES, 2003). Several variations of the theme exist: stimulation by heat (moxibustion), pressure (acupressure), electrical current (electroacupunture), etc. In cancer patients it is mostly used for pain control, for alleviation of chemotherapy-induced nausea and vomiting, to treat radiation induced xerostomia, and to reduce vasomotor symptoms (ERNEST et al, 2006 in TAVARES, 2003).

Hypnotherapy is the practice of using hypnosis for the treatment of illness. Several RCTs (Randomized controlled clinical trials) have demonstrated the usefulness of hypnotherapy in palliative cancer care for controlling pain and nausea and vomiting (TAVARES, 2003).

Relaxation techniques such as imagery, breathing exercises, manual massage, music therapy, art therapy, and reflexology have been used to reduce symptoms and increase the quality of life in cancer patients. Imagery (thoughts, pictures, sounds, memories feelings, sensations) forms the basis for how we experience ourselves - our bodies, our relationships, our work, our environment and our emotional and spiritual lives. Guided imagery makes conscious and creative use of this faculty, to create a psycho-physiological change to reduce stress, adjust to change, and promote health and healing. (KINGHORN, 2001; TAVARES, 2003; LLOYD-WILLIAMS, 2008)

On the end of the session an evaluation form was given to the participants (ANNEXE XXXIII), the feedback was positive and an analysis chart of the evaluation form is presented in annexe (ANNEXE XXXIV).

Evaluation

*Participants of the formation training feedback (ANNEXE XXXIV);

*Tutor's feedback (ANNEXE XVIII).

6. Do a systematic revision of a set of articles from 2010 to 2015 on a theme of interest for the Palliative Care Team:

Activities

- Instead of doing a survey to understand the themes of interest for the Palliative Care Team like I proposed on the project I decided to go for the theme of continuous subcutaneous infusion by syringe driver for symptom control of patients at the end of life theme, because here in the UK it's use is widely spread and common and from my experience on the Portuguese health system its use is limited (after talking with the orientator, Manuel Luis Capelas, he also agreed that this could be a good theme to develop);
- Bibliography research and analysis of the articles of interest for set theme, the original plan was to research articles from 2010 to 2014, but because this was a short periods and 2015 articles were found, I decided to increase the interval to 2015, which also gave me more up to date articles;

- Written presentation of the resume/conclusions of the research on this report.

6.1. Continuous subcutaneous infusion by syringe driver for symptom control of patients at the end of life, a systematic review

A systematic review it's a research method that uses as a source of data the existing literature about a certain theme. This kind of research makes available a summary of the evidence related with a specific intervention strategy, using specific explicit systemized research methods, critical appreciation and synthesis of the selected information. Systematic reviews are useful to integrate information provided by a set of studies done separately about a certain theme that may present conflicting or coinciding results, as well as identifying themes that need evidence, giving guidance for future investigations. A systematic review allows to incorporate a larger spectre of relevant results, to evaluate the consistency and generalization of the results between populations or clinic groups, as well as specificities and variations of treatment protocols. A systematic review it's a retrospective secondary study. The review it's usually conducted after the publication of many experimental studies about the theme, so it depends of the quality of primary source. This systematic review does not include a Meta-analysis. The position occupied by the systematic review on the hierarchy of evidence illustrates the clinical and the research importance (research by level of importance being the first enunciated the most important and so on): randomised control trial, cohort study, case-controlled study, quasi-experimental study, descriptive study, experimental of a single case or series of cases, and expert opinion or case report. Different scales are used to evaluate the relevance of a study like the list of Delphi, PEDro, OTSeeker, Maastricht criteria, Jadad scale, Joanna Brigs Levels of Evidence Chart. The Joanna Brigs Levels of evidence chart is the one used to stablish the relevance of the articles for this systematic review (ANNEXE XXXV). Two independent reviewers are needed to conduct a search and assess the relevance of the articles for the review considering the selection criteria (Marta Calado, registered nurse with masters in palliative care and Vânia Lopes, registered nurse with post-graduation in palliative care). The systematic review follows the structure of an original article and it includes introduction, method, results and discussion. (SAMPAIO & MANCINI, 2007)

A literature review was undertaken to identify the most current evidence regarding syringe drivers management in effective symptom control of adults at the end of life under palliative care. The following databases were searched: CINAHL, Medline, Psycarticles and PsycInfo. The review was limited to adult patients and English language and covered a period of 5 years, from 2010-2015. Search terms included are: syringe drivers, subcutaneous infusions, end-of-

life care and palliative care. An internet search using the google search engine was also undertaken using the same search terms. This identified relevant websites relating to syringe driver management in symptom control of adults at the end of life under palliative care. In addition websites and books about syringe drivers devices identified as relevant to complete this chapter were examined. All abstracts identified during the search were assessed by two reviewers (mentioned above) and the relevant articles for the topic where retrieved (score of 3 or less on the Joanna Briggs Levels of evidence chart where used and the ones within the level 4 were also used because they're the latest articles on the subject). A total of 14 articles were used to do this systematic review.

A summary of the literature used to develop this systematic review is made on annexe, using charts (ANNEXE XXXVI).

Many patients requiring palliative care have multiple symptoms, which, if inappropriately managed, can have a significant impact on their overall comfort and wellbeing as they near the end of their life. The continuous subcutaneous infusion by syringe driver can be an effective mean to deliver continuous medication to control symptoms such as pain, nausea and breathlessness (DERBY-BURTON CANCER NETWORK, 2011; GABRIEL, 2015; MUKOREKA & SISAY, 2015).

A syringe driver is a portable battery-operated infusion device. It is used to deliver drugs at predetermined rate via the appropriate parenteral route (e.g. subcutaneous) and is suitable for symptom management and palliative care (DOUGHERTY & LISTER, 2015; MUKOREKA & SISAY, 2015)

Syringe drivers are used to aid drug delivery when the oral route is no longer feasible. Syringe pumps will not deliver a better analgesic effect than the oral route unless there is a problem with absorption or administration (DOUGHERTY& LISTER, 2015; WATSON et al, 2011).

The indications for the use of syringe drivers are intractable vomiting, severe dysphagia, diarrhoea, patients with bowel obstruction whose gut absorption may be impaired, poor alimentary absorption (rare), patients that are to week or nauseated to swallow oral drugs, decreased conscious levels, patients who are dying and no longer able to manage medication orally (GABRIEL, 2015; NORTHAMPTONSHIRE HEALTHCARE NHS, 2015).

Infusions of a single drug, such as an antiemetic or analgesic, do not generally cause problems with stability. The drug should be diluted with a suitable diluent (sodium chloride is

recommended for most drugs) and given over 12-24 hours. The combination can be problematic, there is anecdotal evidence regarding combination of drugs but not many pharmaceutical studies confirming compatibility. Combinations of up to four drugs have been reported but if compatibility is uncertain, it may be best to use a second syringe driver. It is also important to ensure that the diluent used is compatible with all the drugs in the infusion. It is recommended that infusions are not exposed to direct sunlight or to increase temperatures as drug instability may result. Hyaluronidase may be used to enhance the pharmacokinetics of drugs such as subcutaneous morphine (DOUGHERTY & LISTER, 2015; LORENZL, 2013).

Research has shown that the use of peripheral cannulas rather than steel winged infusion devices results in sites remaining viable for longer. Incidence of needle stick injuries may also be reduced. It is now recommended that subcutaneous infusion be given via plastic cannula. Administration of infusions of drugs requires the insertion of a 25 G winged infusion set or a 24 G cannula. These should be inserted at an angle of 45 degrees and secure with a transparent dressing to enable inspection of the site. (DOUGHERTY & LISTER, 2015).

Drugs administered by subcutaneous infusion include opioid analgesics, antiemetics, anxiolytic sedatives, corticosteroids, non-steroidal anti-inflammatory drugs and anticholinergic drugs (DOUGHERTY& LISTER, 2015).

Three common types of syringe drivers are currently used in the UK. The Graseby MS16A (calibrated in millimetres per hour), MS26 (calibrated in millimetres per day), currently being phased out of use. And the McKinley T34 (ml/h). When using syringe drivers training is essential as is awareness of your guidelines and regulations (WATSON et al, 2011; DOUGHERTY & LISTER, 2015; THOMAS & BARCLAY, 2015). Most sizes and brands of plastic syringes can be used with these devices, however, it is recommended to use Luer-Lok syringes to avoid leakage or accidental disconnection (HABERCHT, 2010; DOUGHERTY & LISTER, 2015).

The advantages of syringe drivers are: avoidance of the necessity of intermittent injections, allowing mixture of drugs to be administered, accuracy of infusion timing (particularly in the community, where it's not possible to constantly monitor rate), constant therapeutic levels, allowing mobility and independence (device is lightweight and compact), allowing rate to be increased, requires simple calculations of dosage over a 12 or 24 hour period, allowing patients to spend more time at home with their symptoms managed effectively, (SKEFFINGTON-

SHEEHY et al, 2014; WEST, 2014; DOUGHERTY & LISTER, 2015; NORTHAMPTONSHIRE HEALTHCARE NHS, 2015).

The disadvantages are: psychological dependence on the device by the patient, inflammation or infection at the insertion site of the subcutaneous cannula, rate calculation differs between certain syringe drivers which can be confusing for the nurse, the alarm system of some devices operates only if the plunger is obstructed (it does not alert the nurse if the rate is too slow or too rapid) (DOUGHERTY & LISTER, 2015; NORTHAMPTONSHIRE HEALTHCARE NHS, 2015).

Choice of site should be based on both thickness of subcutaneous tissue and patient convenience. Sites recommended for subcutaneous infusion of drugs are the lateral aspects of the upper arms and thighs, the abdomen, the chest and the scapula. If the patient is mobile and walking then the preferred sites are the chest or the abdomen. There are areas that shouldn't be used like lymphoedematous areas (absorption may be impaired and infection may be introduced); sites over bony prominences (there may be insufficient subcutaneous tissue); previously irradiated skin areas (absorption may be impaired); sites near a joint (movement may cause the cannula to be dislodge); any areas that are inflamed, infected or broken skin; sites of tumour, skin folds. Rotation of the site every three days should be routine in order to minimize site reactions although in some patients this may not be feasible so the infusion site must be monitored regularly and the device resited as necessary (LORENZL, 2013; DOUGHERTY & LISTER, 2015; NORTHAMPTONSHIRE HEALTHCARE NHS, 2015; THOMAS & BARCLAY, 2015).

Accurate documentation of the site, rate, flow, start time and drugs used is imperative in order to avoid confusion and errors amongst staff. Sites and tubing will need to be changed every 1-4 days. An aseptic technique should be used when preparing and setting up the infusion. Checks should be done at the start of the infusion (record date, time, start volume, infusion rate setting, name of person setting up infusion); based upon the type of infusion and patient's condition, however, at a minimum 15 minutes and 1 hour after the initial set-up and thereafter a minimum of every four hours; at the start of each shift and when setting up an infusion. The nurse should check and record the date, time, rate and volume remaining and that the battery/syringe driver is working; record any reasons for changing drug, dose, rate setting of syringe driver or site; check subcutaneous site (pain or discomfort, swelling or induration, erythema, leakage of fluid,

bleeding) (HABERECHT, 2010; DOUGHERTY & LISTER, 2015; NORTHAMPTONSHIRE HEALTHCARE NHS, 2015)

Some drugs are particularly likely to cause irritation and may need to be diluted in a greater volume of diluent, cyclizine and levomepromazine are amongst these. This may result in skin sites that break down rapidly or site reactions. The nurse can prevent this by checking compatibility of drugs and diluents and consider changing the drug combination; by diluting the solution as much as possible or change the diluent, by rotating site every 72 hours; by using an non-metal cannula; by using a different site cleanser; by changing the dressing used; by considering adding dexamethasone1 mg into the pump (this may be helpful but it's not currently recommended for routine use), care should also be taken as dexamethasone is incompatible with a number of drug combinations. (WATSON et al, 2011; MITCHELL, 2012; LORENZL, 2013; DOUGHERTY & LISTER, 2015; GABRIEL 2015)

The following drugs may be mixed with morphine sulphate (opioid) or diamorphine (strong opioid) cyclizine (antiemetic), clonazepam (benzodiazepine), haloperidol (antipsychotic/antiemetic), hyoscine hydrobromide (antimuscarinic/antiemetic), metoclopramide (antiemetic), octreotide (antiemetic), hyoscine butylbromide (antimuscarinic), glycopyrronium (reduces secretions), levomepromazine (antiemetic and sedation), midazolam (short acting benzodiazepine) and ondasetron (antiemetic) (WATSON et al, 2011). Drugs not suitable for subcutaneous usage are diazepam (anxiolytic), chlorpromazine (antipsychotic), prochlorperazine (antiemetic). To check Compatibility of drugs it's important to check regularly for precipitation and discolouration and discard if it occurs. Cyclizine may precipitate at high doses, particularly in combination with high doses of diamorphine. Other combinations may also cause cloudiness in the syringe. On rare occasions a patient may need two or three separate syringe drivers to separate the drugs. With combinations of two or three drugs in one syringe a larger volume of diluent may be needed, e.g. 20 or 30 ml syringe. Cyclizine is incompatible with 0,9% sodium chloride if needing to use a dose of cyclizine greater than 75mg/24 hours in conjunction with a dose of diamorphine greater than 160mg/24 hours, a 20 ml syringe containing water for injection as diluent should be used. Levomepromazine can be irritant. If skin site soreness becomes a problem, it is recommended to dilute it with 0,9% sodium chloride rather than water for injections. However, please note if diamorphine is combined with levomepromazine, 0,9% sodium chloride can only be used when diamorphine concentration is less than 40mg/ml. if the diamorphine concentration exceeds 40mh/ml, water for injection should be used. If skin site soreness is a problem in this instance, increase the size

of syringe used. If other drugs are in the syringe, check if these are compatible with 0,9% sodium chloride. Use a separate syringe driver for dexamethasone (unless low dose for skin reactions), phenobarbital (anticonvulsant/sedation), diclofenac (anti-inflammatory non steroid), ketamine (neuropatic pain), ketorolac/parecoxib (COX inhibitor, painkillers/sedation). Care should be taken when mixing more than two drugs in a syringe and in ensuring that the diluent used is compatible with the drugs. Water for injection or 0,9% sodium chloride can be used as diluent but water for injection must be used with cyclizine and doses of diamorphine greater than 40mg per ml. (GRPCC CLINICAL PRACTICE GROUP, 2011; WATSON et al, 2011; LORENZL, 2013)

The majority palliative care patients wish to be cared for at home and most of them wish to die at home. Informal carers, usually family members, play an important role in allowing the patients to remain at home, which includes significant input to symptom control management and this can be a stressful and difficult experience for caregivers. Patient and family education promotes safety and acceptance of the syringe driver as a means to providing improved symptom control. Patient and family should be informed about what the device will do, and its advantages and possible disadvantages; safety aspects; ways to incorporate a subcutaneous infusion into their everyday life; troubleshooting guidelines. When educating patient and NOK/carers it's important to outline that syringe driver devices are very reliable; that it's normal for the syringe driver to make a whirring noise every few minutes (it shouldn't be so loud that others are able to ear or to keep them awake); it is normal for a green light to flash on the right hand side of the machine (if this light stops, the battery needs to be changed), instruct the patient to keep a spare 9 volt battery; encourage the patient to get into the habit of checking that the light is flashing and the whirring sound is coming from the machine but not to worry overnight; the machine as an alarm which is a constant and piercing sound, eventually the alarm will turn itself off, instruct the patient not to panic if it alarms and that it will alarm if the syringe is empty or there's a blockage in the tubing. That when carrying the syringe driver they can use a belt bag and carry it discreetly. That the syringe driver must not be immersed in water and it can be damaged by steam (it's possible to disconnect the syringe driver for a short period but this shouldn't be encouraged). That the patient may need reassurance (if they continue to experience some pain, breakthrough medication can be given in these occasions). That if the patient is worried that the device is not working properly the following guidelines should be followed: if the alarm sounds, reassure patient that it is likely to be an easy problem to rectify; check the light on the right hand side of the device (if not flashing change battery and press the

button labelled "start/boast" and light should begin to flash); if the alarm is sounding take out the battery (that is the only way to stop the alarm and check if there is a kink in the tube- untwist it, if the syringe is disconnected from the machine- attach it again, if the syringe is empty or the cannula as come out, or if the cannula site is swollen, painful, the patient will ned to contact their healthcare provider). (SHEEHY-SKEFFINGTON et al, 2014; NORTHAMPTONSHIRE HEALTHCARE NHS, 2015)

The use of syringe drivers in palliative care to achieve symptom control is standard and accepted practice. There are many benefits that syringe drivers present to the patient in terms of convenience and effective management of symptoms. However use of this device has not been without risks and limitations, including the flexibility of prescription, technical problems, safety issues and skin reactions at the site of the infusion: syringe drivers may also cause concerns and fears to some patients and their NOK/carers because they are associated with disease progression. (SHEEHY-SKEFFINGTON et al, 2014)

Evaluation

*Shows knowledge and domain of the theme studied on the written presentation in this report (ANNEXE XVIII).

As part of the internship I need to show management abilities. Considering that it's important to clarify that nurses exercise their management activities on three levels, the operational, intermediate and strategic. The goal of the management is to promote patients safety, to prevent, treat and rehabilitate or palliate patients, through the management of nursing care, the management of services /departments or organizations, the management of competencies of the available resources and the management of the dynamics of the health system. The responsibility of the manager nurse is to plan, organize, conduct, and evaluate the work process that involves care to the patient, always focused on the quality and satisfaction of the patient in relation to the provided services. Nurses need to continuously improve their knowledge so that they can support scientifically their management performance on the work process. It's through knowledge that the nurse develops competencies that make them confident in the decisions made in the conduction of the work process. Considering this, the goals/skills I set myself to accomplish during this internship are related with management, mostly management of the care given to the patient, family and carers and management of the needs for formation/training to get the knowledge to develop competencies to evaluate and assure the quality of care given to patient, family and carers (LAZZAROTTO & FIEWSKI, 2004).

Evaluation

*Able to manage the care given to patient, family and carers (ANNEXE XVIII);

*Able to manage the needs of formation/training that influence the quality of care given to patient, family and carers (ANNEXE XXXIV).

4-Conclusion

This last chapter presents the main reflections and the global appreciation of the internship and the main learning outcomes for my professional and personal life as a nurse. The purpose of this document is to describe the several dimensions and activities observed, approached and performed during the internship.

The acquired and developed skills are related with communication with patient, carers and family to better understand their wish and to allow them informed decisions about their care; between the different members of the MDT and the different settings of Palliative Care in order to provide the best possible quality of life to patient, family and carers; and between staff in order to support each other and also to understand the needs for formation of the team, being able to answer them, through the preparation of a training session in a theme chosen by them. It was very rewarding for me doing the training session, it allowed me to review and deepen my knowledge in Agitation and Restlessness at the end of life and to make me understand that sometimes the original plan for training session needs to be adapted if we want to consider the audience and their interests and areas of intervention. The original session was longer and had more medical information, in order to adapt it to the audience, staff nurses and nursing assistants, so no one with feel bored by this presentation, I had to adjust the original plan. The evaluation was positive and made think that the extra work of adjustment was worthwhile.

The internship allowed me to observe in loco the Palliative Care network in the UK and how this impacts the lives of the patients under Palliative Care and the way they live the last days of their lives. We can see patients staying at home, like they wish, with all the support needed. The study case and the placements at different settings were really important to make me see how the network work (acute setting, Hospice with Inpatient Unit and Day Hospice and community setting) and allowed me to see the work methods of the different setting of care.

It also allowed me the acknowledgement of the proved use of continuous subcutaneous infusion by syringe drivers for symptom control at the end of life in the UK, with concretion of the systematic review on the theme, that can also be adopted by the Portuguese health system, for patients at the End of Life under Palliative Care, so that they can also have the best possible quality of life, relying on the existing and proved technology.

The most positive aspects of this internship were the MDT work, with frequent MDT meetings, that allow good communication between the members, in order to provide the best possible quality of life to the patient, family and carers; open communication between multidisciplinary team and patient, family and carers, trough family meetings at the ward; the possibility for the family and carers to stay with their loved ones the time they wish with a family room for them to spend the night; the importance given to Advance Care Planning, to understand the patient's wishes and to give information so that the patient can make informed decisions about their future care; warming and cosy environment, with lots of light, surrounded by green spaces that the patients, even if bed bound, could access if desired; the two deep Jacuzzi baths available for the inpatients; the support given to staff; access to complementary therapies on the Inpatient Unit and Day Hospice; the Day Hospice services and support offered; the time spent in the acute setting to understand how it relates with St Catherine's Hospice; and the community services offered that allow patients to remain at their preferred place of care for as long as possible.

The less positive aspects of this internship are related with the fact that while doing it I was working full time at East Surrey Hospital, and sometimes because of this I felt really tired, and that tiredness sometimes stopped to make the most of this, already great, personal and professional experience; the fact that there's only one family room at the Inpatient Unit; and because I consider, from my experience that the Hospice gives excellent care more people could benefit from it if there were more inpatient beds and more staff.

My main goal with this internship was to use all the learning opportunities to better myself as a Palliative Care Nurse and the bibliographic research was a constant trough out the internship to clarify doubts and to have a scientific base for the actions behind the activities that I set myself to do and the activities performed. Analysing the goals and the activities done to reach I conclude that this was a positive experience with very positive outcomes for my personal and professional life.

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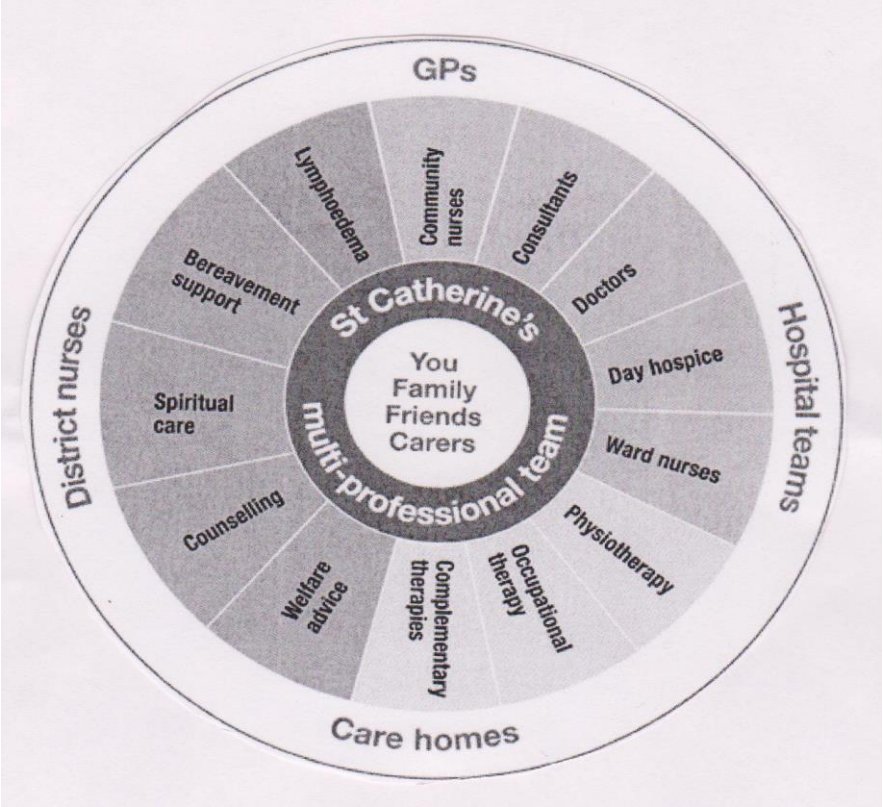
ANNEXES

ANNEXE I

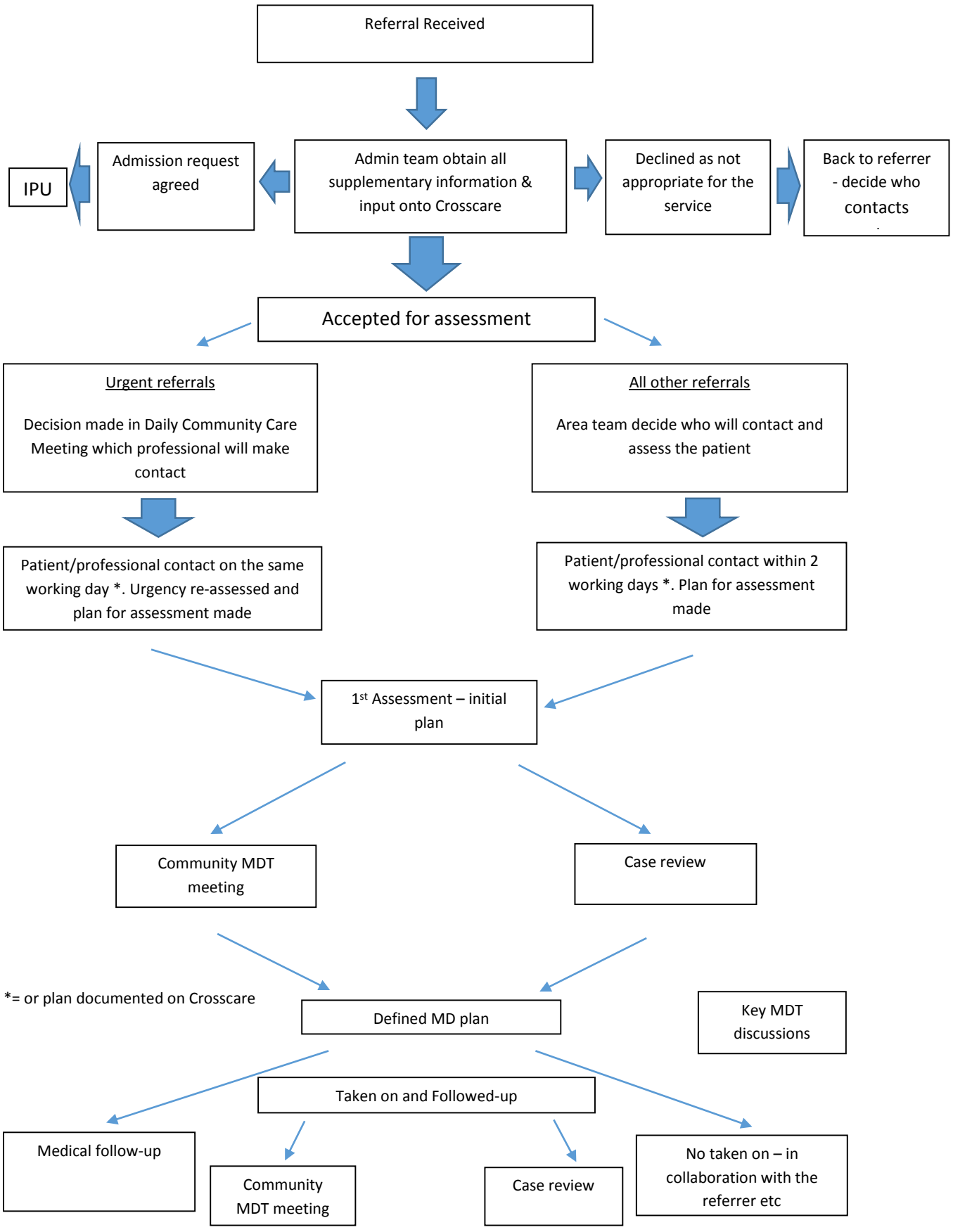
ST CATHERINE'S HOSPICE MULTIPROFESSIONAL TEAM DIAGRAM



- http://www.stch.org.uk/healthcareprofessionals/multiprofessionalteam/teamdiagram, accessed 30/12/2015.

ANNEXE II

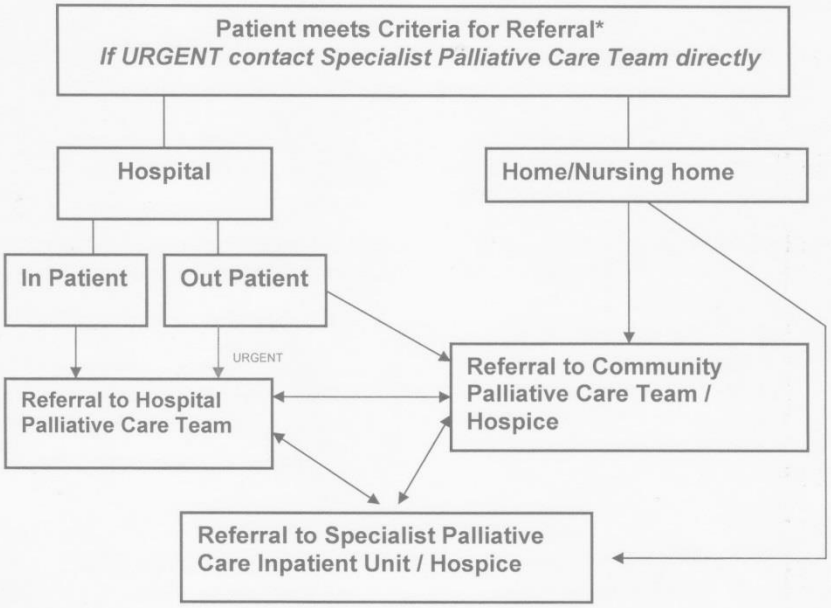
PATIENT REFERRAL PATHWAY (PRP)



ANNEXES III

Referral Guidelines and Pathway for Specialist Palliative Care

SWSH Palliative and Supportive Care Network



***Criteria for Referral**

Most patients will have an advanced, progressive disease, where the focus of care will have changed from curative to palliative and the prognosis is limited. Some patients, who have specialist complex needs, can be referred at an earlier stage, from diagnosis onwards. Patients may be discharged if their condition stabilises.

- A demonstrable need for specialist palliative care must be established. Appropriate reasons for referral may include potential/existing difficulties with the following:
  - Pain and symptom management
  - Meeting the psychological, social and spiritual needs of the patient, their family, and / or significant others.
  - Terminal care/dying
- Where possible, the patient, and if not, the carer, should be informed and in agreement with the referral
- Any Health Care Professional can refer to the Specialist Palliative Care team, but acceptance must be with the agreement of the GP / Inpatient Consultant

Criteria for Urgent Referral: needing advice/assessment within 1-2 working days.

- Difficult physical / psychological symptoms causing distress and *not responding* to current management
- Rapidly deteriorating condition

N.B. For urgent referrals, direct contact with palliative care team is needed to discuss each situation individually

ANNEXE IV

☐ TELEPHONE/FAX ☐ FACE TO FACE ☐ CANCER SERVICES ALERT

REFERRAL TO PALLIATIVE CARE TEAM

Patient name			
dob		Hospital No.	
Location		Consultant	
Date of referral		GP name: Address:	
Time			

Diagnosis

Do they have cancer?	Yes		No	
If yes, where is cancer?				
If no, what is diagnosis?				

Reason for referral (tick all that apply)

Symptom control		Terminal care	
Discharge planning		Psychosocial support	
Other			

Is Patient Aware of Referral? (please tick)

Yes		No	

Urgency of Referral (tick most appropriate)

Same day	
Next working day	
Over next week	

Details of referrer

Name		Contact no.	

Designation (please tick)

Doctor		GP	
Ward Nurse		OT/Physio	
Hospital Nurse Specialist		Community Team	
Discharge Liaison Team		Other	

Who has referral been discussed with and what is outcome?

.....

PLEASE ASK MEDICAL TEAM TO WRITE THE REASON FOR REFERRAL IN MEDICAL NOTES

Date admitted:		
Presented with:		
Past medical history:		
NHS no:		
Please check that all contact details are correct:		
Patient's address:		
Tel:		
NOK name/relationship:		
Address:		
Tel:		
First Assessment:		
Physical:		
Psychological:		
Spiritual:		
Information:		
Carer:		
Known to Hospice:	☐ Yes	☐ No
DNAR:	☐ Yes	☐ No
Preferred place of care	Now:	EOL:
Medications:		
Allergies:		

ANNEXE V

St Catherine's Hospice Internship

Timesheet Andreia Monteiro

Day & Date	Time from	Time to	Break	Total	Signature
25/05/2015	7:00	20:30	1hour	12.5	
02/06/2015	7:00	20:30	1hour	12.5	
03/06/2015	7:00	20:30	1hour	12.5	
11/06/2015	7:00	20:30	1hour	12.5	
1/07/2015	7:00	20:30	1hour	12.5	
2/07/2015	7:00	20:30	1hour	12.5	
9/07/2015	7:00	20:30	1hour	12.5	
10/7/2015	7:00	20:30	1hour	12.5	
16/7/2015	7:00	20:30	1hour	12.5	
22/7/2015	7:00	20:30	1hour	12.5	
23/7/15	7:00	20:30	1hour	12.5	
18/8/2015	7:00	20:30	1hour	12.5	
2/9/15	9:00	16:30	30min	7h	
16/9/15	7:00	16:30	30min	9h	
22/9/15	7:00	15:00	30min	7.5	
25/9/15	7:00	17:30	30min	10h	
9/10/15	7:00	17:30	30min	10h	
10/10/15	7:00	19:00	30min	11.5	
13/10/15	9:00	17:00	1hour	7h	
17/10/15	7:00	20:30	1hour	12.5	
20/10/15	8:00	16:00	1hour	7h	
21/10/15	9:00	17:00	1hour	7h	
23/10/15	7:00	20:30	1hour	12.5	

Day & Date	Time from	Time to	Break	Total	Signature
27/10/15	9:00	17:00	1 hour	7h	
29/10/15	7:00	17:00	30 min	9.5	
02/11/15	8:00	16:30	30 min	8h	
06/11/15	7:00	20:30	1 hour	12.5	
10/11/15	7:00	20:00	1 hour	12 hours	

St Catherine's Hospice Manager

Name: D. CHARMAN

Signature:

East Surrey Hospital Palliative Care Team Manager

Name: ELAINE EDWARDS

Signature:

ANNEXE VI

ST CATHERINE'S HOSPICE INTERNSHIP CRONOGRAM OF ACTIVITIES

MONTHS ACTIVITIES	February	March	April	May	June	July	August	September	October	November
Bibliographic research										
Internship project										
Placement at East Surrey Hospital										
Understand the goal of the palliative care team										
Refer patients to the palliative care team										
Facilitate dying with dignity and comfort										
Ensure good communication with patient, family and carers										
Internship report										
Oral presentation of internship report										
Participation of activities plan for formation										
Systematic revision										

ANNEXE VII

SUMMARY OF ST CATHERINE'S HOSPICE DNA CPR POLICY

St Catherine's Cardiopulmonary resuscitation (CPR) policy states that CPR is a clinical intervention undertaken with the aim of restoring breathing and circulation in an individual who has suffered a cardiac and/or respiratory arrest. There evidence that the survival rate following CPR for a cardiopulmonary arrest occurring outside of the acute hospital setting is low. CPR is unlikely to be clinically successful when an individual is in the final stages of an incurable illness, may prolong or increase suffering and subject the patient to an undignified death. When an individual is in the final stages of an incurable illness a decision may be made that they should not undergo CPR (Do Not Attempt Cardiopulmonary Resuscitation- DNA CPR). This will be an appropriate clinical decision for the majority of patients under the care of St Catherine's Hospice however there may be circumstances when CPR could be successful for a few patients. The principles which inform decisions about CPR are based on the following documents: NHS South East Coast Do Not Attempt Cardiopulmonary Resuscitation principles; Treatment and care towards the end of life: Good practice in decision making General Medical Council, July 2010; Mental Capacity Act 2005. This policy and use of DNA CPR paperwork applies to adults over 16 years of age. CPR is a clinical intervention and should only be offered if there is a reasonable expectation that the patient will benefit from this intervention. Any decision about CPR will be based on individual clinical circumstances and in accordance with ethical and legal guidance. A DNA CPR applies to CPR only. It may be appropriate to suspend a DNA CPR decision if the patient undergoes a procedure that may increase the risk of a cardiopulmonary arrest. This must be discussed with the patients and a decision made as to when the DNA CPR should be reinstated if it is suspended.

ANNEXE VIII

SUMMARY OF ST CATHERINE'S HOSPICE POLICY ON ADVANCE CARE PLANNING

Patients have a fundamental, legal and ethical right to determine what happens to their own bodies. It is a general and legal principle that valid consent must be obtained before starting treatment or physical investigation, or providing personal care, for a person. Seeking consent is also a matter of common courtesy between healthcare professionals and patients. If a healthcare professional does not respect the principle they, and their employing organization, may be liable to legal action and/or allegations of battery (under "common law") or negligence. The department for Health, General Medical Council and Nursing and Midwifery Council (as well as other professional and regulatory bodies) have issued a range of guidance documents on consent and these should be consulted for details of the law and good practice requirements. All health care professionals have a responsibility to keep up to date with the changes that may occur to the current guidance on consent as a result of legal developments. All health care professionals should be aware of the Human rights act 10 and be compliant with it in their practice. St Catherine's hospice policy for Consent and patient choice scope is to set standards and procedures at St Catherine's Hospice which aim to ensure that health care professionals are able to comply with the guidance on consent. This policy focuses on consent and patient choice for episodes of direct patient care (provision of personal care, procedures such as phlebotomy, paracentesis, and pleural tap, undertaking observations, such as pulse, blood pressure, administering medications, providing counselling or spiritual care, physiotherapy or occupational therapy interventions). All health care professionals have a duty to have regard for the Mental Capacity Act's code of Practice which makes it an offence to ill-treat or wilfully neglect someone who lacks capacity when responsible for their care or decision-making powers. A person must be assumed to have capacity to make a particular decision at the time it needs to be made unless it is established that they lack capacity. If there is any doubt about an individual's capacity to make a decision, their capacity must be assessed by using the guidance set out in the Mental Capacity Act Code of Practice. If a patient has a valid and applicable advance directive this has the same force as a contemporaneous decision to refuse a treatment. No-one can give consent on behalf of an individual lacking capacity unless they are acting in their position as a Lasting Power of Attorney or a Court Appointed Deputy. Essential care encompasses measures required to keep an individual comfortable. It concludes warmth, shelter, actions to keep a person clean and free of distress and the offer of food and water by mouth. Patients should always be offered essential care and it should always be provided unless it is actively resisted by a patient. Refusal of essential care by a patient with capacity should be

respected although it should continue to be offered. Advance decisions made under the Mental Capacity Act cannot refuse actions that are needed to keep a person comfortable. The Act allows healthcare professionals to carry out essential care in the best interests of a person who lacks capacity. Health care professionals have a legal duty to care for a patient and prolong life, however, it is recognised that are circumstances where life sustaining treatment stops being of benefit to a patient and is not clinically indicated. In these circumstances discussions must be had with the patient to decide an ongoing plan of management and decisions made in best interests (in accordance with the Mental Capacity Acct) where the patient lacks capacity. Comfort and dignity should always be maintained through the appropriate care. There is no legal distinction between withdrawing and withholding life-sustaining treatment. It must be recognised that these actions are distinct from any deliberate action to end life which is unlawful. If the patient has capacity and (fully informed) refuses life sustaining treatment, this decision must be complied with. Not to do so is unlawful. If the patient has a valid applicable advance directive this has the same force as a contemporaneous decision to refuse treatment. A patient with capacity cannot legally demand treatment that is not clinically indicated. When making a best-interest decision in relation to life sustaining treatment in an individual who lacks capacity, healthcare professionals should be aware that the Mental Capacity Act requires that the healthcare professional must not be motivated by a desire to bring about the person's to death.

Advance care planning requires understanding of potential diseases course and problems, consideration of preferences and priorities, capacity to make and convey decisions, communication, and collaboration. Capacity is the ability to make decision free from pressures, it is independent of age, race, and illness. A person should be assumed to have capacity unless established otherwise. All reasonable steps should be taken to enable capacity. Capacity requires the ability to understand relevant information, retain information for long enough to make a decision, weigh up information relevant to the decision, communicate the decision by any means. A person lacks capacity if their unable to make a decision for themselves due to impairment of their mind or brain (it may be temporary or permanent). If the decision cannot wait, the multidisciplinary team should act within the terms of the Mental Capacity Act. People with capacity have the right to make unwise or unpopular decisions, but they do not have the right to expect others to compromise professional, legal or moral codes. The Mental Capacity Act of 2005, fully effective from October of 2007 in England and Wales, applies to adults (over 16) who lack capacity to make decisions for themselves (people at the end of life, dementia

patients, and people with learning disabilities). It also covers a wide range of decisions on personal and financial welfare. It defines the conditions for making decisions in the patient's best interest (any decision must not be motivated by desire to bring about death), different powers of attorney, regulates advance decisions to refuse treatment, defines statutory rules and public bodies, regulates research, and defines criminal offence of ill treatment or neglect. When acting in a patient's best the multi-disciplinary team should consider potential benefits, harms and risks of proposed care or treatments, information given by NOK/carers (patient's priorities and wishes), statement of values/wishes, valid and applicable advanced decisions, views of anyone named by patient to be consulted (carers, lasting power of attorney, court appointed deputy). Advance decisions to refuse a specific treatment are binding but to request a medical treatment are not. The Act states that an advance decision to refuse treatment must refer to specified circumstances and be both valid and applicable. An advance decision is not valid if the patient has withdrawn it, the patient has capacity, the patient subsequently created lasting power of attorney (person appointed by patient while he has capacity to make decisions about patients personal welfare -health and care- and personal property, when patient lacks capacity, on patients best interest, it must be registered with the Public Guardian, can extend to give or refuse consent), conferring authority to consent or refuse treatment, patient has clearly done anything consistent with negation of the advance decision, the treatment in question is not specified in the advance decision, any circumstances specified in the advance decision are absent, and there are reasonable grounds to believe the circumstances exist which the patient did not anticipate when he made the advance decision and which would have affected the decision if they have known. The additional rules for relevant life sustaining treatment are for the patient to state that the advance decision is to apply to the specified treatment if their life are at risk, it must be written and signed by the patient or by another on patient's behalf, acknowledged by patient in the presence of a witness, and signed by a witness. If the professional is satisfied that the advance decision to refuse treatment is valid and applicable, he would be liable for assault if he carried out or continued the specified treatment despite that advance decision. The patient should be encouraged to plan while he can considering the likely disease course and problems, to explore preferred priorities of care, to document and display, to understand and work within the legal responsibilities and ethical framework.

- www.opsi.gov.uk/acts/acts2015, accessed 15/12/2015

ANNEXE IX

NHS PROCESS FOR FAST TRACK

The whole of the decision-making process should be “person-centred”. This means putting the individual and their views and the care and the care and support required at the centre of the process. It also means making sure that the individual plays a full role in the assessment and decision-making process and gets support to do this where needed. This could be by individual asking a friend or a relative to help them explain their views. The first step for most individuals is the Checklist Tool. This is a screening tool to help health and social care staff judge whether it is appropriate to undertake a full assessment for NHS continuing healthcare. The Checklist will usually be completed when someone is assessing or reviewing health or social care needs. The checklist does not indicate whether the individual is eligible for NHS continuing healthcare, only whether they require full assessment of eligibility for NHS continuing healthcare. If the Checklist has been completed and indicates there is a need to carry out a full assessment of eligibility for NHS continuing healthcare, the individual completing he Checklist will contact the patient’s Clinical Commissioning Group (CCG) who will arrange for a multidisciplinary team to carry out an up-to-date assessment of the patient’s needs.

A multidisciplinary team is made up of two or more health or social care professionals who are involved in the patient’s care. The assessment will, with the patients permission, involve contributions from all of the health and social care professionals involved in the patient’s care to build an overall picture of all the patient’s needs. In some cases the multidisciplinary team will ask for more detailed specialist assessments from these professionals. The multi-disciplinary team will use information from the patient’s assessment to complete a “Decision Support Tool”. The Decision Support Tool looks at eleven types of need, for example, mobility, nutrition, and behaviour. The purpose of the tool is to help decide on the nature, complexity, intensity and unpredictability of the patient’s and so whether the patient have a “primary health need”. The multi-disciplinary team will then make a recommendation to the CCG as to whether the patient is eligible for NHS continuing healthcare. The CCG should usually accept this recommendation except in exceptional circumstances.

ANNEXE X

SUMMARY OF ST CATHERINE'S POLICY ON COUNSELLING – BEREAVMENT

The counselling/bereavement service is available where difficulties clearly relate to loss at St Catherine's Hospice.

Family and carers can be offered up to twelve sessions, renewable under exceptional circumstances.

Patients and their family and friends can access to relevant services during their illness and St Catherine's Hospice Counsellor team expect that these are accessed at times of crises and changes in condition, should the anticipatory change to bereaved, the need will be reassessed. Family and carers will be offered an agreed number of sessions extendable by review.

ANNEXE XI

Authorization request for data use on study case for Masters in Palliative Care report by Andreia Monteiro

I, Andreia Marlene da Silva Monteiro, doing a placement in Palliative Care at St Catherine's Hospice. Declare that I've asked permission to the patient and his NOK (wife) to use his data for a study case and informed that this study case will be a part of the report for the masters in Palliative Care that will be presented at the University. Patient and NOK where informed that his data will remain anonymous and opportunity to assess the final work when it's finished was given to the patient and NOK, that was refused. This request was witnessed by Staff Nurse in charge on the 16-07-2015, Andrew Knight. Patient and NOK gave me permission to use his data on the study case.

This document is signed by me and the witness to this request.

22/07/2015

Andreia Monteiro

Signature Andreia Monteiro

Andrew Knight

Signature

ANNEXE XII

FAST TRACK FUNDING

If the patient needs an urgent POC due to rapidly deteriorating condition which may be entering a terminal phase, then the Fast Track Tool may be used instead of the Decision Support Tool to confirm eligibility for NHS continuing healthcare funding. If this is the case, an appropriate clinician will complete the Fast Track Tool and send directly to the CCG which will arrange for care to be provided as quickly as possible. Occasionally, a CCG may arrange for a review of the patient's needs and arrange a Decision Support Tool to be completed after immediate support has been provided following the completion of a Fast Track Tool. This could lead to a decision that the individual is no longer eligible for NHS continuing healthcare funding. Following every assessment or review the patient should receive a written decision as to whether they are entitled to NHS continuing healthcare together with reasons for the decision. If the patient is entitled to NHS continuing healthcare, the CCG will discuss options with the patient as to how their care and support needs will be best provided for and managed and their preferred setting in which to do that (e.g. at home or in a care home) and which organisation/s will be responsible for meeting their needs. When deciding on how their needs are met, the patient's wishes and expectations of how and where the care is delivered should be documented and taken into account.

ANNEXE XIII

SUMMARY OF ST CATHERINE'S HOSPICE POLICY ON PATIENT AND FAMILY SUPPORT TEAM (PFST)

St Catherine's Hospice PFST counselling is available from the time someone is referred to the Hospice until long after bereavement.

The PFST aims to provide a high quality emotional support service working within hospice policies and within standards set by national service guidelines. In conjunction with the MDT the counselling service aims to offer support to the multi-professional team in dealing with the psychological care of the patient ant the family, emotional support to the patients of St Catherine's Hospice in their acceptance of and preparation for death, support those close to the patient during the illness and during the bereavement process, an emotional support service offering various levels of support (this will be accessed following an assessment of the patient's needs), the service compromises volunteers bereavement support and volunteers student and qualified counsellors who have been recruited through the volunteer services department (the team have attended loss awareness training and relevant mandatory and compulsory training), the service will endeavour to respond to patients needs through audit and evaluation. All members of the emotional support team work within both hospice policies and procedures and within professional guidelines. The Hospice provides a confidential patient-centred approach to emotional support ensuring protection of the patient's identity. The service provides assessment of need within a MDT approach; identification of risk around bereavement; confidential anticipatory counselling and emotional support to inpatients (IP), community patients and families; bereavement counselling; bereavement support; support groups. The PFST service is provided by a multi-professional working contracted counselling time, volunteer counselling time, volunteer counselling time, referring on to other supporting agencies within the local area where appropriate, identifying when patients need referring. The service is provided to patients under the care of St Catherine's Hospice, families and friends with a close link to the patient. Service is provided for bereavement (counselling/bereavement I available where difficulties clearly relate to the loss and up to twelve sessions can be offered, renewable under special circumstances) and anticipatory (patients their family/friends can access relevant services during their illness and this is expected to be at times of crisis/changes I condition, should the anticipatory change to bereaved, he need would be re-assessed, the patients will be offered an agreed number of sessions, extendable by review). The service is accessed through contact with Hospice, referral from GP, referral from ward or St Catherine's team, Request from East Surrey hospital, self-referral, other professionals, other Hospices.

Counselling works by giving the patient a chance to be heard. The counsellor will give the patient time to talk, cry, shout or just think. It is an opportunity to look at a problem in a different way with someone who will respect and explore patient's opinions and decisions with them. PFST counsellors respond to individual needs and seek to support patients, families and carers in the most appropriate way at the most appropriate time. They arrange to see the patient on an individual basis and will talk the patient through any of the issues or experiences that are giving concern to the patient. Every counsellor has their own style and way of working but broadly speaking the counsellor will help the patient trough the following three steps: exploring patients experiences (the nature of patients problems and the impact their having on them, the history of how the problems arose and the changes the patient would like to see); understanding patients experiences (why the patient is struggling with the problem he´s presenting and what may be stopping the patient from overcoming them); working with patients experiences (finding the strength and resources to resolve patients difficulties or at least make them more bearable). Initially St Catherine's Hospice offers six sessions which can take place at home if the patient is unable to go to the Hospice. The sessions are confidential within certain professional limits as all counsellors attend to regular clinical supervision. As the PFST is an integral part of the wider hospice team there may be a need to share appropriate information with the multidisciplinary team: If the patient feels uncomfortable with this that can be discussed with them. Initial calls to the PFST will be handled by the PFST Co-ordinator who will pass the patients details on to a member of the counselling team. If the patient call when the line is busy or out of hours they will be automatically diverted to the hospice's confidential voice mail facility. The patient can leave a message that will be returned. The patient can also contact the counselling team by speaking to another member of the hospice staff.

ANNEXE XIV

SUMMARY OF ST CATHERINE'S HOSPICE POLICY ON COMPLEMENTARY THERAPIES

It is considered that the following therapies can be relaxing and balancing for the body and mind and are therefore offered by St Catherine's:

- Massage
- Aromatherapy relaxation
- Reiki

Volunteers and/or paid qualified therapists offer these therapies to patients who choose to have them.

All patients will be referred for therapies via the internal referrals windows on Crosscare (St Catherine's informatics program of multidisciplinary registration)

Relatives and carers may also be referred for therapies via the referral window on Crosscare. Therapies will be offered to this client group according to supply, with patient need taking priority if demand is great.

All referred patients will be initially assessed by Team Leader, Day Services.

Volunteers and/or paid qualified therapists report to and are managed on a day to day basis by Team Leader, Day Services.

All complementary therapists must have proof of qualification with recognised training organisation to practice within specified remit.

All complementary therapists must have their own insurance.

Documentation will be completed as per hospice policy on Crosscare.

ANNEXE XV

NHS FUNDING GUIDELINES

A patient can receive NHS continuing health care in any setting, including at patients home or in a care home. NHS continuing healthcare is free, unlike support provided by local authorities for which a financial charge may be made depending on patient's income and savings. If the patient is found eligible for NHS continuing healthcare in its own house, this means that the NHS will pay for healthcare (e.g. services from community nurse or specialist therapist) and associated care needs (e.g. personal care and domestic tasks, help with bathing, dressing, food preparation and shopping). It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If the overall assessment of care needs shows that the patient have a "primary health need", it should be eligible for NHS continuing healthcare. Once eligible for NHS continuing healthcare, patients care will be funded by the NHS, this is however, subject to regular reviews, and, should patients care needs change, the funding arrangements may also change. Whether someone has a "primary health need" is assessed by looking at all of patients care needs and relating them to four key indicators: nature (this describes the characteristics and type of the individual's needs and the overall effect these needs have on the individual, including the type of interventions required to manage those), complexity (this is about how the individual's needs present and interact and the level of skill required to monitor the symptoms, treat the condition and/or manage the care), intensity (this is the extent and severity of the individual's needs and the support needed to meet them, which includes the need for sustained/ongoing care), unpredictability (this is about how hard it is to predict changes in an individual's needs that might create challenges in managing them, including the risks to the individual's health if adequate and timely care is not provided).

ANNEXE XVI

SUMMARY OF ST CATHERINE'S HOSPICE REFERRAL POLICY

St Catherine's Hospice provides specialist palliative care to people within the local catchment area as well as support to their families, friends and carers and advice to health care professionals in the community and local hospitals. The IP unit at St Catherine's Hospice provides specialist palliative care to patients with malignant and non-malignant life limiting illness. Patients can be referred for admission by their community or site specific CNS, member of the hospice medical team, their GP, their district nurse or their hospital palliative care team if they are in hospital. Admission to IP unit will be offered to a patient in response to a specific need as identified by the MDT. Patients are entitled to decline admission to the IP unit if it is offered to them. In these circumstances their care needs would be reviewed to ensure their needs can be met in their chosen environment. Occasionally admission is requested by the patient themselves or by their family or carer. In these circumstances the patient would need to be assessed by a member of the St Catherine's team or by their GP to assess (with the patient and their family/carers) whether admission to the IP unit is the most appropriate form of management or not. Patient choice and preference relating to place of care and place of death is respected by St Catherine's Hospice MDT. However, admission requests are prioritised and there may be times when complexity needs to take priority over preferences. In these circumstances this would be discussed with the patient and/or their family/carers and alternative and appropriate plans made. Should no beds be available to admit a patient at the time admission is requested the community team will liaise with the patient, their family/carers and the primary care team to ensure the patient's specialist palliative care needs can be met within their current environment until such time that a bed becomes available. If the patient is in hospital, the relevant hospital team will be kept informed of bed availability to ensure continuity of acre and advance planning. Admission requests to the inpatient unit are audited and reviewed on a regular basis. In order to maintain equity of access to all patients requesting a bed at St Catherine's Hospice they're keen to ensure that as far as possible the same process pathways will be used for all requests. The requests will be predominantly for (criteria from St Catherine's policy) assessment, symptom control and terminal care. Respite admission or day services will not be available for out of area patients (unless in extreme circumstances, where this will be discussed on an individual case by case basis). St Catherine's hospice will be keen to maintain out of area hospice patient links with the patients, particularly for discharge planning meetings, but also for information about patient prognosis. And will ensues that up to date information about patients is available on discharge/transfer/death. If requests for out of

area admission occur out of working hours, contact medical or nursing staff on call for further advice.

ANNEXE VII

SUMMARY OF ST CATHERINE'S HOSPICE POLICY ON CONSENT AND PATIENTS CHOICE

Patients have a fundamental, legal and ethical right to determine what happens to their own bodies. It is a general and legal principle that valid consent must be obtained before starting treatment or physical investigation, or providing personal care, for a person. Seeking consent is also a matter of common courtesy between healthcare professionals and patients. If a healthcare professional does not respect the principle they, and their employing organization, may be liable to legal action and/or allegations of battery (under "common law") or negligence. The department for Health, General Medical Council and Nursing and Midwifery Council (as well as other professional and regulatory bodies) have issued a range of guidance documents on consent and these should be consulted for details of the law and good practice requirements. All health care professionals have a responsibility to keep up to date with the changes that may occur to the current guidance on consent as a result of legal developments. All health care professionals should be aware of the Human rights act 10 and be compliant with it in their practice. St Catherine's hospice policy for Consent and patient choice scope is to set standards and procedures at St Catherine's Hospice which aim to ensure that health care professionals are able to comply with the guidance on consent. This policy focuses on consent and patient choice for episodes of direct patient care (provision of personal care, procedures such as phlebotomy, paracentesis, and pleural tap, undertaking observations, such as pulse, blood pressure, administering medications, providing counselling or spiritual care, physiotherapy or occupational therapy interventions). An intervention is defined as any aspect of direct patient care undertaken by staff and a health care professional involved in direct patient care. For consent to be valid it does not depend on the form in which is given. It must be given voluntarily by an appropriately informed person whoa as the capacity to consent to the intervention in question. Coercion invalidates consent. In certain situations it may be appropriate to see the patient alone in order to establish that they are making the decision regarding an intervention freely and voluntarily. It is the responsibility of the health care professional providing the intervention to ensure that valid consent has been obtained. This may be delegated, however, both remain responsible health care professional and the individual to whom obtaining valid consent is delegated, must be suitably trained and qualified, have knowledge of the proposed intervention and understand the risks involved. All health care professionals have a responsibility to seek advice from senior colleagues if they feel they have reached the limits of their competency. If there is any doubt about the validity of consent, legal advice should be

sought. A patient may actively request a particular intervention (which may, or may not, be appropriate or available), a healthcare professional may suggest a particular form of intervention or there may a number of ways of managing a condition or clinical situation. Patients may express consent non-verbally, orally or in writing or consent may be implied, for example a patient presenting their arm to have a blood test or blood pressure taken. Any intervention must be explained to a patient in a sensitive, balanced and respectful way and in a way they can understand by an appropriately trained healthcare professional who must explain its nature and purpose, inform them of its benefits and any associated risks, inform them of any alternative options to that purpose (including associated risks of the alternatives), inform them of the potential outcomes of not undertaking the intervention. The health care professional must make an assessment of how much information a patient wishes to be given and the approach to explaining an intervention needs to be tailored to each individual patient. The amount of information provided regarding any risk of an intervention will depend on the individual. Serious adverse outcomes should be highlighted even if the risk is small and less serious adverse outcomes should be highlighted if they occur frequently. A Court of Appeal judgement stated that it will normally be the responsibility of the doctor to inform of a significant risk which would affect the judgement of a reasonable patient. The information given should be documented in patient's notes. Signed consent forms are not legally required in most cases, but are good practice for a significant intervention (e.g. surgery, interventional analgesia). Gaining consent is a process carried out jointly between a patient and a healthcare professional based on the patient's values and preferences and the healthcare professional's clinical knowledge. The patient must be given the opportunity to ask questions. Written or other information should be supplied if appropriate and/or requested. It is good practice to involve other members of the MDT as appropriate. If the patient declines the information offered it is good practice to document this in the patient's notes. If the informed and valid consent is obtained, the intervention can then proceed- if this decision is made by the patient. A patient with capacity can withdraw consent at any time, including during procedure. Unless new information becomes available or patient's condition changes significantly (when proceeding with the intervention would need to be reviewed in either case) between the time of obtaining valid consent and carrying out the intervention, valid consent for an intervention remains so indefinitely (unless withdrawn by patient with capacity). It is always good practice to confirm that consent remains valid before commencing the intervention. If the patient with capacity voluntarily declines an intervention (having been fully informed) whether contemporaneously or in advance this decision should be respected and alternative options explored. Assumptions

should not be made about an individual based on their character of beliefs. All patient's views should be respected, including their right to make decisions about acre and interventions. A patient cannot demand a particular treatment, but health professionals must take account of a patient's wishes when making treatment decisions. Gaining consent when an individual lacks capacity. A person who lacks capacity is defined as a person who is unable to make a decision for themselves because of an impairment or disturbance in the functioning of their mind or brain. The disturbance may be temporary or permanent and affects the person making a specific decision at the time it needs to be made. For those who lack capacity to make decisions about their treatment, the Mental Capacity Act of 2005 outlines a statutory framework for making such decisions which must be followed by all healthcare professionals. All health care professionals have a duty to have regard for the Mental Capacity Act's code of Practice which makes it an offence to ill-treat or wilfully neglect someone who lacks capacity when responsible for their care or decision-making powers. A person must be assumed to have capacity to make a particular decision at the time it needs to be made unless it is established that they lack capacity. If there is any doubt about an individual's capacity to make a decision, their capacity must be assessed by using the guidance set out in the Mental Capacity Act Code of Practice. If a patient has a valid and applicable advance directive this has the same force as a contemporaneous decision to refuse a treatment. No-one can give consent on behalf of an individual lacking capacity unless they are acting in their position as a Lasting Power of Attorney or a Court Appointed Deputy. Essential care encompasses measures required to keep an individual comfortable. It concludes warmth, shelter, actions to keep a person clean and free of distress and the offer of food and water by mouth. Patients should always be offered essential care and it should always be provided unless it is actively resisted by a patient. Refusal of essential care by a patient with capacity should be respected although it should continue to be offered. Advance decisions made under the Mental Capacity Act cannot refuse actions that are needed to keep a person comfortable. The Act allows healthcare professionals to carry out essential care in the best interests of a person who lacks capacity. Health care professionals have a legal duty to care for a patient and prolong life, however, it is recognised that are circumstances where life sustaining treatment stops being of benefit to a patient and is not clinically indicated. In these circumstances discussions must be had with the patient to decide an ongoing plan of management and decisions made in best interests (in accordance with the Mental Capacity Acct) where the patient lacks capacity. Comfort and dignity should always be maintained through the appropriate care. There is no legal distinction between withdrawing and withholding life-sustaining treatment. It must be recognised that these actions are distinct

from any deliberate action to end life which is unlawful. If the patient has capacity and (fully informed) refuses life sustaining treatment, this decision must be complied with. Not to do so is unlawful. If the patient has a valid applicable advance directive this has the same force as a contemporaneous decision to refuse treatment. A patient with capacity cannot legally demand treatment that is not clinically indicated. When making a best-interest decision in relation to life sustaining treatment in an individual who lacks capacity, healthcare professionals should be aware that the Mental Capacity Act requires that the healthcare professional must not be motivated by a desire to bring about the person's to death.

ANNEXE XVIII

EVALUATION OF THE INTERNSHIP AT ST CATHERINE'S HOSPICE

DATE: 16/12/15

CO-SUPERVISOR: O. CHARMAN SIGNATURE:

SUPERVISOR: MANUEL LUIS CARCOMA SIGNATURE:

Instructions: Please indicate your level of agreement with statements listed below in number 1 to 6.

1. Understands the goal of the Palliative Care Team:
   - **Activities**
     - Integrates the multidisciplinary team in the care for the palliative patients, their families and carers;
     - Does a study case of a patient since referral until discharge or death, to better understand the plan of action of the palliative care team in the Hospice;
     - Participates of the multidisciplinary team meetings.
   - **Evaluation**
     - Integrates the multidisciplinary palliative care team.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	✓			

2. Understands the referral pathway of the patients to the specialist palliative care team to the Hospice:
   - **Activities**
     - Follows the referral pathway of palliative patients to Hospice.
   - **Evaluation**
     - Able to refer patients to the palliative care team;
     - Able to prioritize referrals.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	✓			

3. To facilitate dying with dignity and comfort and provide carers with support:
    - **Activities**
        - Assesses symptoms regularly (pain, breathlessness, agitation, nausea, vomiting, secretions) and review;
        - In the event of symptoms being present, provides appropriate non-pharmacological and pharmacological interventions;
        - Maintains excellent basic care, regular mouth care, turning for comfort;
        - Monitors bowel and bladder function;
        - Encourages and support oral food-hydration;
        - In conjunction with medical team reviews appropriateness of on-going observations and nursing interventions;
        - Rationalises interventions and medications, focus on comfort and support;
        - Ensures dignity and compassion in all care;
        - Assesses psychological needs of the patient and monitor for any psychological distress;
        - Assesses spiritual/religious needs with patient;
        - Refers to spiritual care lead or own minister as requested;
        - Aims to address other spiritual needs as able;
        - Considers patient preferences;
        - Tries to ascertain patient's preferred place of care and death;
        - Considers transfer to hospital if patient desires to spend final days in hospital;
        - Ensures that up to date contact numbers are available for key family members and when they want to be contacted;
        - Explains facilities available to family and carers;
        - Considers single room.

- **Evaluation**
  - Able to address patients physical dimension;
  - Able to address patients psychological dimension;
  - Able to address patients spiritual/religious needs.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	✓			

4. Ensures good communication with patient, family and carers regarding the deterioration in their relatives condition:
   - **Activities**
     - Communicates with patient and relatives (Independent Mental Capacity Advocate if no capacity or next of kin);
     - If the patient is unable to communicate their needs, discusses with next of keen or carers;
     - Supports patient, family and carers and ensures they are aware of the seriousness of the condition, that death is thought likely to be imminent and the focus of care is now on comfort primarily ;
     - Documents significant conversations in the notes and ensure contact numbers for key family members are recorded;
     - Gives the opportunity to discuss and documents wishes advanced care planning;
     - Encourages patients, family and carers to express their emotions;
     - Encourages patients, family and carers to ask questions;
   - **Evaluation**
     - Able to communicate effectively with patient, family and carers.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	✓			

5. Participation on the activities plan for formation of the Palliative Care Team of the St Catherine's hospice:

- **Activities**
  - Do a survey to understand the Palliative Care Team needs for formation;
  - Organize a formation/training considering the Palliative Care Team needs for formation.
- **Evaluation**
  - Participants of the formation training feedback;
  - Tutor's feedback.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	✓			

6. Do a systematic revision of a set of articles from 2010 to 2014 on Continuous Subcutaneous Infusion by Syringe driver:

- **Activities**
  - Bibliography research and analysis of the articles of interest for set theme;
  - Writes resume/conclusions on internship report.
- **Evaluation**
  - Shows knowledge and domain of the theme studied on the written resume conclusions on the internship report;
  - Tutor's feedback.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	✓			

ANNEXE XIX

SUMMARY OF ST CATHERINE'S HOSPICE POLICY FOR DAY HOSPICE REFERRALS

Referrals of patients to Day Hospice may be made by any member of the multidisciplinary team by completing an internal referral to day Hospice Crosscare (informatics program for the multidisciplinary team notes) and must include priority level. Referred patients will be invite to Day Hospice for an outpatient assessment appointment. If this is not appropriate or possible a trial day will be offered. If there is any question about appropriateness of a patient attending the Day Hospice, then they should be discussed by multidisciplinary team. Patients attending the Day Hospice will be reviewed on a three monthly basis, and the interventions provided assed to ascertain ongoing need. Day hospice patients will be reviewed in the weekly MDT meetings. Patients will be kept updated of their ongoing Day Hospice input by the appropriate member of the MDT. Ultimate decision making about appropriateness of continued input rests with the senior medical and nursing staff. Appropriate, effective and timely communication within the patient's allocated specialist nurse and other professionals, both internal and external to the organization, is the responsibility of trained staff in day hospice, in conjunction with the Clinical Nurse Specialist (CNS)/ team leader. Day hospice team members will be expected to fulfil all aspects of their role. This will be reviewed annually via appraisal process. Specific care needs will be identified within the Day Hospice assessment window and at all times the hospice policies and procedures will be adhered to. Documentation will be in line with current hospice use of Crosscare. It is the responsibility of the Day Hospice senior staff nurse/CNS to monitor and evaluate the care needs of the patient and to support and supervise Nursing Assistants and volunteers in care delivery to ensure safe practice. Medical care for Day Hospice patients remains the responsibility of their General Practitioner (GP). However, members of the medical team will be able to review patients in Day Hospice by prior arrangement. If a patient develops an acute medical problem (e.g. collapse or fall) then a member of the medical team should be asked to attend. If no doctor is immediately available, an ambulance should be called and the patient sent to the emergency room. Volunteers in the Day Hospice are required to have appropriate induction training and will work under the guidance of the Day Hospice Senior staff Nurse and Team leader for Day Services in liaison with the Volunteers Services Manager.

ANNEXE XX

REQUEST FOR IN-PATIENT TRANSFER TO ST CATHERINE'S HOSPICE Date: 16.10.15

Patient's Name					
Date of Birth					
Diagnosis and recent treatment (including chemotherapy dates):					
Referred by (+ contact details)					
Current location of patient					
Ideal admission response (tick):	Urgent (within 48 hours		Soon (2-7 days)		
	Planned				
Reason for referral (tick): Symptom control of pain	Assessment		Terminal care		
	Symptom control		Psychological		
Problems/issues to address (may use additional sheet if required):					
Expectations of patient/family:					
Performance status		Oxygen required ? (l/min)			
Special requirement or nursing needs (including use of syringe driver):					
MRSA status					
Diarrhoea (infective or not?)					
Additional Information (may use additional sheet if required):					
If patient is not known to St Catherine's hospice, fax through front page of notes with demographic details.					

ANNEXE XXI

NHS Continuing Healthcare Fast Track Tool

To enable immediate provision of a package of NHS continuing healthcare

Date of completion of the Fast Track Tool _____

Name		**D.O.B.**	

NHS number:

Permanent address and telephone number	**Current location (i.e. name of hospital ward etc)**

Gender _____

Please ensure that the equality monitoring form at the end of the Fast Track Tool is completed

Contact details of referring clinician (name, role, organisation, telephone number, email address)

NHS Continuing Healthcare Fast Track Tool

To enable immediate provision of a package of NHS continuing healthcare

The individual fulfils the following criterion:

He or she has a rapidly deteriorating condition and the condition may be entering a terminal phase. For the purposes of Fast Track eligibility this constitutes a primary health need. No other test is required.

Brief outline of reasons for the fast-tracking recommendation:

Please set out below the details of how your knowledge and evidence of the patient's needs mean that you consider that they fulfil the above criterion. This may include evidence from assessments, diagnosis, prognosis where these are available, together with details of both immediate and anticipated future needs and any deterioration that is present or expected.

When outlining reasons why a clinician considers that a person has a rapidly deteriorating condition that may be entering a terminal phase, the clinician should consider the following definition of a primary health need:

Primary health need arises where nursing or other health services required by the person are

(a) where the person is, or is to be, accommodated in a care home, more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for the person's means, under a duty to provide; or

(b) of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide.

(continue overleaf)

Please continue on separate sheet where needed. This should include the patient's name and NHS number, and also be signed and dated by the referring clinician.

Name and signature of referring clinician	Date

Name and signature confirming approval by CCG	Date

About you (the patient) – equality monitoring

Please provide us with some information about yourself. This will help us to understand whether everyone is receiving fair and equal access to NHS continuing healthcare. All the information you provide will be kept completely confidential by the Clinical Commissioning Group. No identifiable information about you will be passed on to any other bodies, members of the public or press.

1 What is your sex?
Tick one box only.

- Male ☐
- Female ☐
- Transgender ☐

2 Which age group applies to you?
Tick one box only.

- 0-15 ☐
- 16-24 ☐
- 25-34 ☐
- 35-44 ☐
- 45-54 ☐
- 55-64 ☐
- 65-74 ☐
- 75-84 ☐
- 85+ ☐

3 Do you have a disability as defined by the Equality Act 2010?

Section 6 of the Equality Act 2010 defines a person with a disability as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.

Tick one box only.

- Yes ☐
- No ☐

4 What is your ethnic group?

White
- British ☐
- Irish ☐
- Any other White background, write below

B Mixed
- White and Black Caribbean ☐
- White and Black African ☐
- White and Asian ☐
- Any other Mixed background, write below

C Asian, or Asian British
- Indian ☐
- Pakistani ☐
- Bangladeshi ☐
- Any other Asian background, write below

D Black, or Black British
- Caribbean ☐
- African ☐
- Any other Black background, write below

E Chinese, or other ethnic group
- Chinese ☐
- Any other, write below

5 What is your religion or belief?
Tick one box only.

Christian includes Church of Wales, Catholic, Protestant and all other Christian denominations.

- None ☐
- Christian ☐
- Buddhist ☐
- Hindu ☐
- Jewish ☐
- Muslim ☐
- Sikh ☐
- Other, write below

6 Which of the following best describes your sexual orientation?

Tick one box only.

Only answer this question if you are aged **16** years or over.

- Heterosexual / Straight ☐
- Lesbian / Gay Woman ☐
- Gay Man ☐
- Bisexual ☐
- Prefer not to answer ☐
- Other, write below

Care Plan for Fast Track Patients

Inter-agency multi-disciplinary care plan for palliative care provision & placement. For an individual with a primary health need arising from a rapidly deteriorating condition which may be entering a terminal phase, with an increasing level of dependency.

This care plan is for use with the national fast track pathway tool, for patients who have been referred to the PCT for Continuing Healthcare funding to enable their needs to be urgently met (e.g. to allow them to go home to die or to allow appropriate end-of-life support to be put in place).

Name:	DOB: Age: Male/Female
Home Address: Telephone No:	Name & Address of next of kin/contact: Telephone No: Relationship:
First Language:	Religion/cultural needs:
GP: Address: Tel No: Fax No:	District Nurses Name: Address: Tel: No: Fax No:
Palliative Care Team:	Name of social worker/care manager: Tel No:
Consultants Name: Consultant's Tel No:	Patients Current Location:

Has the individual, main carer or advocate been advised of and given written information regarding the Continuing Healthcare process (DH Leaflet, Carers Information)?	☐ Yes ☐ No
If yes, by whom?	**If no, why not?**
Was the individual offered the opportunity to have a representative, such as a family member or advocate present? ☐ Yes ☐ No Did they attend? ☐ Yes ☐ No If not, please explain why	
Is this assessment a review? If so, please give date of the previous assessment	☐ Yes ☐ No Date of last review

CONSENT TO THE ASSESSMENT PROCESS & INFORMATION SHARING

The Mental Capacity Act set out the definition of a person who lacks capacity. These sections of the act say that a person lacks capacity if he or she has a temporary or permanent impairment of or a disturbance in the functioning of the mind or brain when the decision needs to be made, and as a result is unable to:

- Understand the information relevant to that decision
- Retain that information
- Weigh up information as part of the process of making the decision or
- Communicate his/her decision (whether by talking, using sign language or any other means)

Where the person is incapacitated and unable to consent, information should only be disclosed in their best interests and then only as much information as is needed to support their care. For further guidance, see the Mental Capacity Act 2005 Code of Practice on www.dca.gov.uk/menincap/legis.htm and the guidance booklet 'Making Decisions: a guide for people who work in health and social care' on www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet03.pdf

If the person is deemed to have capacity:	
• Has their consent been obtained for all relevant assessments?	☐ Yes ☐ No
• Have they given consent to have information shared with their next of kin, main carer or advocate?	☐ Yes ☐ No
• Has their consent been obtained for sharing information contained within this assessment with potential care providers, other health bodies and the Local Authority?	☐ Yes ☐ No

Signature agreeing consent to assessment and the sharing of information		
If the person is deemed to not have capacity to consent, how was their capacity determined and by whom?		Signature of person assessing capacity.

Who holds decision making responsibility for Health and Personal Welfare?

Self or Other?	☐ Self ☐ Other (as below)	**Date decision made:**	
Lasting PoA:		**Level of power:**	☐ Health/welfare ☐ Financial
Deputy:		**Level of power:**	☐ Health/welfare ☐ Financial
Enduring PoA:		**Additional Info:**	

Is there an advanced decision to refuse treatment? ☐ Yes ☐ No	**Date decision made:**	**Who holds the advanced decision?**
Name of Best Interest Assessor	**Signature**	**Statement indicating why Best Interest Decision taken.**

Primary Diagnosis	Is the Patient Aware of Diagnosis? Y/N
Secondary Diagnosis	If not why Not?
Other DNAR status: has this been discussed and if so by whom? Is the DNAR form with the patient/in the house?	What is the patient's prognosis? Are they aware of their prognosis? Y/N

Pain:

Does the patient have unremitting and overwhelming pain despite all efforts to control pain effectively?					**Yes/No**
	Absent	Mild	Moderate	Severe	Uncontrollable
Pain					

Patient's current symptoms, aside from pain, which require regular (weekly) review *(please tick boxes)*

	Absent	Mild	Moderate	Severe	Uncontrollable
Nausea					
Dyspnoea/ Difficulty Breathing					

Bleeding				
Cough				
Fatigue				
Drowsy				
Jaundice				
Ascites				
Confusion				
Anxiety				
Depression				
Insomnia				
Oedema				
Other				

Please describe specialist nursing needs and current symptom management and who will be providing this:

Please describe general nursing needs (including Waterlow score, site & grade of any sores, equipment required, continence etc.)
How are these needs currently met?

Current Functional Ability re: Personal Activities of Daily Living:

Current Functional Ability re: Domestic Activities of Daily Living:

Current Mobility Level:
Has a moving/handling risk assessment been completed? Yes/No Is the patient independently mobile? If not, how many carers are required for transfers. Please list any equipment required.

Does the patient have an unstable condition?	**Yes/No**
Does the patient have a rapidly deteriorating condition?	**Yes/No**
Does the patient require a high level of specialist palliative care input?	**Yes/No**

Which multi disciplinary team members have been involved in the assessment for this patient? *(Please tick)*		
☐ Occupational Therapist	☐ Palliative Care Nurse	☐ Hospital Doctor
☐ Physiotherapist	☐ Palliative Care Doctor	☐ Social Worker / Care Manager
☐ District Nurse	☐ Speech & Language	☐ GP
☐ Other:		

Which of the following professionals will continue to be involved and please provide their name and contact details:			
Professional		**Name**	**Contact Phone Number**
District Nurse	Y / N		
Palliative Care Nurse	Y / N		
Palliative Care Doctor	Y / N		
Hospital Doctor	Y / N		
Occupational Therapist	Y / N		
Physiotherapist	Y / N		
Speech & Language Therapist	Y / N		
Marie Curie	Y / N		
Macmillan	Y / N		
Other			

Does the patient have drug regime that requires daily monitoring by a registered nurse to ensure effective symptom and pain management associated with a rapidly changing and/or deteriorating condition?	**Yes/No**

Current Medication:

Medication	Dose	Frequency	Route	Indication

Medication Review completed by:	Date:
Signature/ Designation:	

Name of Patient:

Recommendations for Future Care
To be completed after discussion with patient, relative, friend or advocate:

Home	Nursing Home	Residential Home	Hospice
(Please indicate if care is to be provided at different address to that stated on page 1)			

Has the patient been involved in setting up and agreeing to this care plan?	*Yes / No If not explain why:*
Has the main carer been involved in setting up and agreeing to this care plan?	*Yes/No If not explain why:*

If patient requires a 24 hour care environment. Does the patient, relative, friend or advocate have a preference on which nursing home placement & why?

Whilst the PCT will try to accommodate patient and representative's wishes, there are limits as to what the PCT can provide. Final decisions on placements rests with the PCT.

Are they any specific clinical requirements the nursing home need to be made aware of (e.g. be able to manage syringe drivers, specialist dressings, tracheostomy care)

To be completed if the patient is to be cared for at home

Is there an existing package of care in place? Yes / No

Who is currently providing the care?

Are member of the patient's family involved with care provision? Yes/No

What care are they able to provide?

What services have **previously** been provided to the patient? (please tick/delete where appropriate)

☐ Home Care ☐ Day Hospital/Hospice ☐ Respite Care
☐ Meals on wheels ☐ Day Care ☐ Twilight/ Night Service
☐ CPN ☐ Palliative Care Team ☐ MacMillan
☐ Physiotherapist
☐ Other Specialist Nurses (state specialty) .....
☐ Other (Please Specify) .....

Describe the input of the above. Please be as detailed as possible giving frequency & duration of visits.

If services were offered but declined, please state why

What services **will be needed** to enable patient to return home? (please tick/delete when appropriate)

☐ Home Care ☐ Physiotherapist ☐ Day Hospital/Hospice
☐ Meals on wheels ☐ Day Care ☐ Respite Care
☐ District Nurse ☐ Twilight/ Night Service ☐ CPN
☐ Palliative Care Team ☐ Marie Curie ☐ MacMillan
☐ Other Specialist Nurses (state specialty) .....
☐ Other (Please Specify) .....

Describe the proposed input of the above. **Please be as detailed as possible giving frequency & duration of visits.**

Please complete the grid below detailing the package of care that would meet this individual's current needs.

Approximate timing of visits	Number of staff required	Approximate length of visit	Tasks to be undertaken at visit.
e.g 9am	2	1 hour	Washing, dressing and hoisting out of bed.

*Failure to complete the above will result in a delay in contacting a care agency to commission a package of care.

The PCT will review the above recommendation and contact the referrer if there is a question over the safe delivery of care at home.

Whilst the PCT will try to accommodate patient and representative's wishes, there are limits as to what the PCT is able to provide. Final decisions regarding package of care resides with the PCT.

Accommodation & Environment

Current accommodation circumstances (please tick & give details as appropriate)

☐ House	☐ Bungalow	☐ Sheltered Housing	☐ Ground Floor Flat	☐ Flat above ground floor	☐ Residential Home	☐ Nursing Home

☐ Owner Occupier	☐ Council Tenant	☐ Housing Association Tenant	☐ Private Tenancy	☐ Lodgings

☐ Living Alone	☐ Living with spouse	☐ Living with offspring	☐ Living with siblings	☐ Living with other relative	☐ Living with friend

Suitability of Accommodation	☐ No Problems	☐ Some difficulty due to disability	☐ Confined to one area e.g. sleeps downstairs

Access	☐ Level Front	☐ Level Back	☐ Flight of Stairs	☐ Step or Steps

Heating	☐ Central Heating	☐ Electric Fires	☐ Gas Fires	☐ Calor Gas Fires	☐ Open Fires
Cooking	☐ Microwave Oven	☐ Electric Cooker	☐ Gas Cooker	☐ Calor Gas Cooker	☐ Solid Fuel
Toilet	☐ Inside Downstairs	☐ Inside Upstairs	☐ Outside	☐ Chemical Commode	☐ Commode
Bathroom	☐ Downstairs Shower	☐ Downstairs Bath	☐ Upstairs Shower	☐ Upstairs Bath	☐ None

Comments/ any other observations, entry to property (e.g. keys with neighbour)

Please document any potential hazards to the patient or carers (e.g pets, smokers)

Attach OT assessment if available

Is the patient/their family aware that they need to ensure access to hand washing facilities and toilet facilities for carers, a supply of clean towels and bed linen? **Yes/No**

Is the patient/their family aware that if carers are in the property for any length of time they will need access to facilities to make themselves a drink and if providing a respite/sitting service they will need a comfortable chair to sit in? **Yes/No**

Is the Patient/their family aware that the carers expect the property to be heated accordingly? **Yes/No**

NAME: ***SIGNATURE:***

TITLE: ***DATE:***

ANNEXE XXII

My Advance Decision to Refuse Treatment Document

WE ARE MACMILLAN. CANCER SUPPORT

This form is for people living in England and Wales only.
We suggest you read it alongside our booklet, *Your life and your choices: plan ahead.*

About this document

This document is for you to write down in advance any specific treatments that you don't want to have in the future. It will only be used if you lose the mental capacity to make decisions for yourself about your healthcare needs and are therefore unable to consent to or refuse treatment.

You must ensure that this Advance Decision to Refuse Treatment (ADRT) is up to date and replaces any previous decisions you have made.

By completing this Advance Decision to Refuse Treatment (ADRT) you are not refusing your right to receive basic care, support and comfort.

Section 1: My details

Name

Address

Any distinguishing features in the event of unconsciousness

Date of birth

Telephone

Section 2: My Advance Decision to Refuse Treatment

I wish to refuse the following specific treatments *If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box: 'I am refusing this treatment even if my life is at risk as a result.'	In these circumstances

An Advance Decision refusing life-sustaining treatment must be signed by you (or by another person in your presence and by your direction) and witnessed by someone else.

Section 3: My signature and witnesses

My signature (or nominated person directed by me to sign)	Date of signature
Witness name	Witness signature
Witness address	Date of signature Witness telephone number

Section 4: Person to be contacted to discuss my wishes (optional)

Name

Relationship to you

Address

Telephone number

Section 5: Details of healthcare professionals

I have discussed this Advance Decision to Refuse Treatment with
(eg name of healthcare professional)

Profession/Job title

Contact details

Date

I give permission for this document to be discussed with my relatives/carers yes no
(please circle one and specify if you only wish for it to be discussed with specific people)

My general practitioner (GP) is

Address

Telephone

Section 6: Optional review dates – this Advance Decision to Refuse Treatment was reviewed and confirmed by me

Signed	Date
Signed	Date
Signed	Date
Signed	Date

Section 7: Details of people who have a copy and have been told about this Advance Decision to Refuse Treatment

Name	Relationship to you	Telephone

Section 8: Further information (optional)

I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my Advance Decision to Refuse Treatment but the reader may find it useful.

ADRT adaption This form has been adapted, with permission, from the National End of Life Care Programme's Advance Decisions to Refuse Treatment proforma, which was originally published in September 2008 and is available at endoflifecareforadults.nhs.uk/publications/adrtform

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ANNEXE XXIII

Surrey and Sussex NHS
Healthcare NHS Trust

Specialist Palliative Care Team Referral Criteria

Please note that referral criteria are for guidance only and that all referrals will be assessed and triaged by the SPCT

Referral criteria:

Patients with a diagnosis of a life-limiting, progressive illness can be referred from the time of diagnosis or throughout disease progression for the following reasons:

- Identification of specialist palliative care needs and/or complex end of life care needs
- Complex symptom management issues
- Complex terminal care issues
- Review for appropriate transfer to hospice
- Support and advice for rapid discharge of terminal care patients to their preferred place of care
    - i.e. patients who may die in the next 72 hours
- Psychosocial support for patients and their carers, i.e. high bereavement risk,
- Advice to staff:
    - Advance Care Planning
    - Preferred Priorities of Care
    - Clinical decision making
    - Ethical dilemmas
    - Bereavement risk

In addition to the above:

- Patients should ideally have an awareness of their diagnosis or suspected diagnosis
- Patients if able or patient representative if appropriate must agree to the involvement of the SPCT
- The medical team/lead consultant should be aware of and in support of referral
- The ward multi-disciplinary team should be in agreement with referral
- Patients and carers may request referral but this will require support from ward team
- Community Specialist Palliative Care services may refer to Acute Specialist Palliative Care teams using the SWSH referral form or via locally agreed referral process. If referral request is urgent please telephone to discuss with the Acute Specialist Palliative Care team.
- Patients must be 18 years and over

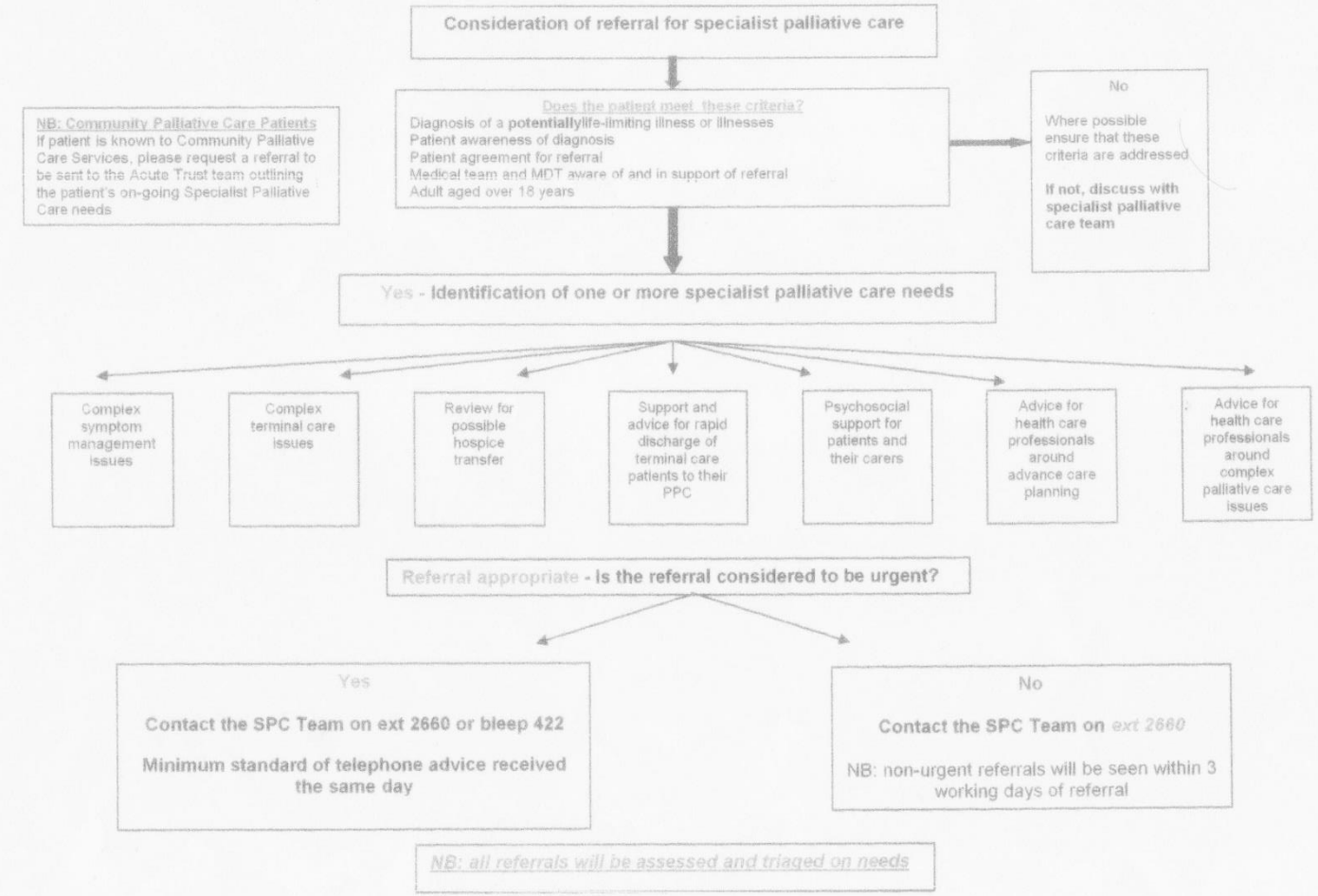
Discharge criteria:

Decision to refer back/discharge from Specialist Palliative Care service is a SPC MDT decision. *Reasons may include change in disease progression, improvement in symptom management, no identifiable SPC needs and patient choice.*

How to make a referral – *Telephone referrals can be made on ext 2660, urgent referrals can also be received on this number or bleep 422.*

ANNEXE XXIV

Process for referral to Acute Trust Specialist Palliative Care Team



ANNEXE XXV

Surrey and Sussex NHS
Healthcare NHS Trust

Care Plan for the Patient in the Last Few Days of Life

Patient's Name:
Date:
Doctor's Signature:

REVIEW

Deterioration in patient's condition suggests the **patient has the potential to die** in hours/days or is imminently dying.

1. Exclude reversible causes eg.opioid toxicity, renal failure, infection, hypercalcaemia
2. Is there an Advance Care Plan or an Advanced Decision to Refuse Treatment (ADRT)?
3. Is preferred place of care known?

MULTIDISCIPLINARY TEAM ASSESSMENT

COMMUNICATE

COMMUNICATION

Where the Consultant (or SpR) has identified that a patient under their care is dying or has the potential to die, they must discuss the agreed care plan with the patient (if they have capacity and wish to be involved in decisions - not all patients wish to discuss they are dying).

- Suggest conversations involve a discussion that their condition is likely to be irreversible and the rationale for that decision.
- Some patients may wish their families to be involved in these discussions. It is seen as good practice to involve families in discussions. Document any concerns raised and your response to these.

For patients that lack capacity see notes on page 3.

DOCUMENT

DOCUMENTATION

The Consultant (or SpR) must ensure that the care plan and all conversations are clearly documented in the patient's medical records.
DNAR decisions need communicating and documenting.

RE-EVALUATE

Patient is NOT diagnosed to be dying

Explore patient's understanding and wishes for treatment and care

Treatment trials and timescale for review
- Escalation plans
- Define ceiling of care

Document review outcome

Patient is imminently dying and no reversible cause identified or patient opts for comfort care

See key areas to be addressed overleaf

Contact SASH Palliative Care Team for advice if needed (ext. 2660)

Surrey and Sussex NHS
Healthcare NHS Trust

End of Life Care Plan

Patient name:	NHS No.
	Hospital No.

Patient Problem
The MDT/Senior clinician agree that the patient is likely to be approaching end of life and the patient therefore requires high quality, holistic end of life care.

Date:	Sign:

Goal

To facilitate dying with dignity and comfort for patient and provide carers with support.
To ensure good communication with the patient and family/carers regarding the deterioration in their relative's condition.

Interventions

1. **Physical**
   Assess symptoms regularly, e.g. pain, breathlessness, agitation, nausea and vomiting, retained secretions and review **at least every 4 hours**.
   In the event of symptoms being present, provide appropriate non-pharmacological and pharmacological interventions.
   Maintain excellent basic care, regular mouth care, turning for comfort.
   Monitor bowel and bladder function.
   Encourage and support oral food-hydration as patient is able.
   In conjunction with medical team review appropriateness of on-going observations and nursing interventions.
   Ensure dignity and compassion in all care.
2. **Psychological**
   Assess psychological needs of the patient and monitor for any psychological distress.
   Ensure good communication at all times with the patient.
   Encourage patients and carers/relatives to express their emotions.
   Encourage patients and carers/relatives to ask questions.
3. **Spiritual/religious**
   Assess spiritual/religious beliefs and needs with the patient.
   If the patient is unable to communicate their needs, discuss with next of kin.
   Refer to hospital chaplain or own minister as requested.
   Aim to address other spiritual needs as able.
4. **Patient Preferences**
   Has the patient expressed any wishes regarding end of life care, e.g. tissue donation?
   Try to ascertain patient's preferred place of care and death.
   Consider alternative care setting if patient is stable enough to be transferred out of hospital.
5. **Care of the Family/Carers**
   Ensure up to date contact numbers are available for key family members and when they would want to be contacted.
   Explain facilities available, e.g. parking permits, folding bed for relatives.
   Consider single room.
6. **After Care**
   Follow procedure in the care of the dying policy, certification of death.
   Family bereavement booklet.
   Inform GP and other clinicians involved.
7. **Additional Interventions**
   Consider referral to the specialist Hospital Palliative Care Team (HPCT) on ext. 2660 with the agreement of the medical team.

ANNEXE XXVI

- Further information is available at: http://www.nhs.uk/chq/Pages/2593.aspx

What other advice about taking my opioids is important?

- Always keep an up to date list of your current medicines, including ones you buy from the pharmacy, supermarket, via the internet and from health food shops, and take this to all health-related appointments.
- Always take your medicines as directed by the doctor.
- Do not stop taking your prescribed medicines without discussing with your doctor.
- Never let other people take any medicines that have been prescribed for you.
- Alcohol can enhance some of the side effects of opioids. Intake should be avoided if you are experiencing side effects and used with caution while taking any medications (including opioids) that can cause drowsiness.
- Always discuss any concerns and questions you may have about any aspect of taking opioids with your doctor, nurses or pharmacist.

How should I store my opioids at home?

- Securely closed in the original container with the label intact.
- Out of sight and reach of children.
- Safely where you or your carer can easily find them.
- Away from direct sunlight, heat and moisture.

How should I dispose of unwanted opioids?

- Return to a community pharmacy for safe disposal.
- They must not be flushed down the sink or toilet or placed in the refuse bin.

This leaflet is based on one produced by St Catherine's Hospice and Kamsons Pharmacy

St Catherine's Hospice,
Malthouse Road, Crawley RH10 6BH
Registered as a charity no. 281362
and as a company in England no. 1525404

Care
Compassion
Understanding

Kamsons Pharmacy

THIS INFORMATION CAN BE MADE AVAILABLE IN OTHER LANGUAGES AND FORMATS, INCLUDING LARGER TEXT. CONTACT 01737231958 FOR HELP.

我們可以提供這些資料的中文譯本和其他版本，
包括大字體版。請致電01737231958要求協助。
CHINESE

આ જાણકારી મોટાં લખાણ સહિત, અન્ય ભાષાઓમાં અને ફૉર્મેટમાં ઉપલબ્ધ થઈ શકશે.
મદદ માટે 01737231958 પર સંપર્ક કરો.
GUJARATI

NINIEJSZE INFORMACEJE MOŻNA OTRZYMAĆ W INNYCH JĘZYKACH I FORMATACH, NP. DUŻYM DRUKIEM. DZWONIĄC POD NUMER 01737231958
POLISH

PODEMOS DISPONIBILIZAR ESTA INFORMAÇÃO NOUTRAS LÍNGUAS E NOUTROS FORMATOS, INCLUINDO
TEXTO GRANDE. CONTACTE O 01737 231958 PARA RECEBER AJUDA
PORTUGUESE

یہ معلومات دوسری زبانوں اور صورتوں میں مل سکتی ہے، جس میں بڑے حروف میں عبارت شامل ہے۔ مدد کے لیے 01737 231958 پر فون کریں۔
URDU

MR6107

Surrey and Sussex NHS
Healthcare NHS Trust

Morphine and other opioid medicines

Key facts about these medicines and how they are used

Putting people first
Delivering excellent, accessible healthcare

Morphine is one of a group of painkillers called 'opioids' that are prescribed for moderate to severe pain. Other drugs in the opioid group include oxycodone, fentanyl and buprenorphine.

1. Using Opioids

Opioids:

- Can be effective at any stage of an illness; they are not just reserved for the end of life.
- Are not usually addictive when taken for pain relief and can be safely stopped if the pain improves.
- May be prescribed with other types of pain killers depending on the type of pain that you have. A combination of pain killers may give more effective pain relief.
- May also be prescribed for breathlessness rather than pain.

The most commonly used opioids are morphine and oxycodone in the two main forms taken by mouth:

- **Immediate release (i/r)** - these formulations provide fairly rapid onset of pain relief (usually 10-20 minutes). The effect lasts approximately 3-4 hours therefore repeated doses may be needed to control pain effectively.
- **Modified release (m/r)** - these forms release the drug slowly over 12 hours or longer depending on the preparation, so that pain relief lasts longer. These preparations are designed to be taken regularly at 12 hour intervals (e.g. 8am and 8pm) or once daily at the same time each day.

If you are not able to swallow your medication reliably, morphine and oxycodone can also be given by subcutaneous injection and fentanyl and buprenorphine are available as skin patches.

What happens when I start taking opioids?

- You will be prescribed either an **immediate release** preparation or a **modified release** preparation starting at a low dose. It is helpful to keep a note of how well your pain responds to the opioids so that you can discuss this with your doctor or nurse.
- Your doctor or nurse will arrange to review your pain regularly so that the opioid dose can be adjusted until your pain is controlled.
- When your pain is stable, your doctor will normally change you to a **modified release** preparation taken every 12 hours or to a skin patch which lasts for several days.
- **It is important to ensure you know which type of preparation you are taking and how to take it. Your doctor, nurse or pharmacist will explain this to you.**

What should I do if I experience pain even though I am already taking opioids?

- Usually your doctor or nurse will recommend taking a 'breakthrough dose' of an immediate release preparation (such as Oramorph or Oxynorm) in addition to your regular opioid.

  This will be explained to you by your doctor or nurse when you start taking opioids.
- Ensure that you continue to take your regular medication as prescribed.
- If the pain persists despite taking a 'breakthrough dose', or the pain becomes worse, consult your doctor or nurse as soon as possible.

2. Side Effects

What are the most common side effects of opioids?

- **Feeling and being sick**. This is common but usually wears off within the first 48-72 hours of starting opioids or increasing the dose. Your doctor may prescribe anti-sickness medicine to prevent this.
- **Constipation** is very common. Your doctor will usually prescribe a laxative to take regularly with your opioid medicine.
- **Drowsiness, dizziness and/or mild confusion** can occur when you first start taking opioids or when you increase the dose. It is usually mild, wearing off within 48-72 hours.
- If you get side effects which do not settle as expected, your doctor or nurse can advise about options to resolve these.
- Do not stop your opioids without consulting with your doctor or nurse.

What should happen if I develop breathing difficulties or confusion/ impaired consciousness while taking opioids?

- Breathing difficulty or impaired consciousness due to opioids is rare.
- **If this happens at home, dial 999 for an ambulance. If an ambulance is called, please remember to keep any medicines that have been taken, and their containers, to show the doctor, nurse or paramedic.**

3. Driving and Travelling

Can I drive while taking opioids?

- Drowsiness may be caused by opioids, particularly when they are first started. This may affect performance of skilled tasks such as driving, using tools or operating machinery.
- You should avoid driving after being started on opioids or after increasing the dose (this includes taking additional breakthrough doses) until you are on a stable dose and any drowsiness has settled – this can take several weeks.
- You should make sure your reactions are normal before driving or operating machinery.
- You must inform your motor insurance company of your medical condition and about any medications you are taking; if you do not it may invalidate your insurance policy.
- If you are taking medication which may impair your ability to drive it may be necessary to notify the DVLA. Further information about driving regulations and medical conditions (including when taking medications) is available at: http://www.dft.gov.uk/dvla/medical.aspx
- If in any doubt about your ability to drive it is safer not to drive.

What must I do if I'm travelling abroad and need to take my opioids with me?

- You will usually be able to take a sufficient supply of your medication with you. Talk to your doctor, nurse or pharmacist who will advise you about regulations in the countries you are visiting and regulations for taking opioid medication out of the UK. You may need a detailed letter or special licence to take with you.

ANNEXE XXVII

Date of publication: May 2015
Review date: May 2017
Author: Palliative Care Team

THIS INFORMATION CAN BE MADE AVAILABLE IN OTHER LANGUAGES AND FORMATS, INCLUDING LARGER TEXT. CONTACT 01737231958 FOR HELP.

我們可以提供這些資料的中文譯本和其他版本，
包括大字體版. 請致電01737231958要求協助.

CHINESE

આ માહિતી મોટા લખાણ સહિત, અન્ય ભાષાઓમાં અને ફૉર્મેટમાં ઉપલબ્ધ થઈ શકે છે. મદદ માટે 01737231958 પર સંપર્ક કરો.

GUJARATI

NINIEJSZE INFORMACJE MOŻNA OTRZYMAĆ W INNYCH JĘZYKACH I FORMATACH, NP. DUŻYM DRUKIEM. DZWONIĄC POD NUMER 01737231958

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URDU

MR6202

Surrey and Sussex NHS
Healthcare NHS Trust

Syringe Driver Information Leaflet for Patients and Relatives

Putting people first
Delivering excellent, accessible healthcare

What does a syringe driver look like?

Surrey & Sussex Healthcare NHS Trust use McKinley T34 Ambulatory Syringe Drivers. They are operated by battery, measure approximately 30cm in length by 5cm wide and are protected by a plastic cover.

What does a syringe driver do?

A syringe driver is a small, portable pump which can be used to deliver a constant supply of medicines under the skin over a 24 hour period. The pump is fitted with a syringe which contains the medicine. Attached to the syringe is a fine tube at the end of which is a very small needle that is placed under the skin and held in place with a see through dressing. The medicines are absorbed from under the skin into the blood stream. The syringe is replaced each day with a new syringe containing the medicine.

Why do I need a syringe driver?

Starting a syringe driver doesn't mean that the medicine being given has stopped working or is not strong enough. Giving the medications through a syringe driver can be a more effective way of getting them into the body if they cannot be taken by mouth. Reasons it may be difficult to take medicines by mouth include:

- Nausea or vomiting and finding it difficult to keep your medicines down. Medicines to stop vomiting can be given in the syringe pump. Once the vomiting has settled the medicine can be changed back to be taken by mouth.

- Too many medicines to take and it becoming difficult to manage to swallow them all. Unfortunately not all medicines are made in a way which can be given via a syringe driver, but changing those that can to this route may reduce the number you need to take by mouth.

- Being unable to, or finding it difficult to, swallow medicines at all. Using a syringe driver means that a constant supply of medicine can be provided without the need for repeated injections.

It is usually only necessary to use a syringe driver to deliver the medicine for a few days (changing the syringe every 24 hours as above) but there is no limit to how long one can be used if it is needed.

Who will look after my syringe driver?

The nursing staff on the ward will set the driver up and check it regularly to make sure it is working correctly. The syringe containing the medicine will be changed each day. The site where the needle enters the skin will also be checked regularly to ensure it is comfortable. Usually the needle can remain in position for up to 3 days, however, if the skin is becoming reddened or swollen it may need to be changed more often.

It is possible to be discharged from hospital with a syringe driver. In this case, the district nurse will come each day to replace the syringe, check that the needle is comfortable and that there are no problems with the medicines.

How will I know the syringe driver is working correctly?

Once set up, the green light on the case will flash and the display screen will indicate the infusion is in progress.

If the pump detects a problem the light will turn red or the pump will give an audible alarm.

If the alarm sounds it may mean that the infusion is coming close to being completed or that the battery needs replacing, or that there is a problem with the pump such as the line has become blocked. If the alarm sounds please inform the nursing staff who can check the driver and correct the problem.

Is there anything else I should know about the syringe driver?

The syringe driver cannot go in water so please do not allow it to get wet.

ANNEXE XXVIII

PLAN OF TRAINING SESSION "AGITATION AND RESTLESSNESS"

TIME	SUBJECT	TUTOR	STUDENT
14:00-14.10	1. Introduction Introduce myself 2. House Keeping 3. State aims and objectives 3. Training session outline	-Building -Fire -Facilities -Safety aspects -Principles: definition -Causes -Process: assessment and management -Give handouts	1. Introduction 2. Brainstorming based on experience
14:10-14:30	"Agitation & Restlessness" training session presentation	-Power point presentation	-Participation and Questions
14:30-14:45	Relaxation session	-Read relaxation script (Relaxation CD, sound of the sea)	-Participation
14:45-14:55	**Revisit objectives and learning outcomes** Evaluations Time for questions Summary	-Give out evaluation form	-Fill in evaluation form -Questions

ANNEXE XXIX

AGITATION & RESTLESSNESS

- Aims and Goals:
  - Definition
  - Causes (physical discomfort & confusion with restlessness)
  - Assessment (Holistic view of the patient– physical, phychosocial and spiritual)
  - Management (Holistic management with drug and non-drug management)

AGITATION & RESTLESSNESS

- ❖ May occur as a pre-terminal event (in final hours or days of life);
- ❖ 10% of agitated patients may need some sedation;
- ❖ Consider underlying causes wich may be treatable:
  - Physical discomfort;
  - Confusion with restlessness.

(WATSON et al, 2011)

AGITATION & RESTLESSNESS

- **Agitation**
  - A state of anxiety accompanied by motor restlessness
- **Confusion**
  - A mental state characterised by a lack of clear and orderly thought and behaviour
- **Restlessness**
  - *Restless*
  - Marked by a lack of quiet, repose, or rest
  - Not able to rest, relax, or be still
  - Never still or motionless

(BARBOSA & NETO, 2010; WATSON et al, 2011)

PHYSICAL DISCONFORT

- COORDINATED MOVEMENTS, SOME VOLUNTARY CONTROL (WATSON et al, 2011)

- CAUSES:
  - Uncontrolled pain
  - Full bladder
  - Faecal impaction
  - Nausea
  - Pruritus from opiod

CONFUSION WITH RESTLESSNESS

- COORDINATED MOVEMENTS OR UNCONTROLLED TWITCHING (WATSON et al, 2011)

- CAUSES:
  - Metabolic failure
  - Opioid toxicity
  - Infection
  - Cerebral metastases

SEDATION

(WATSON et al, 2011)

Haloperidol	2.5 mg SC stat	5-10 mg per 24h CSCI
Midazolan	5 mg or buccal stat	10-100 mg per 24h CSCI
Levomepromazine	25 mg stat	25-150 mg per 24h CSCI
Phenobarbital	On advice from specialist	Pallitive care team only

WHAT IS PAIN?

- Pain is a complex phenomenon and the experience of pain is unique for each individual. It has been described in many ways:
  - "An unpleaseant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (WATSON et al, 2011).
  - "An experience that affects and is affected by both mind and the body. It envolves the perception of painful stimulis by the nervous system and the reaction of a person to this"(WATSON et al, 2011).
  - " Pain is what the patient says hurts"(WATSON et al, 2011).

ACUTE PAIN

- Has a well defined onset, generally associated with subjective and objective physical signs and with hyperactivity of the autonomic nervous system.
- It usually responds to analgesic drug therapy and treatment of its underlying cause.

(BARBOSA & NETO, 2010; WATSON et al, 2011)

CHRONIC PAIN

- Persists over weeks or months and may be associated with significant changes in lifestyle, functional ability and personality.
- Management is challenging as it requires carefull assessment, not only of the intensity and nature of pain, but also of the degree of psychological distress.

(BARBOSA & NETO, 2010; WATSON at al, 2011)

ASSESSMENT OF PAIN

- PHYSICAL

Related with:

- Underlying disease
- Treatment
- Associated factors
- Chronic conditions

(WATSON et al, 2011)

ASSESSMENT OF PAIN

- PSYCHOSOCIAL

- Psycossocial factors may have profound influence on an individual's perception and experience of pain and can effect how the sufferer responds emotionally and behaviourally.
- There is a large body of scientific evidence to support the role of anxiety and depression, fear, pain-related beliefs and coping styles in the mediation of pain perception in chronic non-malignant pain.

(BARBOSA & NETO, 2010; WATSON et al, 2011)

ASSESSMENT OF PAIN

- SPIRITUAL

- People suffering from chronic unremitting pain can experience spiritual distress/pain.
- It is important to identify spiritual needs in order to offer approprite support.
- The spiritual dimension of an individual includes meaning, relatedness, hope and forgiveness- this may or may not include a religious system.

(BARBOSA, & NETO, 2010; WATSON et al, 2011)

ASSESSMENT OF PAIN

1. CLINICAL HISTORY
2. PHYSICAL EXAMINATION
3. IDENTIFICATION OF THE LIKELY CAUSE OF PAIN AND CLASSIFY THE TIPE OF PAIN
4. ARRANGEMENT FOR APPROPRIATE DIAGNOSTIC INVESTIGATIONS
5. ARRANGEMENT FOR MULTI-DISCIPLINARY PROFESSIONAL ASSESSMENT WHEN PRACTICABLE
6. REGULAR REVIEW TO DETERMINE THE EFFECTIVENESS OF TREATMENT

(WATSON et al, 2011)

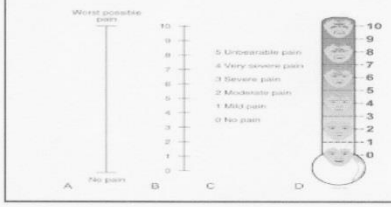
ASSESSMENT OF PAIN

- PHYSICAL (10 point numerical rating scale)
- PSYCHOSOCIAL (routine screening for psychosocial distress using a astandardised tool such as Hospital Anxiety and Depression Scale)
- SPIRITUAL (HOPE is a simple spiritual assessment tool that can be incorperated into a medical assesment):
  - H- sources of hope, meaning, comfort, strengh, peace, love and connection
  - O- organized religion
  - P- personal spirituality and practices
  - E- effects on medical care an end of life care

(WATSON et al, 2011)

ASSESMENT OF PAIN

(WATSON et al, 2011)



PRINCIPLES OF PAIN MANAGEMENT

1. Understanding that pain is a subjective experience.
2. Comprehensive, individualised and holistic assessment and treatment planning.
3. Patient and carer involvement, wich should include information about pain and its management.
4. Actiology should be considered to optimise pain management.
5. Treatment should start at the level of the World Health Organization analgesic ladder appropriate for the severity of the pain.
6. Oral analgesia should be the preferred form of delivery where possible, titrated until pain is relieved and given regularly if pain is persistant.
7. Morphine is currently considered to be the strong opiod of choice.
8. Analgesia for continuous pain should be prescribed on a regular basis and also prescribed as needed for breakthrough pain in appropriate dosages.
9. Adjuvant analgesics should be considered where appropriate as per WHO ladder.

(BARBOSA & NETO, 2010 ; WATSON et al, 2011)

PHARMACOLOGICAL MANAGEMENT OF PAIN
World Health Organization Analgesic Ladder

- STEP 1: mild pain
- STEP 2: pain persisting or increasing (mild to moderate)
- STEP 3: moderate to severe pain

(BARBOSA, & NETO, 2010; WATSON et al, 2011)

STEP 1

DRUG OPTIONS

- NON OPIODS +/- ADJUVANT
  (BARBOSA & NETO, 2010; WATSON et al, 2011)
  - Paracetamol 1g QDS
  - Non-steroidal anti-inflamatory drugs (NSAIDS)

STEP 2

- OPIOD + NON-OPIOD +/- ADJUVANT
(BARBOSA, & NETO, 2010; WATSON et al, 2011)

- Consider a combination preparations (e.g. Co-codamol 30/500- max 8 tablets in 24h).
- Tramadol (up to 400mg/24h)

STEP 3

- OPIOD FOR MODERATE TO SEVERE PAIN+ NON-OPIOD+/- ADJUVANT
(BARBOSA & NETO, 2010; WATSON et al, 2011)

- OPIOD OPTIONS
  - Oral 1st line: morphine
  - Oral 2nd line: oxycodone
  - SC 1st line: diamorphine/morphine
  - SC 2nd line: oxycodone

ADJUVANT ANALGESIA

- CORTICOSTEROIDS
- ANTIDEPRESSANTS
- ANTI-EPILETICS
- ANTI-MUSCARINICS
- BENZODIAZEPINAS
- BISPHOSPHONATES
- KETAMINE

(BARBOSA & NETO, 2010; WATSON et al, 2011)

1. GIVE STAT DOSE

- If not on strong opiods start with Oromorph 5-10mg p.o. Or morphine/diamorphine 2.5-5mg SC.
- If on strong opiods work out the total 24h dose and divide by 6 to get the equivalent breakthrough dose of the same opiod and route.
  - e.g. modified release morphine 30mg b.d. = oral morphine 60mg in 24h breakthrough dose = immediate release morphine 10mg

To convert most commonly used opiods:

- p.o. morphine to SC diamorphine divide by 3
- p.o. morphine to SC morphine divide by 2
- Fentanyl patch 25mcg/hr = diamorphine 30mg SC in 24 hours

REMEMBER BREAKTROUGH DOSE IS THEN 1/6-1/10 OF THE 24hr DOSE
(WATSON et al. 2011)

2. ASSESS RESPONSE

- SHOULD BE EFFECTIVE WITHIN 30 MIN

(WATSON et al. 2011)

3.CONSIDER REPEAT DOSE

- ENSURE REPEAT DOSES AVAILABLE IF IT IS EFFECTIVE

(WATSON et al. 2011)

4. INEFFECTIVE

- IF REPEAT DOSE INEFFECTIVE ASK FOR ADVICE (WATSON et al, 2011)

NAUSEA AND VOMITING

- **Consider underlying cause:**
  - Select appropriate treatment/antiemetic
  - Treat reversible causes e.g. Infection, constipation, medication, hypercalcaemia.
- **Consider route of administration:**
  - Parenteral drugs likely to be needed.
- **Consider non drug measures**

(KINGHORN, 2001; BARBOSA, & NETO, 2010; WATSON et al, 2011)

CAUSE

(WATSON et al, 2011)

CAUSE	1st line	2nd line
Gastric stasis	Metoclopramide	
Intestinal obstruction- no colic	Metoclopramide +/- dexamethasone	Levomepromazine
Intestinal obstruction- with colic	Cyclizine + Hyoscine butylbromide	Haloperidol or Levomepromazine
Drugs or biochemical disturbance	Haloperidol	Levomepromazine
Raised intracranial pressure	Cyclizine + Dexamethasone	Levomepromazine (may reduce seizure threshold)
Other/uncertain cause	Levomepromazine	

DRUG

(WATSON et al. 2011)

DRUG	SC p.r.n. dose	SC 24 hr range
Metoclopramide	10-20 mg	40-100 mg
Cyclizine	25-50 mg	100-150 mg
Levomepromazine	6.25 mg	5-25 mg
Haloperidol	0.5-1.5 mg	1.5-5 mg

COMPLEMENTARY THERAPIES

- NICE (National Institute for Clinical Excellence) guidance on supportive and palliative care:
  - Complementary therapies are be included as one aspect of the *Guidance on Improving Supportive and Palliative Care for Adults with Cancer.*
  - *Complementary therapies* refers to those therapies wich are used alongside conventional health care.
  - Therapists trained to the standard required for registration with a professional complementary therapy bodies should be knowledgeable about the general contraindications and precautions for the therapy they practice.
  - Staff in conventional healthcare who are not therapists will need familiarisation, guidance or training on when, and when not, to refer patients to complementary therapies, how to communicate with patients about complementary therapies, so as not t raise false hopes.

(TAVARES, 2003)

COMPLEMENTARY THERAPIES

- Evidence base for complementary therapies is a significant consideration for managers and clinicians, as well as commissioners and providers of care.
- Evidence based care is described as the conscientious, explicit use of the current best evidence in making decisions about the care of individual patients.
- It requires practitioners to integrate the best external evidence based practice.
- Evidence derived from randomised controlled trials or reviews of randomised trials; from prospective studies with a comparison group (non-randomized controlled study or observational studies); from comparison group, calculation of sample size and accurate, standard definition of outcome variables; from cross-sectional studies; and from professional consensus.

(KINGHORN, 2001; TAVARES, 2003)

COMPLEMENTARY THERAPIES

- These include touch therapies (e.g. massage, aromatherapy, reflexology) and psychological interventions (e.g. relaxation, hypnotherapy, meditation) and are often used alongside mainstream treatments in managing cancer pain.
- Cognitive behavioural interventions can help minimise the impact of pain on mood and function in this group.
- The evidence to support other interventions is week but there may be short term benefits.
- Creative therapies include art, music, and writing therapies. Evidence for efficacy in reduction of pain is sparse. They may used to assist in exploration of non-physical pain.

(KINGSNORTH, 2001; TAVARES, 2003; LLOYD-WILLIAMS, 2008)

COMPLEMENTARY THERAPIES

- The best available evidence suggests that massage, aromotherapy and reflexology may be useful to:
  - Promote relaxation
  - Alleviate anxiety
  - Reduce depression
  - Reduce pain
  - Reduce nausea
  - Alleviate symptoms
  - Alleviate side effects of chemotherapy
  - Improve sleep pattern
  - Reduce stress and tension
  - Reduce psychological distress/provide emotional support
  - Improve well-being and quality of life
  - To with altered body image

(TAVARES, 2003; LLOYD-WILLIAMS, 2008)

MASSAGE

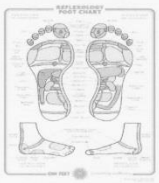
COMPLEMENTARY THERAPIES

- Massage therapists, aromatherapists and reflexologists are trained to assess and screen for conditions in wich treatment is contraindicated for any individual (e.g. pyrexial)
- Therapists with limited experience will need further training from experienced therapists in the use of the therapy in palliative care

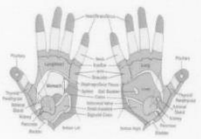
(ARNOLD-TAYLOR, 1992; TAVRES, 2003)

MASSAGE AND AROMOTHERAPY

REFLEXOLOGY



REFLEXOLOGY



ACUPUNCTURE

ACUPUNCTURE

- "A practice in Chinese medicine in which the skin, at various points along the meridians, is punctured with needles to remove energetic blockages and stimulate the flow of qi".
- Several variations of the theme exist : stimulation by heat (moxibustion), pressure (acupressure), electrical current (electroacupunture), etc.
- In cancer patients it is mostly used for pain control, for alleviation of chemotherapy-induced nausea and vomiting, to treat radiation induced xerostomia, and to reduce vasomotor symptoms.

(TAVARES, 2003; LLOYD-WILLIAMS, 2008)

HYPNOTHERAPY

HYPNOTHERAPY

- Is the practice of using hypnosis for the treatment of illness.
- Several Random Controlled Trials have demonstrated the usefulness of hypnotherapy in palliative cancer care for controlling pain and nausea and vomiting.

(TAVARES, 2003; LLOYD-WILLIAMS, 2008)

RELAXATION THERAPY

- Relaxation techniques such as imagery, breathing exercises, manual massage, music therapy, art therapy, and reflexology have been used to reduce symptoms and increase the quality of life in cancer patients.
- Imagery (thoughts, pictures, sounds, memories feelings, sensations) forms the basis for how we experience ourselves- our bodies, our relationships, our work, our environment and our emotional and spiritual lives.
- Guided imagery makes conscious and creative use of this faculty, to create a psycho-physiological change to reduce stress, adjust to change, and promote health and healing.

(KINGHORN, 2001; TAVARES, 2003; LLOYD-WILLIAMS, 2008)

REIKI

REIKI

- Central to this system of healing is the concept that an energy flow exists within living beings which supports life by helping to maintain homeostasis. This energy is known as Ki. When Ki is diminished ill health can arise.
- The other important concept is that Ki can be channelled from its originating source by a Reiki practitioner and passed on to a recipient.
- A Reiki treatment for oneself or another, involves the practitioner placing his/her hands either on, or just above, certain points on the body. The recipient may sit or lie and remains fully clothed. Reiki can also be used as a method of distant healing during which the practitioner works using visualization techniques.
- Reiki energy is channelled for the greatest and highest good of the recipient and is understood to flow in response to the needs of the recipient. Recipients often report a feeling of deep relaxation during and following the therapy.

(KINDHORN, 2001; TAVARES, 2005; LLOYD-WILLIAMS, 2008).

SUMMARY

- Causes:
  - Uncontrolled pain; full bladder; faecal impaction; nausea; pruritus from opioid: metabolic failure; opioid toxicity; infection; cerebral metastases.
- Assessment:
  - Physical; psychosocial; spiritual.
- Management:
  - Drug and non drug management

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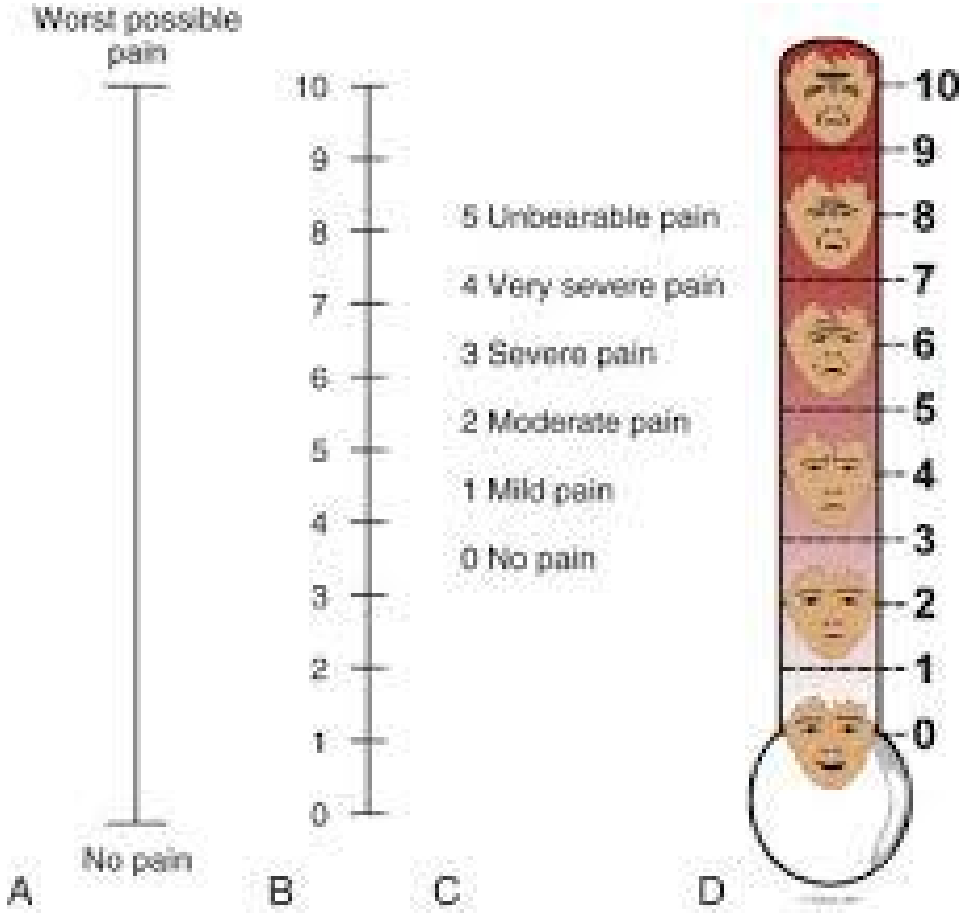
- WATSON M, et al. Palliative Adult Network Guidelines. Anglia, Kent, Medway, mount Vernon, Northern Ireland, South east London, South West London, Surrey, West Sussex & Hampshire, Sussex Cancer Networks and Palliative Care Cymru Implementation Board. 3rd edition, 2011.

ANNEXE XXX


Worst possible pain
No pain
A
10
9
8
7
6
5
4
3
2
1
0
B
5 Unbearable pain
4 Very severe pain
3 Severe pain
2 Moderate pain
1 Mild pain
0 No pain
C
10
9
8
7
6
5
4
3
2
1
0
D

ANNEXE XXXI

Hospital Anxiety and Depression Scale

NFER-NELSON
Health & Social Care

Name ..... Date .....

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

fold along dashed line

A

3 **I feel tense or 'wound up':**
- Most of the time

2 - A lot of the time

1 - From time to time, occasionally

0 - Not at all

D

0 **I still enjoy the things I used to enjoy:**
- Definitely as much

1 - Not quite so much

2 - Only a little

3 - Hardly at all

A

3 **I get a sort of frightened feeling as if something awful is about to happen:**
- Very definitely and quite badly

2 - Yes, but not too badly

1 - A little, but it doesn't worry me

0 - Not at all

(continued overleaf)

HOSPITAL ANXIETY AND DEPRESSION SCALE

fold along dashed line

D
0 I can laugh and see the funny side of things:
1 As much as I always could
2 Not quite so much now
3 Definitely not so much now
Not at all

A
3 Worrying thoughts go through my mind:
2 A great deal of the time
1 A lot of the time
0 From time to time but not too often
Only occasionally

D
3 I feel cheerful:
2 Not at all
1 Not often
0 Sometimes
Most of the time

A
0 I can sit at ease and feel relaxed:
1 Definitely
2 Usually
3 Not often
Not at all

D
3 I feel as if I am slowed down:
2 Nearly all the time
1 Very often
0 Sometimes
Not at all

A
0 I get a sort of frightened feeling like 'butterflies' in the stomach:
1 Not at all
2 Occasionally
3 Quite often
Very often

(continued overleaf)

HOSPITAL ANXIETY AND DEPRESSION SCALE

fold along dashed line

I have lost interest in my appearance:

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things:

- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

Now check that you have answered all the questions

For office use only:

D : ☐ Borderline 8–10

A : ☐ Borderline 8–10

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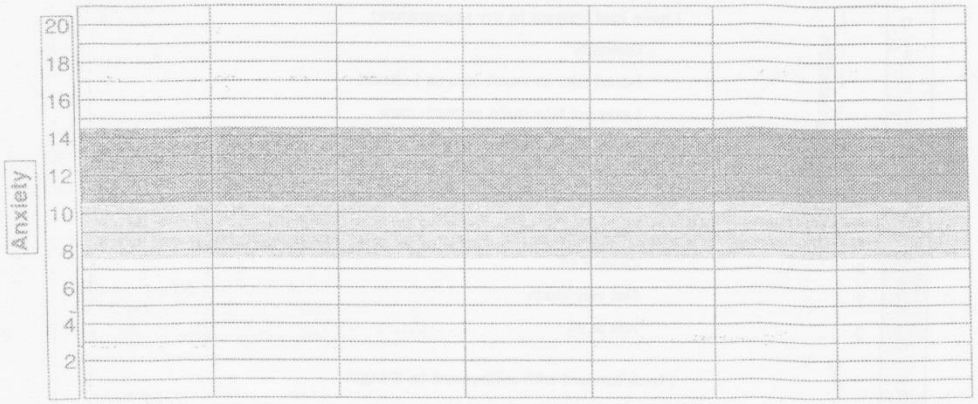
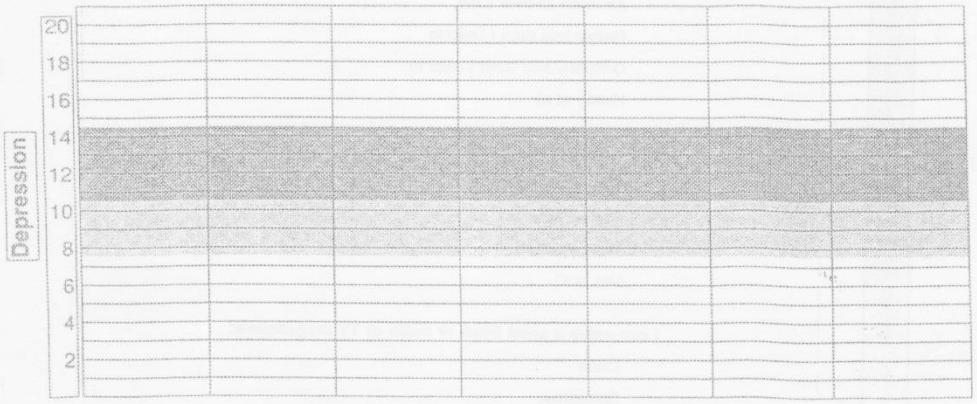
Hospital Anxiety and Depression Scale Chart

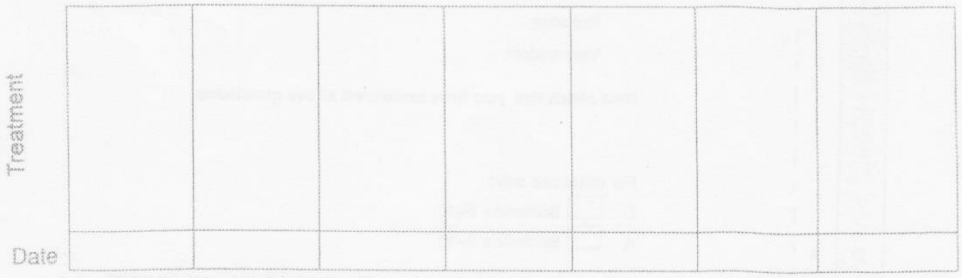
for the monitoring of repeated scores

NFER-NELSON
Health & Social Care

Name: ..... Age: ..... Sex: .....







© Zigmond and Snaith, 1983. From 'The Hospital Anxiety and Depression Scale', *Acta Psychiatrica Scandinavica* 67, 361–70. Reproduced by kind permission of Munksgaard International Publishers Ltd, Copenhagen.

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ANNEXE XXXII

SUMMARY OF ST CATHERINE'S HOSPICE POLICY ON THE USE OF IN COMPLEMENTARY THERAPIES

USE OF ESSENTIAL OILS

- St Catherine's Hospice endorses the therapeutic use of essential oils for:
    - Massage
    - Use in massage, baths, aromatherapy fans, creams and 'sniff-sticks'
    - For pain, odours, distress/anxiety, sleep and breathing, as appropriate.
- These oils must be dispensed by a qualified Aromatherapist and label should state the contents/effects/number of drops for an aromafan and expiry date.

GUIDELINES FOR ESSENTIAL OILS

- All patients/clients must be assessed by a fully qualified aromatherapist before any use of essentials oils.
- The therapist must do a full consultation and document medical history and oils that are being used.
- No essential oils to be used or handled by anyone who is pregnant.
- It is important that essential are mixed with a carrier oil and are not poured directly to the bath or apllied to the skin.
- All essential oils to be kept in a locked cupboard. Keys can be accessed by aromatherapists only.
- The aroma fans to be used in side rooms only.

ANNEXE XXXIII

Training Evaluation Form

Date: _____

Title and location of training: _____

Trainer: _____

Instructions: Please indicate your level of agreement with the statements listed below in number 1-11.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. The objectives of the training session were clearly defined.	○	○	○	○	○
2. Participation and interaction were encouraged.	○	○	○	○	○
3. The topics covered were relevant to me.	○	○	○	○	○
4. The content was organized and easy to follow.	○	○	○	○	○
5. The materials distributed were helpful.	○	○	○	○	○
6. This training experience will be useful in my work.	○	○	○	○	○
7. The trainer was knowledgeable about the training topics.	○	○	○	○	○
8. The trainer was well prepared.	○	○	○	○	○
9. The training objectives were met.	○	○	○	○	○
10. The time allotted for the training was sufficient.	○	○	○	○	○
11. The meeting room and facilities were adequate and comfortable.	○	○	○	○	○

12. What did you like most about this training?

13. What aspects of the training could be improved?

14. How do you hope to change your practice as a result of this training?

Thank you for your Feedback

ANNEXE XXXIV

EVALUATION OF TRAINING SESSION

Question 1.The objectives of the training session were clearly defined?

Question 2. Participation and interaction were encouraged?

Question 3. The topics covered were relevant to me?

Question 4. The content was organized and easy to follow?

Question 5. The materials distributed were helpful?

Question 6. This training experience will be useful in my work?

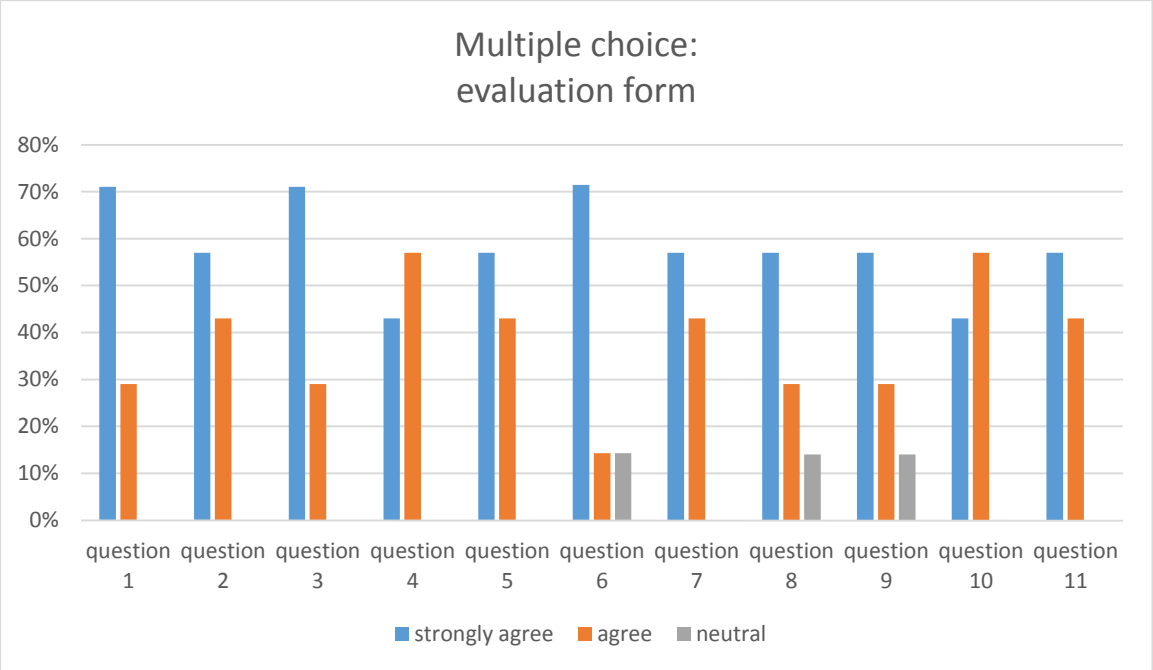
Question 7. The trainer was knowledgeable about the training topics?

Question 8. The trainer was well prepared?

Question 9. The training objectives were met?

Question 10. The time allotted for the training was sufficient?

Question 11. The meeting room and facilities were adequate and comfortable?



Open questions

Question 12. What did you like most about this training?

Complementary therapies overview.

Holistic approach.

Trainer very open and friendly.

Reversible causes.

Relaxed approach.

Encouraged some discussion.

New information.

Relaxation session.

Refresh memory.

Audience participation.

Question 13. What aspects of the training session could be improve?

A little repetitive therefore shorter.

More group activities.

Time.

Question 14. How do you hope to change your practice as a result of this training?

Refocus on the need for complementary therapies.

Be more competent in helping patient to relax.

Looking at usual routine of the patient to individualise care plans.

Part of the admission process.

More aware of the problem.

More knowledgeable.

ANNEXE XXXV

Joanna Briggs Levels of Evidence Chart

Level of evidence	Effectiveness
1	• Systematic Review (with homogeneity) of Experimental studies (eg. Randomized control trial with concealed allocation); • Or 1 or more large experimental studies with narrow confidence intervals.
2	Quasi-experimental studies (eg. Without randomisation).
3	• 3a. Cohort studies (without control group); • 3b. Case-controlled; • 3c. Observational studies without control groups.
4	Expert opinion without explicit clinical appraisal, or based on physiology, bench research or consensus.

- JOANA BRIGGS INSTITUTE. Levels of Evidence. Joanna Briggs Institute. Available at http://www.joannnabriggs.edu.au/pubs/best_practice.php. Accessed December 31rst, 2015.

ANNEXE XXXVI

CHARTS WITH LITERATURE SUMMARY

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
GABRIEL, J. Syringe drivers: their key features. International Journal of Palliative Nursing, Jul 2015, vol. 21, no. 7, p. 328-330.						
4	Non applicable	Not specified	To establish that the Subcutaneous route for delivering continuous medication is more effective on symptom control for patients at the end of life that can't receive medication orally.	Literature research	Literature review	Highlighted that the Subcutaneous route for delivering continuous medication can have a significant impact on the patients overall comfort and wellbeing as they near the end of life.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
MUKOREKA, J & SISAY, I. Safe practice in syringe pump management. Nursing times, Apr 2015, vol.111, no 14, p. 19-21.						
4	Not applicable	Not specified	How to administer drugs safely using syringe	Literature research	Literature review	Highlighted that a continuous infusion of medication

			pumps to improve symptom control when the oral route can't be used.			can improve symptom control.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
THOMAS, T & BARCLAY, S. Continuous subcutaneous infusion in palliative care: a review of current practice. International Journal of Palliative Nursing, Feb 2015, vol. 21, no 2, p. 60-64.						
3	General practitioners, community nurses and nursing home teams	Primary care setting and nursing homes	Review the challenges and outstanding questions associated with their use. The advantages of newer devices, safety and efficacy of drug combinations, selection of diluent and management of site	Literature research	Literature review	Good levels of knowledge concerning syringe driver use has been found among General practitioner and community nurses, although this is not the case in some of the nursing

			reactions are discussed.			home teams.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
SHEEHY-SKEFFINGTON et al. Caregivers experiences of Managing Medications for Palliative Care Patients at the End of Life: A Quality Study. American Journal of Hospice and Palliative medicine, Mar 2014, vol. 31, no. 2, p. 148-154.						
2	Three focus groups of Informal caregivers (bereaved caregivers of patients that had died at home)	Patients dying at home	Explore the experience of caregivers managing medications for patients dying at home, focusing on the impact of polypharmacy, the use of syringe drivers and the use of when needed medications for symptom control.	Analysing three focus groups of informal caregivers though content thematic analysis; Literature research	Qualitative study	The themes that emerged include the significant burden of polypharmacy, the positive impact of subcutaneous infusions, the value of being able to give medications as needed for symptom control, the importance of clear guidance to assist with medication management. Strategies are suggested that might ease the

						burden of medications at the end of life. More research is needed to address formal clinical evidence on the strategies suggested.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
WEST, C. The use of syringe drivers in the community: considerations for palliative care providers. International Journal of Palliative Nursing, Feb 2014, vol. 20, no.2, p. 56-59.						
4	Not applicable	Community	Commentary on the use of syringe drivers for symptom control in palliative care patients being cared for in the community.	Literature research	Literature review	The practical implications for professionals, patients and carers of commencing the use of a syringe driver in the home environment are discussed and the importance of a trusting therapeutic relationship

						is highlighted.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
LORENZL, S. Infusion pumps in palliative care are vital, but many need updating. British Journal of Nursing, Sep 2013, vol. 22, no 17, p S4.						
4	Not applicable	Not specified	Consider the concerning related with the infusion site of syringe drivers.	Literature research	Literature review	The infusion site has an important impact on the uptake of the drug. Any site with enough subcutaneous tissue can be used. Delivery medication by syringe drivers is limited in oedematous tissue, irradiated skin and in infected, broken or bruised skin.

						Furthermore, the site is important for the mobility of the patient. For patient's safety syringe drivers with rate based on volume, device alarms and with internal memories should be used.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
MITCHELL K, et al. Incidence and causes for syringe driver site reactions in palliative care: A prospective hospice-based study. Palliative Medicine, Dec 2012, vol. 26, no. 8, p. 979-985.						
1	170 Hospice inpatients	Specialist palliative care inpatient facility in the UK	Investigate whether there was a correlation between drugs administered subcutaneously via syringe driver and the incidence of	Prospective quantitative data collection.	Syringe driver recording forms were retrieved from case notes of consecutive patients who	An association between the presence of cyclizine and levomepromazi-ne and the incidence of syringe driver site reactions was identified. A

			syringe driver site reactions, further linking this to time to syringe driver site reaction.		received medication via a syringe driver.	marked difference in incidence of syringe driver site reaction was observed between the two study centres (26.5% vs. 7.7%). Although baseline patient characteristics were comparable, a difference in practice between the centres was identified, i.e. use of parenteral cannulae. An association between the time a syringe driver was in situ and the occurrence of a syringe driver site reaction was also demonstrated. Recommendations can be made for the frequency of syringe driver site changes based on which drigs are in use. Incidental findings from the study have been used to change practice at the

						hospice study site, with regard to choice of parenteral cannulae.

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
DOUGHERTY, L; LISTER, S. The Royal Marsden Manual of Clinical Nursing Procedures. The Royal Marsden NHS Foundation Trust: West Sussex, 2015, 9th edition, p. 733-739.						
4	Not applicable	Not specified	Not specified	Reference book on clinical nursing procedures (including a chapter on syringe drivers subcutaneous infusions)	Not applicable	Not applicable

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
British National Formulary. Syringe drivers.www.bnf.org. Accessed 4th of December of 2015.						

4	Non applicable	Not specified	Not applicable	British National Formulary website	Not applicable	Not applicable

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
WATSON M, et al. Palliative Adult Network Guidelines. Anglia, Kent, Medway, mount Vernon, Northern Ireland, South east London, South West London, Surrey, West Sussex & Hampshire, Susses Cancer Networks and Palliative Care Cymru Implementation Board: 2011, 3rd edition.						
4	Not applicable	Not specified	Not applicable	Reference book on Adult Palliative Care (including a chapter on syringe driver subcutaneous infusions).	Not applicable	Not applicable

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
NORTHAMPTONSHIRE HEALTHCARE NHS. Guidelines for the use of syringe driver CME Mckinley T34, Version 5: 2015.						
3	Not applicable	Northamptonshire Healthcare NHS Foundation trust	A county wide approach to the use of syringe	Literature research. Evidence based guidelines.	Literature review	Not aplicable

			drivers to ensure consistency in approach. Patients receive their medication in the most appropriate place and time and with adequate support. A knowledge base for clinicians to ensure that clinical practice is based on evidence and best practice.			

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
British National Formulary. Continuous subcutaneous infusions. https://www.evidence.nhs.uk/formulary/bnf/current/guidance-on-prescribing. Accessed 5th December, 2015.						

4	Not applicable	Not specified	Not applicable	British National Formulary Website	Not applicable	Not applicable

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
HABERECHT J. Guidelines for subcutaneous infusion device management in Palliative Care. Herston Multimedia Unit: Queensland, 2010, 2nd edition.						
3	Not applicable	Not specified	Not applicable	Evidence based guidelines	Not applicable	Not applicable

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
GRPCC CLINICAL PRACTICE GROUP. Subcutaneous Drug Infusion Compatibility Guidelines. Palliative Care Consortium: Gippsland Region, 2011.						
3	Not applicable	Not specified	Inform about clinical practice, policies and procedures in health services. To promote a region wide adoption of best practice.	Evidence based guidelines	Not applicable	Not applicable

Level of evidence	Sample (if applicable)	Setting	Aims	Design	Methods	Results
DERBY-BURTON CANCER NETWORK. Syringe driver guidelines. National Patient Safety Agency: Derby City, 2011.						
3	Not applicable	NHS organizations across the UK	The use of syringe drivers enables health care practitioners to deliver prescribed combinations of medication at a predetermined rate, via an appropriate parenteral route (continuous subcutaneous infusion) safely and efficiently, to the patient for symptom	Literature research. Evidence based guidelines.	Each patient has their symptoms regularly assessed, recorded, discussed and acted upon by the multidisciplinary team, in accordance with the patients (and carers) wishes utilising evidence based practice.	The condition of a patient with advanced, progressive disease is likely to deteriorate, such that parenteral administration of drugs becomes necessary. The use of a syringe drive to deliver a continuous subcutaneous infusion of drugs allows improved symptom control with the least discomfort and inconvenience for both

			control. For the patient this avoids high peaks and low throughs in plasma serum drug levels and eliminates the need for repeated injections.			patient and carer.